Multiple Sclerosis Society

04

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MS Essentials

For people living with MS

This publication is available in large print
Call 020 8438 0999 or email shop@mssociety.org.uk

Tremor

It's not clear exactly how many people with MS are affected by tremor, although studies have suggested it's between 25 and 60 per cent. For some people, the tremor is so mild that they're the only person aware of it. For others, it's more obvious. It might be difficult to carry a drink without spilling it, or to a hold a pen steady to write. For a few people, it can be so severe that everyday activities like eating, drinking, or getting dressed are difficult or impossible without help.

If tremor is affecting your day-to-day life, you can speak to your GP or MS nurse. If you are already in contact with a physiotherapist or occupational therapist, you could also discuss it with them.

Tremor is one of the more difficult symptoms of MS to manage, but there are things that can make a difference. Rehabilitation involving physical or occupational therapy, drug treatments and, in some cases, surgery, have all been shown to help some people. There is no single approach that works for everyone, so you may have to try a number of different treatment options before you find what's best for you.

Through the booklet, we refer to a number of organisations that can help with particular issues – just look for the ℹ. Their details are listed at the back of the booklet in the 'Useful organisations' section (page 16).

Contents

What is tremor?

Tremor can be described as a trembling or shaking movement that you cannot control. While it is usually a rhythmic, back-and-forth shaking, tremor can also be irregular and unpredictable. Tremors can also be either ‘fine’ – small, shaking movements – or ‘gross’ – larger movements.

Everyone has a small level of tremor – known as ‘physiological tremor’ – that caffeine, alcohol or stress can make more noticeable.

Types of MS-related tremor

> “My tremors are a bit of a pain in my life at times, as they come on – as most MS things do – when you do not want them to. I can be having a very good time at a party and all of a sudden my hands start to shake. That means I have to find a table to put my glass down before I spill my drink. And the nearer the item is to pick up the more my hands shake. – *Sylvia*”

There are two types of tremor that are most common as a result of MS. These are known as ‘intention tremor’ and ‘postural tremor’, although it’s not always easy to tell the two types apart.

- **Intention tremor**
  This can come on when you want to do something, or reach for something. It often gets worse the closer you get to the object. This is the type of tremor people most often experience in MS.
- **Postural tremor**
  This is when you shake when you are sitting or standing. It comes on while your muscles are trying to hold part of your body still against the force of gravity.

MS-related tremors are most common in the hand or arm, but they can also affect other parts of the body, including the head. Tremor can sometimes affect the lips, jaw, tongue or eyes, making it difficult for someone to speak clearly, or to coordinate their eye movements.

Other reasons for tremor

If you have intention or postural tremor because of your MS, you will probably find that while your muscles are completely relaxed – such as when you are lying down or asleep – your tremor goes away. If it doesn’t, there may be another reason for it.

Tremor can be the result of muscle weakness and problems with posture, or a side effect of some medications (such as drugs for asthma). It could also be caused by other neurological conditions, such as Parkinson’s.

Ataxia

You may come across the word ‘ataxia’ used instead of, or as well as, tremor. This is a medical term for a group of symptoms that includes problems with balance and coordination alongside tremor. Many people with MS experience ataxia, and the term is often used in relation to MS-related tremor.

Muscle spasms and stiffness

Not all involuntary movements are the result of a tremor. Muscle spasms and stiffness – or ‘spasticity’ – can also cause your arms or legs to move in an uncontrolled way. For example, they might ‘jerk’ when you try to stretch an affected muscle, or your arm or leg might suddenly bend inwards towards your body, or shoot outward.

There’s more information in the MS Society booklet *Muscle spasms and stiffness*.

What causes tremor?

In MS, there is damage to the protective material – called ‘myelin’ – around the nerves in the brain and the spinal cord. When myelin is damaged – known as ‘demyelination’ – messages get slower or distorted or do not get through at all, causing the symptoms of MS. MS tremors are usually caused by damage to myelin in an area of the brain known as the ‘cerebellum’, and the nerves leading to and from it. The cerebellum is the part of the brain that controls your balance and coordination. It ‘smoothes out’ the movement of your limbs, eyes and speech. Tremor can also be the result of demyelination in other areas of the brain – including the thalamus and the basal ganglia, which are both involved in controlling movement.

Like other MS symptoms, tremor can come and go, or it could be progressive. If you experience tremor as the result of a relapse, you might find that you are still left with some level of tremor once the relapse is over.

Effects of tremor

> I was sitting there with a drink in my hand, and it was shaking, and I was thinking that the other people there would notice it and they'd think I was drunk. I was conscious of it. But I think I was just being afraid. Maybe the other people noticed it, but they know I've got MS.
> – *Tony*

Some tremors are slight and have little impact on day-to-day living. But others are more pronounced, and can affect basic activities, such as eating, dressing, shaving, writing and so on.

This can make living with a persistent tremor difficult. It can also be exhausting, as these continuous movements use energy in the same way as voluntary actions do. If your tremor is severe, it can have a significant impact on your independence.

If you have a tremor, particularly one that's noticeable to other people, you may feel embarrassed or self-conscious about it. There is support available to help you cope with these feelings. See 'Counselling and support', on page 9.

Diet and nutrition

Constant tremor not only uses up calories, it can also make it difficult to prepare and eat food. As a result, it's quite common for someone with a tremor like this to be underweight. If this affects you, adding high-energy foods and drinks to your diet can help. You can also speak to your GP or MS nurse for advice, and they can refer you to a dietitian if necessary.

There's more information about maintaining a healthy diet in the MS Society booklet *Diet and nutrition*.

Managing tremor

> Anyway, tremor is something I experience from time to time, in my hands. As with everything else it tends to be heightened when I'm tired or have been doing something quite physical – for me that can be something as trivial as peeling potatoes! Tremor for me will mean I get out of making coffee or filling the dishwasher up.
> – *Lorraine*

Managing tremor is an ongoing process. As there is no single approach that works for everyone, you will probably need to try different things before you find what works best. You may need to try different approaches at different times, and as your needs change.

Your GP or other health care professionals involved in managing your tremor will want to know how it affects you, what makes it worse and what helps. Keeping a diary can help you to give an accurate picture of how tremor affects you day-to-day. This will help them to know what treatment options might work best for you.

Whichever member of your health care team you speak to, they should either be able to suggest ways of managing your tremor or refer you to other specialists. These could include a physiotherapist, an occupational therapist, a speech and language therapist or a counsellor.

See the MS Society website for more information about the different health care professionals who may be involved in your care.

Rehabilitation

> “Like everything else we go through, it means adaptation – swapping hands for a while to perform certain tasks. I also try to plan everything I do and span time so that I don’t let my hands get too tired. – *Lorraine*”

A key part of managing tremor involves finding ways to reduce its impact and make the most of what you are able to do. This approach is known as ‘rehabilitation’, and it can help with managing day-to-day activities that have been affected by tremor.

Rehabilitation brings together nursing, physiotherapy, occupational therapy and other disciplines in a team approach. This approach alone can’t make tremor disappear, but it can reduce its disabling effects.

Physiotherapists and occupational therapists may jointly assess the problems that tremor causes for you, and then find ways to make them interfere less with your daily life. A physiotherapist can help you maintain and make the most use of your strength and range of movement. An occupational therapist can help you to find practical ways to manage particular tasks and reduce the effort involved.

If you don’t already have a physiotherapist or occupational therapist, you can ask your GP for a referral.

In their assessment, there are a number of areas a physiotherapist or occupational therapist might focus on, including:

- **Posture and balance**
  The positions we use for sitting, standing and lying down – our posture – can affect the muscles we use and the range of movements we can make. This can have an effect on tremor.

Having the right support for your torso while you're sitting down is important – whether in a wheelchair or any other kind of chair. If you sit in a chair that's too big, you might be using too much effort to balance and hold yourself upright. This can lead to tension in your muscles, or to over-using muscles that aren't designed for the job of balance. This can make tremor worse. If your arm rests are too high, this can restrict how you use your arms for certain tasks. So having a chair that's the right size and is properly supportive can relax your muscles and calm your tremor, as well as making your movements more coordinated.

Being upright can help develop and maintain your balance, and to align muscles so they work together more efficiently. If you use a wheelchair, or you spend a lot of your time sitting, you may be able to stand using supportive equipment, with the help of your physiotherapist. This can help you develop better control of your posture.

A physiotherapist can help you develop stable and controlled posture. An occupational therapist can help you learn to carry out daily tasks in ways that keep your body as aligned and well-balanced as possible. You can also speak to your physiotherapist or occupational therapist about getting the right support from a chair.

There's more information about balance in the MS Society booklet *Balance and MS*, and the factsheets *Posture and movement 1: an introduction* and *Posture and movement 2: moving well with MS*. For more specific advice about posture or balance, speak to your physiotherapist or occupational therapist.

- **Exercise**
  However your MS affects you, regular activity can keep your body working to its full potential. A physiotherapist can work with you to develop a series of exercises to increase the range of movement you have in specific muscles. This could be a routine you can carry out at home or in the gym, and would be tailored to your abilities and energy levels.

  The MS Society has produced an exercise DVD, *Exercising with MS*, which features a number of stretches for people with MS. You can watch the routines on the MS Society website or on YouTube (search 'exercising with MS'), or contact the shop (see page 15) to order a copy of the DVD.

  Before trying any of the exercises in the DVD, you should speak to your doctor or physiotherapist to make sure that they are safe for you to do.

- **Core stability**
  If you improve your core stability, it can reduce tremor in your limbs. Core stability is the ability to control the position and movement of your torso – the core of your body. A physiotherapist can help you to work on this, by finding exercises that target muscles running the entire length of your torso. These exercises are usually done lying or sitting down.

  Pilates is a form of exercise that specifically focuses on improving core strength. While there hasn't been any research looking into its effect on MS tremor, an MS Society-funded research project found that it may improve other areas including pain, posture, function and quality of life in people with MS who use wheelchairs.

- **Speech therapy**
  If you have tremor in your lips, tongue or jaw it can affect how you speak. This might be either with breath control, which affects phrasing or volume, or with the ability to pronounce sounds.

  A speech therapist can help you to speak more fluently. This could be by changing the speed you speak at, or how you phrase your sentences. They will also look at how you place your lips, tongue and jaw to make sounds, and make suggestions for how you can improve it. If needed, a speech therapist can also offer advice on assistive technology, such as communication charts, speech aids and computer-assisted alternative communication systems.

  Your GP or MS nurse can refer you to a speech therapist.

Managing day-to-day

> I'm right handed, and used to hold the fork in my left hand, like most people do. But now I switch it over to my right hand, so I don't poke myself in the eye or something like that. Sometimes I still use it in my left hand, so I can hold the knife in my right hand, but then I end up putting the knife in my mouth! – *Tony*

An occupational therapist can help you to find techniques for coping with tremor on a day-to-day basis. This might include general advice such as:

- try to plan movements in your head before doing them
- try to work in sequence and give conscious thought to how you move
- try to concentrate on one thing at a time
- plan and prioritise what you want to do, and build in rest breaks
- minimise stress

- keep as fit as you can, and try to eat healthily
- make sure you are sitting in a supported position

Practical tips for day-to-day living

> “I can’t wear jewellery that is fiddly, such as earrings with butterfly clips. I lost so many of them when I dropped them. A friend bought me a necklace where the chain has a simple magnetic fastening – it is brilliant! – *Carole*”

You may have found your own solutions for particular activities – such as using your ‘good’ arm to steady your shaky one, or propping your elbows on the table to eat without spilling your food. An occupational therapist can help you to find other ways to manage, and to reduce the amount of effort involved.

Solutions might include learning to do an activity in a different way, using different equipment or utensils, or making changes to your environment. An occupational therapist can also help you to identify any personal triggers that make your tremor worse, such as heat or stress, and how to avoid them.

Some techniques and equipment that can help include:

- Making sure your clothes don’t have fiddly zips or buttons. This can make getting dressed easier.
- If you’re a woman and your tremor makes it difficult to apply make-up, consider getting an eyelash tint. This will make it look as if you’re wearing mascara.
- In the kitchen, things like non-slip working surfaces, electrical labour-saving gadgets, two-handed cups, and specially designed cutlery, crockery and kitchen utensils can all make preparing and eating food more manageable. Boiling vegetables in a wire basket within the saucepan, so that you don’t have to lift a heavy pan full of water to drain them, can also help. There are more tips in the MS Society booklet *Adaptations and your home*, along with information on sources of funding for equipment like this.
- Eating different foods, if your tremor affects holding or reaching for things. For example, a sandwich may be easier to manage than spaghetti or soup. But sometimes, finding a way to still eat what you love could be as simple as using a different shaped pasta.
- Using pre-chopped or frozen vegetables reduces the amount of preparation you need to do.
- If you find it difficult to hold a drink without spilling it, you could use a straw so you don’t have to lift it.

- Sitting, rather than standing, to do things. You might find a ‘perching stool’ particularly helpful. It’s designed so you can ‘perch’ on it while carrying out daily tasks.
- When you’re using a computer, voice-recognition software can help if you find typing difficult. Adaptive technology such as keyboard guards or a mouse with reduced sensitivity may also help.
- Weighted wristbands or weighted cutlery can be used to dampen down a tremor. However, they appear to only have a temporary benefit, and they may not work for you – particularly if you have problems with fatigue, which they can add to.
- Weighted pens are also available, and some people find them helpful – although they, too, can add to problems with fatigue.
- A Lycra splint (tight-fitting Lycra sleeves, gloves, leggings and so on) may help to stabilise and control movement in the part of your body affected by tremor. You would need to be individually assessed for a Lycra splint, and it would need to be fitted by an experienced therapist.

These are just some of the aids and techniques available – your occupational therapist will be able to advise you what might work best for you. The Disabled Living Foundation also has information about the kinds of equipment available. i

Counselling and support

> “I have friends with MS who have a tremor, too, and I obviously noticed it with them the first time I saw it. But then it just doesn’t seem to matter or be an issue anymore. That made me realise that people were less conscious of it or bothered by it than I thought they would be. That meant I became less self-conscious about my own tremor. – *Carole*”

It can be difficult to live with tremor, as it can directly affect your general well-being, work and social life. You might feel embarrassed about your tremor, and may be avoiding situations which make you feel self-conscious about it. Or it might make you feel anxious, and that anxiety may be making your tremor worse.

Whatever you feel – and it may be different at different times – you don’t have to cope alone. You might find that talking to other people with tremor helps. Your MS nurse, for example, may know about any support groups in your area and may be able to find further support for you and your family. Your local branch of the MS Society may also be able to offer support as well as other activities.

If you think that counselling might help, you can ask your GP or MS nurse for a referral. This may be particularly helpful if anxiety is making your tremor worse. Bear in mind, though, that the availability of counselling on the NHS is quite limited, so you may have to wait a while and may only get a certain number of appointments. You can also ask your GP to recommend a private counsellor, or if counselling is available from any voluntary organisations in your area. Many MS National Therapy Centres offer counselling services.

The MS Society booklet *Mood, depression and emotions* has more information about the emotional impact of MS and how to deal with it. The MS Society freephone Helpline also offers emotional support and information for anyone affected by MS.

Getting support at home

> “I had to ask people to help me more, such as with opening packets. That is very difficult when you are used to being independent – to have to ask for help with little things. But people were always OK and seemed happy to help. – *Carole*”

If tremor is making it difficult for you to do day-to-day tasks, such as preparing meals, shopping or getting dressed, you can ask for an assessment to see if you can get support from social care services (called social work in Scotland). The assessment will look at what your support needs are, and what you would like help with. For example, you may need someone to help you out at home every day, or just for a few hours every week.

The support you get will depend on the outcome of the assessment, and what your local authority can offer. This can vary from place to place. Depending on your income and savings, you may have to pay a contribution towards the cost of the support you receive.

There's more information in the MS Society booklets *Getting the best from social care services*, *Getting the best from social work in Scotland* and *Getting the best from social care services in Wales*. You may also find the MS Society booklet *Adaptations and your home* useful.

Drug treatments

There are a few drug treatments that you can try to help with managing your tremor, but none of them have been specifically developed for MS tremor. Nor have they been tested in large-scale clinical trials. However, there is some evidence that they might help.

How you approach drug treatments for tremor will probably depend on how severe your tremor is, what impact it is having on you, and what the side effects may be. Some people respond to one drug and not another, some to a combination, and some gain little or no benefit from any – it can be a process of trial and error.

A drug called propanolol (a beta-blocker) may reduce tremor when taken in high doses, but this hasn't been confirmed in clinical trials and the effect can be temporary. Furthermore, high doses can also make fatigue worse. But if your tremor severely affects what you are able to do, you may find that even a small impact for a short time makes a significant difference.

Isoniazid (an antibiotic usually used to treat TB) can also reduce tremor if it's taken in high doses. There is some evidence that it has a greater effect on postural tremor than on intention tremor. However, you might find it unpleasant to take as it can cause stomach upset. Isoniazid must also be taken with a form of vitamin B6 known as 'pyridoxine', to help prevent it causing damage to the peripheral nerves (the nerves outside the brain and spinal cord).

Other drugs, such as clonazepam, carbamazepine and gabapentin, may also help but they haven't been properly evaluated for treating tremor. Muscle relaxants, such as tizanidine and baclofen, have been tried as treatments for tremor, but with limited success. Although there is little proven evidence that any of these drugs work for tremor, you can still talk to your GP or neurologist about whether it would be worth trying them.

If your tremor is related to a relapse, a course of steroids can be used to shorten the duration of the relapse – although they have no effect on the tremor itself. Nor have they been shown to affect the progression of MS.

Brain surgery

Surgery may be an option if your tremor is severe, and the other treatment options haven't worked for you.

Most neuroscience centres have the capability to carry out this kind of surgery, but it is not routinely performed on people with MS. It's more widely used in the case of neurological movement disorders such as Parkinson's.

Types of surgery

There are two types of surgery for MS tremor:

- Thalamotomy – sometimes called lesional surgery. This involves burning a tiny lesion in the thalamus. This is a walnut-sized area situated deep within the brain, which controls movement messages. This small burn blocks the message sent from the brain that is causing the tremor.
- Thalamic stimulation – sometimes called deep brain stimulation. This involves leaving electrodes in place in the thalamus. They deliver a small electric current to the thalamus, which has the effect of calming the tremor.

Risks and side effects

These are major surgical procedures, with risks and potentially serious side effects associated with both. These include weakness, mild stroke and problems with speech. These risks appear to be lower with deep brain stimulation, although there is not yet enough evidence to confirm this.

Potential benefits

Thalamotomy and deep brain stimulation can reduce both head and limb tremor in people with MS, although not for everyone who undergoes the surgery. For some people whose tremor is reduced by surgery, symptoms can reappear to some degree, either months or years later.

The technique of deep brain stimulation was originally used to treat tremor in people with Parkinson's. So far it has been less clearly successful in treating MS tremor. Unlike Parkinson's, lesions in MS vary in number and position in the brain and spinal cord, and have different effects on the overall symptom of tremor. This makes it more difficult to relieve MS tremor with surgery.

Complementary therapies

> “I did have massage and acupuncture, not just for the tremor but for other things, and found that it helped, probably because it relaxed me. I know that if I was tired or was suffering from fatigue, the tremor would be worse. Also stress wasn’t good, but that could be because it made everything worse! – *Carole*”

Some people with MS use complementary therapies – such as acupuncture, aromatherapy, or homeopathy – to help manage their tremor, either alongside or instead of conventional treatments. Some people find they help to relieve their symptoms, but others find they make no difference.

Complementary therapies are difficult to research. There is little high-quality research evidence about their effectiveness in treating MS tremor.

If you are thinking about trying a complementary therapy for your MS tremor, it is worth finding out as much as possible about it beforehand. Some complementary therapies have risks and side effects as well as possible benefits. They can also interact with other medications, so it’s always a good idea to discuss it with your GP or neurologist. There’s more information in the MS Society booklet *Complementary and alternative medicine*.

Research

Ongoing research may provide information that could help in the development of treatments for tremor.

- **Surgery**
  There have been a number of studies looking further into the role of surgery in treating tremor. These have evaluated the effectiveness of surgery, and identified key questions for future studies to answer – such as which part of the brain to focus on in surgery, and how to identify the people most likely to benefit from surgery.
- **Cooling**
  Other research includes a small study which looked into the benefits of cooling for MS tremor. Researchers cooled down participants’ arms, aiming to reduce their intention tremor. The results showed improvements in their fine wrist and finger movements. However, as this was only a small trial it’s not yet clear if this cooling could be used in the long term, or who might benefit.

In the meantime, cooling is not yet widely used for treating tremor. Cooling therapies need to be treated with care, and you should speak to your doctor, MS nurse or physiotherapist before trying them. MS can cause changes to the way you experience temperature, distorting the feeling that would normally tell you when something is too hot or too cold.

Further information

Read more

Our free booklets help explain MS, look at its practical and emotional effects, and help you find your own ways to manage life with MS. Information is available in large print, audio format and a number of languages. For copies, email shop@mssociety.org.uk or call 020 8438 0999.

We can help you find and borrow other books, research articles and DVDs about living with MS. Search online or call the librarian on 020 8438 0900.

Find out more online

Get the latest on research, campaigns, and MS news. Chat online with our message boards and Facebook. Follow us on Twitter, see the MS community at Flickr and watch us on YouTube.

Join us

Just by being a member you strengthen the voice of all people affected by MS. For only £5 a year you will receive our national magazines – *MS Matters* and *Research Matters* – local newsletters and details of local events, as well as being able to vote on how we are run. Help us continue our vital work and join online at www.mssociety.org.uk/joinus or by calling 020 8438 0759.

Get in touch

The Freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers. Information is available in over 150 languages through an interpreter service. 0808 800 8000 (weekdays 9am-9pm) or helpline@mssociety.org.uk

Near you

Our volunteers run over 300 local branches and support groups. They provide information about MS and local services, and a chance to meet others affected by MS and take part in a range of activities.

In many parts of the country, you can pick up our booklets at MS Society Info Points. Larger information centres – including ones in our national offices in London, Belfast, Cardiff and Edinburgh (Newbridge) – can help you with information about MS and services in your area.

Or come along to our local and national events and learn more about MS from expert care professionals, researchers and other people with the condition. Find out more online or call your national office.

Useful organisations

DIAL UK

Provides information and advice on all aspects of living with a disability.

Telephone 0808 800 3333
www.scope.org.uk/dial

Disabled Living Foundation

Provides information and advice to disabled people and others who use equipment or assistive technologies to enhance their independence.

Ground Floor
Landmark House
Hammersmith Bridge Road
London W6 9EJ

Helpline 0300 999 0004 (Monday to Friday, 10am-4pm)
www.dlf.org.uk

MS National Therapy Centres

A network of centres offering a range of therapies and support for people with MS.

PO Box 2199
Buckingham MK18 8AR

Telephone 0845 367 0977
www.msntc.org.uk

National Tremor Foundation (NTF)

Provides information and support to anyone affected by tremor, whatever type and whatever the cause.

National Tremor Foundation
Long Term Conditions Centre
Gubbins Lane
Harold Wood RM3 0AR

Telephone 01708 386 399
www.tremor.org.uk

Further reading

Coping with multiple sclerosis: A practical guide to understanding and living with MS by Cynthia Benz and Richard Reynolds. Published by Vermillion (Revised edition 2005), ISBN: 0091902460.

This book includes information on coping with the symptoms and uncertainties of MS, where to find help and a summary of MS research.

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, by email on librarian@mssociety.org.uk or visit www.mssociety.org.uk/library

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If you have any comments on this information or on the work of the MS Society, please send them to resources@mssociety.org.uk

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The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call 0800 100 133 or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

MS Society

100,000 people live with multiple sclerosis in the UK. Every one of them shares the uncertainty of life with MS.

The MS Society is the UK charity fighting to improve treatment and care to help people with MS take control of their lives.

We're a world-leading funder of MS research. We've already made important breakthroughs, and we're now at the start of a generation of MS research that holds incredible promise.

With your support, we will beat MS.

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