

# Annual Review 2021











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Dear valued supporter,

MS-UK is here to support people affected by multiple sclerosis (MS) to live healthier and happier lives. Enclosed you will find a round-up of MS-UK's achievements in the last year.

2021 was not without its difficulties for all charities, MS-UK included. Covid continued to impact fundraising events, which meant we saw many of our events moved to the latter half of the year or cancelled. Relying significantly on fundraising we felt the loss of these events, but it also inspired some amazing ideas for virtual events which helped recoup some of the money lost.

Despite these uncertain times, the team at MS-UK have continued to ensure our services, information and support are delivered to as

many people affected by MS as possible, to help support them to live well with MS.

I'd like to send my sincerest gratitude to everyone who has supported MS-UK in the last year with their time and generous donations, including those who gave anonymously. We simply couldn't do it without you and as we all continue to navigate through difficult times, we appreciate your continued support.

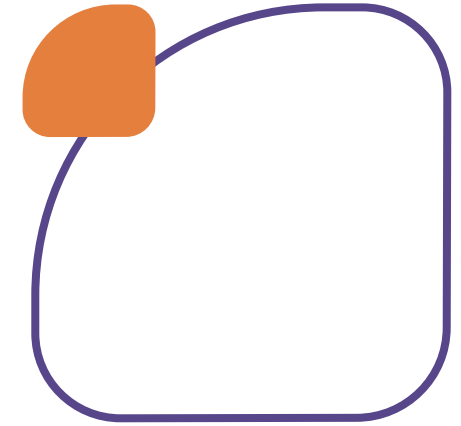
Yours faithfully

A handwritten signature in black ink that reads "Amy".

Amy  
MS-UK Chief Executive







## Who we are

MS-UK is a national charity here to support people affected by multiple sclerosis (MS) to live healthier and happier lives. Around 130,000 people are living with a diagnosis of MS in the UK and 2.3 million worldwide.

MS is a long-term health condition that affects the central nervous system (the brain and spinal cord) and there is currently no cure. The symptoms people experience can vary greatly from person to person and over time. Symptoms may include fatigue, pain, sensory problems such as vision, cognition difficulties and issues with bodily functions such as speech and swallowing and bladder and bowel.

Just as there is no cure, there is also no definitive understanding of the cause of MS. There are also some unknowns around

the best way to treat the condition, which adds to the uncertainty in the lives of those diagnosed and the people around them.

This is why MS-UK has always been at the forefront of promoting choice. We provide information and support to people affected by MS so they can make informed decisions about how they would like to live their life with MS. Whether that is through drugs, complementary therapies, lifestyle changes, a mixture of all, or none at all. We will always respect people's rights to choose for themselves.

MS-UK listens to those we support and provides crucial services to help people affected by multiple sclerosis live healthier and happier lives.

## Our vision, mission and values

### 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

All of the staff at MS-UK sign up to our values and actively use them in their day-to-day roles.

These are the values that guide our work...

#### 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





## MS-UK Helpline

The MS-UK Helpline offers information and emotional support to anyone affected by MS. Whether that's a person living with the condition, a friend, family member, caregiver, or medical professional.

Whether you need information or just to talk to someone who understands, our trained helpline information officers are at the end of the phone, email or web chat to offer any information needed to make informed decisions about living with MS. They will never give advice but present the information needed to make your own choices about living with MS and provide emotional support along the way.

**The MS-UK Helpline is open between 10am-4pm, Monday-Friday.**

Each year the helpline supports over 1,200 people living with MS. In 2021, the MS-UK Helpline experienced a 4% increase in contacts compared to the previous year, receiving a total of 1,322 contacts.

During those calls, the top five subjects callers wished to speak about were symptoms, diagnosis, covid 19, medication and emotional support.



### Information booklets

The MS-UK Helpline team also produce a variety of information materials, these are called Choices booklets. Last year the team reviewed and updated eight booklets, these included Vitamin D, Cannabis and MS, Fatigue, Personal Budgets, Visual Symptoms, Low-Dose Naltrexone, Smoking and Disease Modifying Therapies. Over 180 people requested copies of our Choices booklets in print format. Digitally our booklets were downloaded 14,111 times throughout 2021 and the webpages where the information also is held were viewed more than 40,000 times.



**The MS-UK Helpline made a huge difference to me. While going through a possible MS diagnosis I found the waiting very difficult. But a chat with the helpline honestly made me feel less stressed and anxious. They made me see even if I do have MS it is not the end of anything, I just I need to adapt**





said they got the information  
and/or support they needed  
from the MS-UK Helpline

87%

said that the information  
that was provided was  
unbiased and balanced

90%

100%

said the MS-UK Helpline  
treated them fairly, with  
respect, care and compassion

100%

of people said they found the  
MS-UK Helpline staff to be  
professional, knowledgeable and  
provided a high-quality service





“

**I felt like I was talking to a supportive friend when I rang the 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.”

**Kayleigh Eagle**



## MS-UK Counselling

MS-UK Counselling is the only UK-wide counselling service specifically for people affected by multiple sclerosis. We understand the importance of maintaining good mental health and the particular difficulties people with MS face. Half of all people with MS will experience depression in their lifetime, far higher than the general population. Sadly, two in five people with MS have suicidal thoughts at some point in their lives. And over 60 per cent of the disabled population live in poverty and cannot afford to pay for counselling themselves. Our service, therefore, runs on a donation basis, where people are asked to donate what they can.

When someone comes to us, they are first assessed to ensure that counselling is the right option for them. After this, they are offered six weekly sessions with one of our counsellors over the phone or via Zoom, depending on their preference. To ensure we

can support everyone that needs us, sessions are available on weekdays, evenings and Saturdays.

People come to us for help with mental health issues such as anxiety, depression and the challenge of coming to terms with and living with, a diagnosis of a long-term health condition. Also, people can struggle with difficult emotions such as grief, loss, anger, low self-esteem and confidence, and sometimes suicidal thoughts.

From January to March 2021, we saw a 170% increase in referrals to MS-UK Counselling. Unable to keep up with that level of demand, we had to make the difficult decision to stop accepting referrals. We opened again in October and referrals continued to be high, showing growth of 21% compared to 2020. During the year we received 429 referrals and provided 973 counselling sessions.







# 217

people completed  
counselling







**I feel like a massive weight  
has been lifted and I am so  
much more positive about  
my MS and my future**







**The service I had was amazing and the difference made to me and in turn my family's life is huge. The tools I've been given are priceless**

increase in referrals to MS-UK  
Counselling compared to the  
previous year

621%

said they were more able to  
cope when things go wrong

86%

76%

were able to  
sleep better

61%

55%

of people felt less helpless and  
less despair after completing  
MS-UK Counselling

said they felt happier





**I would always feel much better after talking to my counsellor, and over the sessions felt more and more at ease**

“I was having difficulty coming to terms with what my diagnosis of multiple sclerosis (MS) meant for my future, specifically for whether it was safe to have more children, as it was always something I wanted before diagnosis. I also wanted someone to talk to about my fears who wasn’t a close friend or relative.

“Having never had counselling before, I wasn’t sure what to expect and was worried that it would be embarrassing or difficult talking to a stranger about my experiences.

“I would always feel much better after talking to my counsellor, and over the sessions felt more and more at ease. She helped me to understand that what I was feeling was to be expected, and that talking is really important.

“I am now pregnant! The counsellor gave me the confidence to meet

my future head-on and not to let my diagnosis stop me from making important decisions. She also helped me to understand the importance of voicing how I was feeling to my husband, which ultimately led us to have a conversation about how my MS was making me feel day-to-day, and whether I would cope with having a baby.

“I feel closer to my husband as I am more confident telling him how I’m really feeling rather than just saying ‘I’m fine’ all of the time.

“To someone wondering whether counselling is for them, I’d say 100% give it a try. Speaking to someone external from my family was so needed, as they provided me an opportunity to ‘bare all’ without worrying about the other person’s emotions.”

**Lucy Wright – counselling**



**MS-UK and the counselling service in particular was a true lifeline after a less than good experience with the medical experts after my one line letter diagnosis. Thank you for helping me get to grips with my new reality**









## MS-UK Online

In January 2021 we launched MS-UK Online. In the previous year, we took the difficult decision to sell our properties so we could withstand the pressures that the pandemic had on our ability to fundraise. A result of which was the closure of our local wellness centre in Essex, Joesphs Court. During the restrictions that came with the pandemic, we had worked closely with our clients to replicate our services to something similar online so that they continued to feel connected and could exercise at home. Once the decision to close the centre was communicated a consultation process was carried out with users of the centre to explore how we could continue these online activities more permanently and they were supported to use the technology so they could access the new online offering from the comfort of their own homes.

Since then and throughout 2021, we have worked closely with our online community to significantly grow the range of activities on offer. This has also led to us supporting hundreds of more people across the UK.



**Knowing there are other people in my position, it makes me feel less alone**





## Our online services have included

### Classes

Over the course of the year, we have expanded upon the classes available. We began offering three accessible levels of exercise classes each week, before introducing activities including chair yoga poetry, and mindfulness.

### Information sessions and workshops

Held monthly and delivered by experts in their field, information session subjects have included neuroplasticity, regular vs functional exercise, spasticity management, fatigue management, hand therapy and strengthening to name a few.

The workshops are interactive, offering participants the opportunity to try something new. Activities have included introductions to chair yoga, mindfulness, poetry, and Pilates, plus sessions on nutrition, hand reflexology, cognition and working rights for MSers. From these workshops, we have listened to the feedback and as a result, launched eight-week courses in both poetry and Pilates.

### Peer pods

Our peer support service enables people to connect with others in a safe space and share experiences on topics of interest or if they wish to, discuss their MS. We ended the year with nine peer pods running weekly via Zoom. These included a newly diagnosed pod, men and womens', and hobbies.



**4500 attendances**



**300 exercise classes**



**4 mindfulness courses**



**83 chair yoga classes**



**30 information sessions**



**40 peer pods attendees every month**

of participants said the activity they took part in helped them to maintain or improve the symptoms of MS

97%

said the activity had helped them to maintain or improve their ability to look after themselves

96%

96%

93%

said the activities had helped them to maintain or improve their positivity about themselves and their future

reported the activity helped them to maintain or improve their participation in work, volunteering, study and other activities





“

**This is a perfect forum for anyone to reach out to. It's all on your terms and in the comfort of your own home**

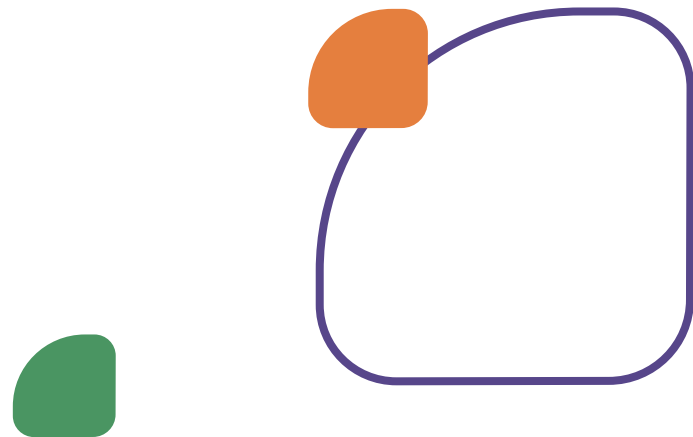
”

‘I came across MS-UK Online during lockdown. The exercise sessions were a lifesaver. They have been outstanding.

‘The information sessions have answered many questions for me. I have had multiple sclerosis (MS) for nearly 30 years. Some questions I had never asked. It made me feel I was not alone in dealing with issues.

‘This is a perfect forum for anyone to reach out to. It's all on your terms and in the comfort of your own home.’ **Anonymous MS-UK Online user**





## New Pathways magazine

Our bi-monthly magazine is a go-to resource for people affected by MS. The magazine has been a lifeline for people by providing the latest news, research and thinking about how to live well with the condition. Our editor understands the importance of ensuring there are no taboo subjects and that all possible options for managing life with MS are researched and presented in a balanced way. Subjects covered vary from the latest research news and letters pages to complementary therapies and peoples' stories providing support and inspiration to others.

Over the past few years, we have seen subscriptions to our magazine New Pathways fall, which we believe is in keeping with much print media. However, we are committed to continuing this vital service, particularly for those that are not on the internet and rely on our magazine for up-to-date MS information. We are very pleased that this year, we saw subscriptions to the magazine rise.







## Over to you

Whether it's gripes or groans, a pat on the back, or hints and tips, we want to hear from you

at home



the magazine. I pull out the centre pages and stick them to the wall. They are really easy to follow for someone with limited mobility like me.

Jire Parker,  
Bridge Wells

POST MS-UK\*  
(required)  
00  
ys@ms-uk.org

Lisa Forester,  
Brighton

### Overcoming MS

Dear New Pathways,  
I was happy to see the interview with Grazina Berry, the new CEO of Overcoming MS (OMS). I've been loosely following the protocol for years and while I can't say for definite that it's the reason, I am still very well and mobile many years after my diagnosis. I believe after exercise along with stress management are good pillars of any healthy lifestyle and it's a shame in a way that doctors don't encourage it more.



### The power of pets

Dear New Pathways,  
Like everyone this year, I've felt quite lonely at times, but one thing that's really brought me comfort is my cat, Clive. I've realised that if I'm sitting alone, watching TV or reading a book, just having

him on my lap to stroke helps me feel so calm and relaxed. I now live alone and his company has proved so comforting to me. He's lived with me for 12 years and I wouldn't be without him.

Jenny Frost,  
Chichester

Ainsley Enright,  
Birmingham

www.ms-uk.org

MS-UK



New Pathways magazine was my first port of call when I wanted to find out the latest about MS



**I absolutely love New Pathways magazine which is both informative and inspiring**



'I absolutely love New Pathways magazine which is both informative and inspiring, with recipes thrown in to boot! (Without success, I have desperately been trying to find a recipe for nut loaf which I'm sure featured fairly recently.)

'If I was telling anyone about MS-UK, I'd lend them a back copy of the magazine to read, which would help them.'

**New Pathways reader, Helen Weber**







## e-learning

We have now developed two online courses – Understanding MS and Counselling people with MS. These interactive digital courses include both information and lived experiences of people affected by MS and are primarily aimed at professionals. We hope that by providing insight to life with MS, professionals will be able to shape their services to better meet the needs of people with MS.



I have learnt a lot more about MS. I have gained extremely helpful knowledge in this course. I found this course very informative and listening to various people was extremely helpful. Thank you

# 29

**people completed  
our MS Awareness  
training course**



## Fundraising

MS-UK is an independent charity and we do not accept pharmaceutical funding. This allows us to be completely independent and unbiased, but it does mean that we rely heavily on our amazing fundraisers.

2021 was another challenging year for fundraising at MS-UK. Whilst we saw some mass participation events return in the autumn and we were able to run some of our corporate events, it was far from a “normal” year.

There was a national lockdown from January-April with many restrictions still in place until July. Our London Marathon income was severely impacted due

to the 2020 event being cancelled and many places and fundraising rolled over from 2020 to 2021.

Despite this, our fundraising team continued to work hard to generate as much income for the charity as possible. We developed new virtual events including The Big Purple Dog Walk and two virtual auctions. We also hosted two successful national skydiving days and launched the MS-UK Supporters’ Club to encourage regular giving.

We recruited 123 new fundraisers in 2021 which was brilliant in a difficult year.





## My MS Marathon

We were very proud to win **Campaign of The Year** at The Institute of Fundraising's Eastern Region awards for My MS Marathon 2020. We know this much-loved fundraising event is always popular and plan to bring back My MS Marathon in 2022 bigger and better than ever!







I feel incredibly honoured to be supporting this wonderful charity and to have the genuine enthusiasm and kindness from Lucy and the team







The support the fundraising team have given was fantastic. The telephone calls to say well done were very much appreciated

## Developing the MS-UK brand

In 2021, we looked at the MS-UK brand and consulted with the MS community to refresh our branding, add a strapline to the logo and redesign our website and e-newsletter communications, ensuring that accessibility remained at the heart of our work and we appealed to the people we are representing.

Our communications team ran an impressive 22 campaigns last year varying from one-day promotions to week-long promotional campaigns depending on the subject. Some were exclusively MS-UK campaigns to promote our Choices booklets, legacy giving, and e-learning, to name a few. Other campaigns were based around national awareness events related to MS and the services we provide, such as Carers Week, MS Awareness Week, and World Mental Health Week to name a few more. These campaigns allowed us to reach new people that we wouldn't have reached before, resulting in new service users and fundraisers, as well as increased awareness of multiple sclerosis and MS-UK.





Our blogs, which provide information about MS as well as real-life stories from others living with the condition were read **78,372** times

Our e-newsletter was sent to a total of **17,599** people in 2021



We reached **1,239,364** people on Facebook with messaging about MS-UK and multiple sclerosis

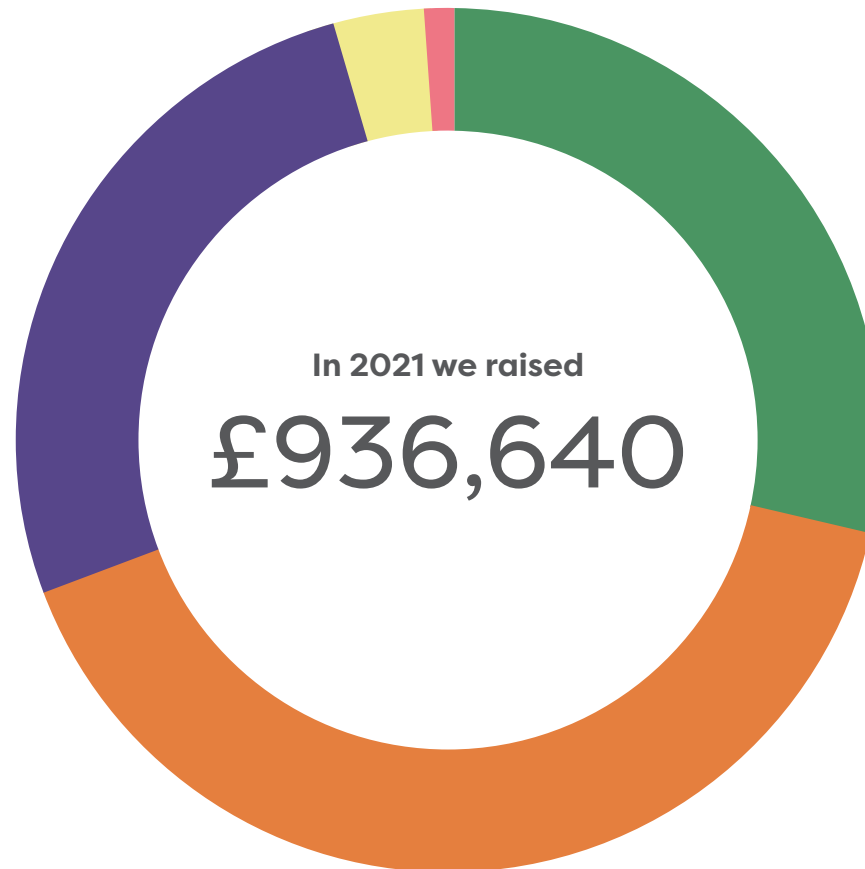


The MS-UK website was visited **193,996** times



## What we raised together

Donations and legacies	£265,775
Charitable activities	£381,028
Other trading activities	£245,661
Investments	£637
Other income	£43,539



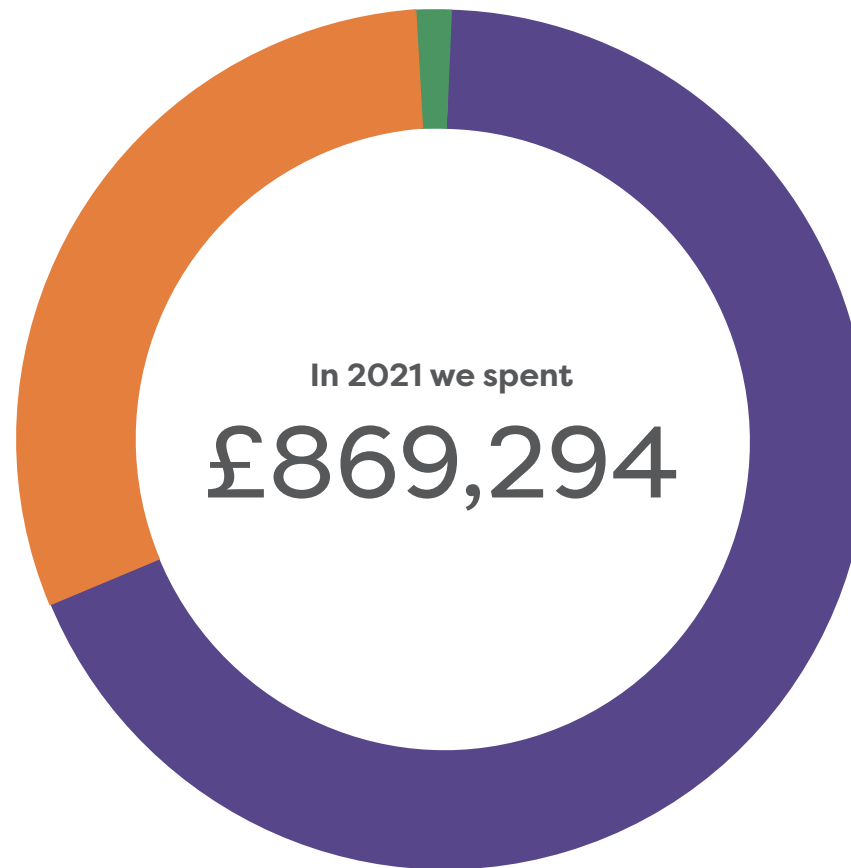
- Donations and legacies
- Charitable activities
- Other trading activities
- Investments
- Other income



## Where the money went

Governance	£2,350
Fundraising	£261,629
Services	£605,315

We are committed to ensuring every penny raised is spent most effectively and sustainably for the charity to ensure we can continue to support people affected by multiple sclerosis to live healthier and happier lives in the future.



- Fundraising
- Services
- Governance



## The future

In 2022, MS-UK will continue to support people affected by multiple sclerosis (MS) to be healthier and happier. We will continue to provide our MS services while improving and growing them to keep up with demand. We will develop more information resources for everyone and increase support for professionals. We plan to host more information sessions and workshops, run courses, grow our peer support groups and make them even more accessible to even more people.

By launching our new website, piloting a new podcast, running awareness campaigns, promoting our new

e-learning course and implementing a robust marketing plan we will continue to increase understanding of MS nationwide.

Managing our charity as efficiently and effectively as possible is also one of our key aims. We will do this by investing in staff development, including training in equality diversity and inclusion. We also plan to welcome even more volunteers and community fundraisers. While reinstating the much-missed in-person fundraising events we know and love. These events will include four virtual fundraising events. We will also increase corporate support and strengthen our board by recruiting new trustees.









## Thank you!

In 2021, 161 volunteers donated 662.5 hours of their time to support MS-UK. Whether you supported our fundraisers at an event, helped out in our office or even hosted a peer pod we are so grateful!

We would also like to say a big thank you to our fundraisers for their hard work, dedication and determination, as well as those who made generous donations including those who gave anonymously. MS-UK relies heavily on the support from fundraisers, donors and volunteers and we simply couldn't do it without you. Thank you!

**A special thanks to the trusts and foundations who awarded grants to MS-UK, they are...**

- Charities Aid Foundation
- Edith Murphy
- Edward Gostling
- February Foundation
- National Lottery Community Fund
- Texel Foundation





# Stay in touch

MS-UK

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@MSUK6



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[www.instagram.com/multiplesclerosis\\_uk](http://www.instagram.com/multiplesclerosis_uk)

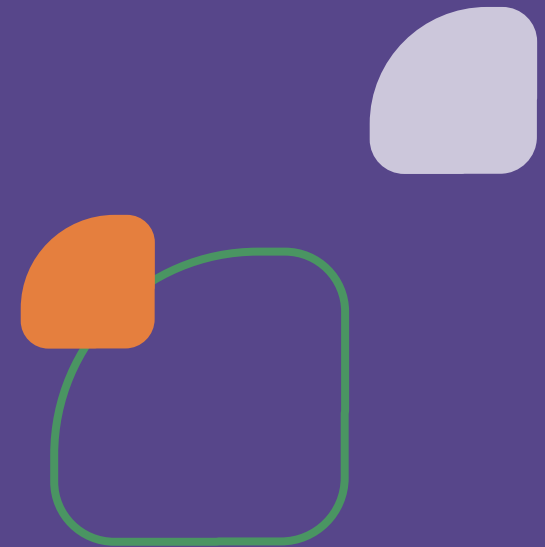
01206 226500

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**Registered Company Name** Multiple Sclerosis-UK Limited, trading as MS-UK.

**Company Number** 2842023. **Registered Charity Number** 1033731.

**VAT Number** 632 2812 64. **Registered Office** D3 Knowledge Gateway, Nesfield Road, Colchester, Essex, CO4 3ZL



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REGULATOR**