# **MS Trust Information Services**

Secondary progressive

multiple sclerosis

Disease

modifying drugs

A guide to treatments for relapsing MS



Need to make sense of MS? We're here to help.

mstrust.org.uk

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# A diagnosis of multiple sclerosis is the start of a long and unpredictable journey.

You may need to learn about managing a whole range of confusing symptoms. You might need to get to grips with some complicated treatment options.

And you might need help finding the MS health professionals who can help you live well with MS.

Wherever you are with MS, chances are you have a lot of questions. You'll need information you know you can trust. And you may find it helpful to talk with someone who understands what you're going through and can help you find what you need.

The MS Trust is here for you. We're ready to help from day one, and every day after.



# How can the MS Trust help me?



Our publications and online resources are written by experienced information professionals, in conjunction with experts in MS research and treatment. You can call or email our Information Service with questions about any aspect of MS, and we'll do our best to help you find some answers.

All our information is free, whether it's an enquiry, a webpage or books posted to your door, but we receive no funding from the government or NHS. It's only thanks to our supporters that we can provide our vital services.

#### Or Browse our range of information at mstrust.org.uk

**C** Enquiry Service: call Freephone 0800 032 38 39 or email infoteam@mstrust.org.uk Write to MS Trust, Spirella Building, Bridge Road, Letchworth SG6 4ET

# Specialist Health Professionals

At the MS Trust, we believe in supporting the people living with MS today, and we know that specialist MS therapists and nurses are a huge part of that support network. We train, fund and support the MS health professionals who make such a massive difference to people with MS, and help them to respond to the challenges facing their services.

"Find out more: mstrust.org.uk/nurses

# Connection to the MS community

Our quarterly magazine **Open Door** and our social media channels are packed with news and views from the MS world. You can sign up for our regular email newsletters to keep up with MS news and research updates, and you can find online peer support in our moderated Facebook Group.

#### With the MS Trust, you are not alone with MS.

- f Visit facebook.com/mstrustuk and facebook.com/groups/multiplesclerosistrust
- 💟 Əms\_trust
- ☑ ∂MSTrust
- MSTrustGroup and MSTVUK

### Newly diagnosed

When you're newly diagnosed with MS, there can be a lot to take in. Making Sense of MS is designed to help you find the right information, when you're ready for it. If you prefer online information, our website is the perfect place for you to start exploring what an MS diagnosis might mean for you and your family.

#### *Visit: mstrust.org.uk/newlydiagnosed*

#### Making Sense of MS: booklet

This small booklet is a good place to start learning about MS. It provides a brief introduction to MS and answers the most commonly asked questions.

#### Making Sense of MS: core pack

This folder contains more information about MS, the lifestyle changes and treatments which can help, and the health professionals who can support you. Order code: 448

The core pack contains the following four information sheets. However, if you prefer, you can order just the ones you'd like using the codes below:

#### About MS Order code: 440

**What happens after diagnosis?** *Order code: 456* 

**Making the most of appointments** *Order code: 445* 

Living well with MS Order code: 443







When you are ready to build up your knowledge, Making Sense of MS has further information sheets you can order to add to your core pack.



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Explaining MS to others Introduces MS for family, friends and colleagues.

### Disease modifying drugs: an introduction

Introduces the drugs that can decrease the amount and severity of relapses and slow the long term accumulation of disability.

#### MS and life choices

Explores how you can make the best choices for you.

#### MS and your feelings

Explores what you may be feeling and how you can adjust.

#### **Progressive MS: an introduction**

Answers the key questions about your symptoms and the treatments to help you manage them if you've just been diagnosed with progressive MS. *Order code: 449* 

#### **Relapsing remitting MS**

Introduces symptoms, relapses, support and symptomatic treatments if you've just been diagnosed with RRMS. *Order code: 450* 

#### **Research and MS**

Explores research into MS and how you can keep up to date.

#### Telling people about your MS

Suggests helpful ways to explain MS to others.

#### Treating MS symptoms

Outlines the range of treatments for MS symptoms.

#### Working and studying with MS

Supports you in employment, university, school or college.

### The A-Z of MS

Find clear and comprehensive information at the touch of a button. Browse our online A-Z of MS to find out more about the symptoms, treatments, services and health professions that are involved in multiple sclerosis. Our Information Team regularly review the evidence for every topic in the A-Z, and ensure that you have the most up-to-date and relevant information on MS.

#### Or Visit: mstrust.org.uk/a-z

# **Enquiry Service**

If you can't find your answers in the A-Z, ask our Enquiry Service. Our information professionals can give you a personal and confidential response to any query about MS, from finding your nearest MS nurse through to understanding your treatment options, and everything in between.

#### ♂ You can email infoteam mstrust.org.uk

Call Freephone 0800 032 38 39 between 9am – 5pm on working days Write to us at Enquiry Service, MS Trust, Spirella Building, Bridge Road, Letchworth SG6 4ET

### **About MS**

Do you want to explore the facts and myths surrounding MS? Our webpages discuss in depth topics like the causes of MS, different types of MS, new drugs in development and the diagnosis journey you may follow from the earliest signs and symptoms you noticed.

#### ✓ Visit: mstrust.org.uk/about-ms

"I just wanted to say how fantastic the person on your enquiry service was. I am feeling quite confused about my daughter's diagnosis and he talked me through the condition with such calmness and gave me so much information. A service like this is quite amazing. Thank you so, so much."

Enquiry line caller, 2017

**MS Decisions** 

If you have relapsing remitting MS, there's good evidence that a disease modifying drug could help you stay healthy in the long term as well as reducing the number and severity of relapses you have. But working out which drug is right for you can be complicated. We bring together information about the way the drugs work, how you take them, possible side effects, and what additional tests or monitoring might be required.

"Using MS Decisions I was able to make the most informed decision regarding treatment choice."

**MS** Decisions

Jane, 2018

MS Decisions is our award-winning interactive guide to making a choice that works for you.

MS Decisions helps you to compare information about the different drugs and prepare for your appointments with your neurologist or MS Nurse.

Or Visit: mstrust.org.uk/msdecisions

### Disease modifying drugs: a guide to treatments for relapsing MS

This comprehensive book covers the same ground as MS Decisions in a printed form. It includes a handy pull-out comparison chart of all the disease modifying drugs currently available for relapsing remitting MS.



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Read how other people with MS came to their own DMD decisions. *Visit: mstrust.org.uk/about-ms/ms-treatments/personal-stories* 

comparison chart of all th currently available for rela Order code: 90

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### **Progressive MS**

These books explore the physical and emotional aspects of identifying and living with progressive forms of MS. They include how progressive MS can be managed, the health professionals you may encounter, and give tips from other people living with primary and secondary progressive MS.

**Primary Progressive MS** Order code: 352



#### **Secondary Progressive MS** Order code: 458



### **Online tools**

Our online tools can help you explore the treatment options to deal with your MS symptoms, and help you find out more about what could be causing or worsening those symptoms.

#### **Treatment finder**



✓ Visit: mstrust.org.uk/about-ms/ ms-treatments/treatment-finder

#### What's causing my symptoms?

Or Visit: mstrust.org.uk/about-ms/ ms-symptoms/whats-causing-mysymptoms

Read personal stories about managing life with MS. **Visit:** mstrust.org.uk/life-ms/your-stories

### Managing your symptoms

When you have a long-term condition like MS, it's important to get the right treatments. We have worked with experts in MS treatment to bring together the key information you need, to help you manage some of the most common MS symptoms vourself. If these issues affect you, you can order copies of our books for free or read them online.

#### Living with fatigue

Practical ideas to help you manage fatigue and make the most of your energy levels. Drder code: 204



### Managing your bladder: A guide for people with MS

Drder code: 429

#### Managing your bowels: A guide for people with MS

Drder code: 430

Bladder and bowel problems can be an uncomfortable part of living with MS. These books contain practical suggestions to help you manage symptoms like constipation and incontinence and reduce their impact on your daily life.



#### Sex and MS: A guide for women Order code: 213

Sex and MS: A guide for men

Drder code: 356

These books explore how MS can affect intimacy and your sex life, and give practical suggestions to help men and women manage their symptoms and talk about their concerns.



#### **Spasticity triggers**

Tight, aching muscles can be a problem for many people with MS. Our book helps you identify the underlying trigger factors and the health professionals who can help you manage them. 🛄 Order code: 400



### Living well with MS

You may spend as little as three hours a year with a health professional, so life with MS can mean finding practical solutions to some everyday problems. We have information on simple things you can do to take control of your MS and your life.



#### Exercise

Staying active is a vital part of maintaining good health, whatever your mobility level. We have exercise classes and exercise programmes you can view online and join in with, as well as ideas to help you get involved with all kinds of active hobbies.

*Visit: mstrust.org.uk/life-ms/exercise* 

#### Diet

Many people with MS report that small dietary changes have helped them to maintain their wellbeing, and there is good evidence to support this. We explore the different dietary advice out there for people with MS, so you can make an informed choice that suits you.

✓ Visit: mstrust.org.uk/life-ms/diet

#### Home and travel

What does MS mean for car drivers, going on holiday, or getting around at home? Learn about some adaptations and organisations that can help you stay independent.

Or Visit: mstrust.org.uk/life-ms/home-and-travel

#### Your finances

You may have worries about your working life and your legal rights. We can put you in touch with sources of financial support and legal advice on everything from benefits to insurance.

"Visit: mstrust.org.uk/life-ms/your-finances

# Wellbeing

When you have MS, looking after your mind and brain are as important as looking after your body. We have a range of resources to help you recognise anxiety and depression, protect against their negative effects, and seek mental health support when you need it. You might also want to think about some of the lifestyle choices you can make to keep yourself healthy.

#### **Staying Smart**

Our micro-site on coping with thinking and memory problems has ideas to help you if you are struggling to remember things or order your thoughts, and tips to help you build your confidence.



Or Visit: stayingsmart.org.uk

#### Relaxation

Build rest and calm into your everyday life with our tips on relaxation and mindfulness. Join in with an expert in our mindfulness video sessions or relaxation podcast.

Visit: mstrust.org.uk/a-z/relaxation
Visit: mstrust.org.uk/a-z/mindfulness

#### Getting through tough times

Learn how to recognise the signs of depression in yourself and others, and find ideas to help build resilience and improve your mental health.

Visit: mstrust.org.uk/a-z/depression
Visit: mstrust.org.uk/a-z/anxiety



Find out how others responded to their MS diagnosis *Visit: mstrust.org.uk/life-ms/wellbeing/ms-and-your-emotions* 

# Family life with MS

MS affects the whole family, not just the person with the diagnosis. We have ideas on how you can explain MS to your children, and an engaging book that they can read themselves.

#### © Visit: mstrust.org.uk/life-ms/relationships-and-family-life



**Kids' guide to MS** Order code: 286

**The young person's guide to MS** The young person's guide to MS Download at support.mstrust.org.uk/shop

**Talking with your kids about MS**Order code: 316

#### Pregnancy and parenthood

Having MS need not affect your plans for a family. Our myth-busting information will put your mind at rest and explain what to bear in mind when planning a pregnancy.

♂ Visit: mstrust.org.uk/pregnancy

#### **Childhood MS**

It's becoming clear that MS can begin before adulthood. We have information on symptoms, treatments and where to get support.

© Visit: mstrust.org.uk/a-z/childhood-ms

# MSTV

Our dedicated YouTube channel for young people affected by MS features young people talking about living with MS, whether they or their parents have the condition. It features the things you want to know about MS; from coping with fatigue at school to telling your friends; and more.



Subscribe to our channel: youtube.com/mstvuk

Or visit: mstrust.org.uk/life-ms/young-people-and-ms



### Let's be social

Get connected with the wider MS community, and you'll have a support group with you wherever you are.

We know some people prefer to get their information on the go, and so you'll find the MS Trust in all major social media channels. Keep up with our news on our Twitter, Facebook or Instagram accounts, and join in with the conversation on our moderated Facebook group.

#### With the MS Trust, you are not alone with MS.

Visit: facebook.com/mstrustuk and facebook.com/groups/multiplesclerosistrust
@ms\_trust
@MSTrust
MSTrustGroup and MSTVUK



Find local support groups, blogs and online forums. *Visit: mstrust.org.uk/a-z/support-groups*  Find the MS specialists near you with our map of UK MS services. *Visit: mstrust.org.uk/map* 

### Who can help me?

Because MS is a complex, lifelong and unpredictable condition, we believe that people with MS need access to a full team of MS specialists, from neurologists and nurses to physiotherapists and other health professionals.

We estimate that around 68,000 people with MS in the UK live in areas where there are not enough MS nurses to look after everyone. Our Specialist Nurse Programme funds, trains and supports new MS Specialist Nurses and their teams to deliver better services for people with MS across the UK.

Our new Advanced MS Champion programme is helping guide care for people with advanced MS symptoms and complex needs.

Or Find out more: mstrust.org.uk/ms-trust-projects

# We couldn't do it without you

- Take part in a fun event or sponsored challenge such as a cycle ride, run or skydive
- Make a donation, you could even give every month by Direct Debit
- Remember the MS Trust in your will and leave a lasting gift for people with MS
- We can support you to fundraise your way please get in touch



Call our fundraising team on 01462 476707 Email: fundraising@mstrust.org.uk

- Visit: mstrust.org.uk/get-involved
- Donate: mstrust.org.uk/donate



"When I was diagnosed with MS the bottom fell out of my world and I didn't have a clue what the future had in store. The free information from the MS Trust was of real value to me. My friends and I did a sponsored skydive because we feel it's important they can continue to produce this information for everyone affected by MS."

Karen

### Keep in touch with the MS Trust

The world of MS is changing. Keep up to date with the latest developments with our emails and newsletters.

First Name	Last Name
Address	
City	Postcode
Email	

Phone (please specify whether work, home or mobile)

### **Order MS Trust publications**

All our publications are free to UK residents. They can be ordered or downloaded from **mstrust.org.uk/pubs** or by calling 01462 476700. Alternatively list the order codes of the publications you'd like. You'll find them in the listings inside wherever you see the 🛄 icon.

Order code:	Order code:	Order code:
Order code:	Order code:	Order code:
Order code:	Order code:	Order code:

We would like to send you information about MS, the MS Trust and the work we do as a charitable organisation, and updates as to how you can get involved or help to support us.

Would you like to receive this information from the MS Trust? (please tick)

By email By post

The MS Trust and our trading company value your support and promise to protect your privacy. We will only contact you about our work and will never exchange your details or sell or rent your data to any other commercial or charitable organisation. You can unsubscribe or change the way we communicate with you at any time. To read our privacy policy please go to **mstrust.org.uk/privacy**. If you would like to contact the MS Trust about the information we send you, please call **01462 476700**.



#### Return to:

Multiple Sclerosis Trust, Spirella Building, Bridge Road Letchworth Garden City, Hertfordshire SG6 4ET

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