

Tremor

Practical living for everyday life with MS

04

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Up to 75% of people with MS experience tremor at some time.¹

Tremor can affect people in very different ways. For some, tremor may be so mild it is not obvious to anyone else. For others, tremor may be more pronounced, causing a drink to spill when the cup is full, for example, or affecting handwriting. For a small percentage of people, it is more severe, causing limbs to shake so that it becomes difficult or even impossible to eat, drink or get dressed without help. Tremor can be frustrating, embarrassing and exhausting to live with.

While tremor is one of the most difficult symptoms of MS to manage, there are things that may be worth exploring to try to alleviate problems. Rehabilitation and drug treatments, and in some cases even surgery, have helped some people with MS tremor. There is no single 'best' approach, so it is likely to take both time and perseverance to work out what will be of most benefit.

What is tremor?

A tremor can be described as a rhythmic, trembling or shaking movement that you cannot control voluntarily. This is different from spasm. When affected muscles stretch, spasticity may also cause them to jerk in an uncontrolled way. This is one kind of muscle 'spasm' that people with MS can experience.

If muscles jerk repeatedly, this is known as 'clonus', for example, when a foot taps repetitively on the floor.

Some people with MS experience other spasms – sudden involuntary movements that can make the arms or legs move in different ways. These can occur even without the muscle being stretched.

For many people with MS, tremor comes on when they want to do something or reach for something. And, frustratingly, the closer they get to the object, the more their hand or arm shakes. This is called intention tremor or movement tremor and is the type of tremor people most often experience in MS. Tremor can also be postural, when you have a tremor as you sit or stand while your muscles try to hold part of the body still against the force of gravity.

In MS, neither of these types of tremor is present when a person is lying down or asleep, that is, when the muscles are completely at rest.² If tremor occurs when you are lying down or asleep, there may be a different reason for it, such as the effects of drugs or perhaps some other condition.

Intention tremor and postural tremor are the two forms of tremor commonly experienced by people with MS, but in practice it is very difficult to classify individual tremors like this. People often experience tremor together with other movement difficulties, such as muscle weakness and problems with co-ordination. The medical term for reduced co-ordination is ataxia, and this word is often used instead of, or as well as, tremor.

Tremor may be experienced as small, shaking movements ("fine" tremor) or as larger movements ("gross" tremor). While it is usually a rhythmic, back-and-forth shaking, tremor can also be irregular and unpredictable.

If tremor develops, it tends to be some years after people's first symptom of MS, typically between five and 15 years, though it can also develop earlier or later than this. A tremor may become gradually noticeable or develop quite swiftly.

Not every tremor is related to MS and there can be other reasons why you experience shaking or trembling. For example, everyone has a small level of tremor (physiological tremor), which caffeine, alcohol or stress can make more noticeable – you may be able to see this when you hold out your hand.

Tremor can also be the result of muscle weakness and problems with posture, a side effect of some medications such as drugs for asthma, or result from other neurological conditions such as Parkinson's.

What causes tremor?

In MS, there is damage to the protective material – or myelin – around the nerves in the central nervous system. (The central nervous system is made up of your brain and spinal cord.) When myelin is damaged, messages are slower or distorted or do not get through at all, causing the symptoms of MS.

MS tremors are most often caused by damage to myelin (known as 'demyelination') in an area of the brain called the cerebellum and the nerve pathways leading to or from it.³ The cerebellum is the part of the brain that controls your balance and co-ordination, 'smoothing out' movements of limbs, speech and eyes. Tremor can also be the result of demyelination in other parts of the brain: the thalamus and the basal ganglia.

Some people may experience tremor during relapses and, like other symptoms, it will often lessen when a relapse is over. However, some level of tremor does tend to remain after a relapse. Even with almost-complete recovery, tremor often remains noticeable because it is associated with such precise, fine movements – such as those involved in reaching for and picking up objects.

People with primary progressive MS, who do not experience relapses, may develop tremor. People who move from having relapsing remitting MS into the secondary progressive phase of MS may also experience tremor. In these people, tremor tends to be a progressive symptom that becomes more severe over time.

Effects of tremor

People are most likely to have a tremor in their hand or arm but tremor can also affect the legs, trunk or head. Some people with tremor may also have problems speaking clearly and co-ordinating their eye movements. Living with a persistent tremor can be difficult. It can be exhausting, as the continuous movements use energy in the same way as voluntary actions do. An intention tremor can affect just about any activity – eating, dressing, shaving, writing and so on – because you reach out and use your hands for so many different activities, so many times each day. If tremor is severe, it can have a significant impact on your abilities and independence. For some people, tremor can also cause feelings of acute embarrassment and self consciousness.

Advice and assistance

For advice or assistance in managing tremor, you can speak to: your GP, MS nurse, neurologist, physiotherapist, occupational therapist or public health nurse. They should also be able to refer you to other experts when needed. These could include, for example, an orthotist (who provides aids to support or help movement of weak joints and muscles), speech and language therapist or counsellor. If specialists are not available locally, referral to experts based outside your local service may be helpful.

Professionals may work as part of a single, multidisciplinary team that cares for people with MS, or you may be referred to specialists based in different departments. This depends on where you live and the way services for people with MS are organised. Care tends to work best when experts work together in a co-ordinated programme.

In many places, MS nurses are the 'key worker' for MS care, the main point of contact for people with MS and their families. They work closely with neurologists, communicating with other professionals to co-ordinate the care you need. Your GP or neurologist should be able to tell you if there is an MS nurse in your area.

Active management

An active approach

Learning to live with tremor is an on-going process. You may need to try different approaches at different times and as your needs change. Be prepared to experiment and work alongside the professionals involved in your care – it may take some time to find out what helps most. Find out all you can and be prepared to be persistent.

The professionals involved in your care will be concerned to find out if there are things that make your tremor worse, what helps and which activities tremor affects most for you. The more you know, the more you can help the professionals to help you. You may want to keep a note of how tremor affects you day to day, to help you give an accurate picture.

Rehabilitation

Rehabilitation medicine brings together nursing, physiotherapy, occupational therapy and other disciplines in a team approach, combining their different expertise.

Rehabilitation can help all people with MS at every stage of their condition. It can help minimise some of the effects of MS, helping you retain your independence, make the most of your abilities and gain relief from distressing symptoms. For many people with MS tremor, rehabilitation can help with managing day-to-day activities.

Physiotherapy and occupational therapy cannot make tremor disappear but they can and do reduce its disabling effects.⁴ A physiotherapist helps you maintain and make the most use of your strength and range of movement.

An occupational therapist helps you find practical ways to manage particular tasks and minimise the effort involved. Physiotherapists and occupational therapists may assess jointly the problems that tremor and other movement difficulties are causing for you and find ways to make them interfere less with daily activities.

Posture and balance:

How you stand or sit – your posture – affects the range of movements you can make, the muscles you use for each activity, and therefore the tasks you can do. A physiotherapist can help you develop stable and controlled posture, both standing and sitting down. An occupational therapist can help you learn to carry out functional daily tasks in ways that help you keep the body as aligned and well-balanced as possible.

Being upright can help develop your balance and help to align muscles so that they work together efficiently. If you use a wheelchair, a physiotherapist may help you stand using supportive equipment as part of developing better postural control. To compensate for tremor, some people might hunch their shoulders, fold their arms or lean to one side, but this can make movement more difficult. Physiotherapists can help you to be more aware of your body and movement.

Seating and support:

The right support for your back and trunk is important, in both armchairs and wheelchairs. If you sit in a chair that is too big, you use unnecessary effort to balance and hold yourself against gravity. This results in tension in the muscles or the need to use muscles that are not designed for the job of balance, which can make the tremor worse. The right support can relax the muscles and calm the tremor. Arm rests that are too high for you may restrict how you use your shoulders. When they are at the right height they can enable your movements to be more co-ordinated.

Exercise:

Whatever your level of disability and MS fatigue, keeping up exercise is important and an appropriate exercise programme can maximise the range of movement you have in specific muscles. A physiotherapist can devise a movement or exercise programme for you to carry out either at home or in the gym.

MS Ireland runs various programmes around the country as part of its Getting the Balance Right campaign. The campaign has proven that there are many benefits to appropriate related exercise activity. The programmes can involve: group or one-to-one physiotherapy; fitness instructor-led gym sessions; yoga, tai chi or other gentle exercise, or hydrotherapy. New participants of the programme are offered an initial assessment with a chartered physiotherapist, and an exercise programme will be developed to most suit your needs.

Meanwhile, MS Ireland also has two booklets on exercise available for download on its website, www.ms-society.ie. *Everybody Stretch* and *MS and Fitness* have been made available courtesy of the MS Society of Canada. Both booklets explore the various facets of exercise, demonstrating practical and safe exercise routines for all levels and ability. The aim is to keep fit and stay active.

Core strength

Physiotherapists can help you to find exercises that can be done from a sitting or lying position. They will try to help you to improve core stability. (This is your centre of movement, the trunk of your body). If you can improve this core stability before taking the limbs away from the trunk it can improve tremor.

Techniques and equipment that can help:

Many people find their own solutions for particular activities – using a ‘good’ arm to steady a shaky one, for example, or propping their elbows on the table in order to eat.

An occupational therapist can help you find other practical ways to manage and to minimise the effort involved. The solution may include learning to do the activity in a different way, changing the equipment or utensils you use and making changes to your environment. It can also involve learning to identify and avoid any personal triggers that make your tremor worse, such as heat or stress.

Even small things can make a real difference – like making sure your clothes don’t have fiddly zips or buttons, for example. A wide variety of equipment can help with particular tasks – from two-handed cups and non-slip working surfaces to electrical, labour-saving gadgets in the kitchen. Techniques to reduce effort can be as simple as boiling vegetables in a wire basket so that you don’t have to lift a heavy pan to drain them.

Additional weight, in the form of weighted wristbands or weighted cutlery for example, can be used to dampen down a tremor, and provides a temporary or partial solution for some people. Weights do not appear to have a lasting benefit, however, and an important consideration is that they could add to problems of fatigue.

Some people have found that a splint or a brace, used to immobilise the affected part of the body, can help them to carry out a specific task, such as writing. Other solutions people have found for writing difficulties include, for example, using plastic overlays to position their signature when they sign cheques, and using voice recognition software – now widely available – to write with a word processor.

Tremors of the lips, tongue or jaw may affect speech by interfering either with breath control for phrasing and loudness or with the ability to pronounce sounds. Speech therapy focuses on increasing the ability to speak fluently. It may involve changing the rate of speaking or the phrasing of sentences. Suggestions may be made as to the placement of the lips, tongue or jaw for the best possible sound production. Speech therapists can also advise on assistive technology like electronic aids, communication charts, or computer-assisted alternative communication systems may help with communication. A GP or MS nurse can refer you to a speech therapist.

Tremor can affect your nutritional needs or your approach to eating. Constant tremor uses up calories, so high-energy foods and drinks between meals might be necessary to avoid weight loss or worsening fatigue. A GP or MS nurse can refer you to a dietician who can advise you. If tremor affects your ability to hold or reach for things, certain foods may be easier to eat than others. A sandwich, for example, may be easier to manage than spaghetti or soup. Specially designed cutlery, crockery and kitchen utensils, can make the preparation and eating of food more manageable.

Quick tips

- Try to plan movements in your head ahead of doing them
- You may find it easier to sit or perch to do things
- Try to work in a sequence and give conscious thought to how you move
- Try to concentrate on one thing at a time
- Plan, prioritise what you want to do, and build in rest breaks
- Minimise stress
- Keep as fit as you can and try to eat healthily

These are just some of the aids and techniques available. An occupational therapist can advise on what may be appropriate for you. The Disabled Living Foundation can provide information on the kind of equipment that is available.

Counselling and support

In a world where people are so conscious of body image, it can be difficult to live with tremor. It can directly affect some people's general well-being, work and social life.

Whatever you feel – and it may be different at different times – you don't have to cope alone. An MS nurse, for example, may be able to find further support for you and your family. Some people also find that counselling helps in the longer term. Your MS nurse, GP or MS Regional Community Worker can refer you to an experienced counsellor. A free time-limited counselling programme is available through MS Ireland.

See the information booklet Living publication *Mood, depression and emotions*, for further information. Some people find it helpful to socialise with other people with MS. You could ask any of the professionals involved in your care or your local MS Ireland Regional Office about support and activities near you. Regional Office and voluntary Branches offer a number of social opportunities.

Self-help groups can also be a great help. Your local Regional office can advise of suitable groups near you.

The MS Ireland Information Line, 1850 233 233, also offers emotional support and information for anyone affected by MS.

Getting help at home

If tremor makes it difficult to do day-to-day tasks, you are entitled to have an assessment for a home help, a carer or a personal assistant. The assessment will be used to decide what services you need. For example, you might benefit from carers helping out at home for just a few hours per week, or for a few hours every day. Carers can help with tasks such as preparing meals, shopping or getting dressed. Services provided by the HSE vary from area to area. Where this service is not available through the HSE you may have to pay for the cost of these care services. Sometimes it can be difficult to allow strangers into your home to help but if family members aren't available and you feel that day-to-day tasks would be improved greatly by a carer's presence, then you should consider it.

Drug treatments

There are no drugs specifically for treating MS tremor. However, some people have found that drugs licensed for treating other conditions can be beneficial in reducing tremor. Few of these drugs have been evaluated in trials or studies for tremor in MS and none has been tested in large-scale clinical trials for MS tremor.

A drug called Propranolol has been said to reduce tremor for some people when taken in high doses,⁵ but this has not been confirmed in clinical trials and its effect can be temporary.⁶ However, for some people, even a small decrease in tremor for a short time may make a significant difference to what they are able to do.

Another drug, Isoniazid, can also lessen tremor when taken in high doses, and there is some evidence that it may have a greater effect on postural tremor than on intention tremor.⁷ However, many people find it unpleasant to take as it can cause stomach upset. Isoniazid must also be taken with another drug, Pyridoxine, to help prevent it from causing any damage to peripheral nerves (nerves outside the brain and spinal cord).

Some benefit has been reported from drugs such as Clonazepam, Carbamazepine and Gabapentin but they have not been properly evaluated. Other drugs with a muscle-relaxing effect have also been tried as treatments for tremor, though with very limited success. While the evidence is not available to say with any certainty whether or not they will be beneficial, you may want to ask your GP or neurologist whether it would be worth trying

them. Your approach to trying drug treatments for tremor will depend on how severe your tremor is, what impact it is having on you and your carers, and what the side effects may be. Some people find little or no benefit, some respond to one drug and others to a combination – it can be a process of trial and error.

When tremor is related to a relapse, steroids may be used to shorten the duration of the relapse. Steroids do not have an effect either on tremor itself or the progression of MS.⁸

Surgery

For a few people with severe tremor, surgery may offer a chance of improvement in their quality of life. Surgery would be considered only when other options are not effective, and is appropriate for only a few people.

Surgery to reduce tremor in MS is still at an early stage of development. Few centres carry out this surgery and there remains much to learn about it.

There are two types of surgery:

- Thalamotomy or lesional surgery. This involves burning a tiny lesion in the thalamus, 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 movement.⁹
- Thalamic stimulation or 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. The first deep brain stimulation procedure in Ireland took place at the Mater Private Hospital in 2009.

These are major surgical procedures, with risks and potentially serious side-effects associated with them both. These include weakness, hemiparesis (a mild stroke) and problems with speech. These risks appear to be lower with deep brain stimulation but the comparative benefits and risks of lesional surgery and deep brain stimulation in treating MS tremor are not yet clear.

Thalamotomy and deep brain stimulation have been shown to reduce both limb and head tremor in people with MS, though not for everyone who undergoes the surgery. The effects of either surgery are not always permanent.

For some people whose tremor is reduced by surgery, tremor can re-appear 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.¹⁰ 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. Therefore, it is more difficult to relieve tremor in MS through surgery.

Work continues to try to refine surgical techniques for MS tremor.^{11, 12}

Complementary therapies

Complementary therapies include a wide range of options: acupuncture, aromatherapy, herbalism and homeopathy are just a few. Some people find complementary therapies help to relieve particular symptoms or make them feel better. Others find they make no difference.

Complementary therapies are difficult to research. There is little high-quality research evidence about their effectiveness, even less about complementary therapies and MS specifically, and less still about complementary therapies and MS tremor.

As with orthodox treatments, there are risks and side effects associated with complementary therapies, and they can also interact with other medications in adverse ways; 'natural' does not necessarily mean 'benign'.

If you are considering any complementary therapy, you should first find out as much as you can and discuss it with your GP or neurologist.

Research

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

As mentioned before, there has been considerable interest in the role of surgery in treating MS tremor. Recent studies have evaluated the effectiveness of surgery and identified key questions for future studies to answer, such as which part of the brain is best to focus on in surgery, and how best to identify the people who might benefit from surgery.

In recent years, there has also been research into cannabis-based medicines for MS symptoms. Two 'placebo-controlled, double-blind' trials (generally considered the most reliable form of research) have been carried out, but found no benefits from using cannabis-based medicines to treat MS tremor.^{13,14} To date, no cannabis-based drug has been licensed specifically for MS tremor in Ireland. However, Sativex has been licensed in the UK and Canada, after GW Pharmaceuticals announced results of two trials in 2009, and reported that in 74% of people with MS, taking a fixed dose of Sativex led to an improvement in levels of spasticity.¹⁵

Sativex has so far been used in people who have not gained adequate relief from their existing treatment. While a large proportion of people with MS are helped further during treatment with Sativex, some people may not improve at all.

Further information

MS Ireland publications

MS Ireland has a number of publications relating to many aspects of living with MS. To view and download all our publications for free, log onto our website www.ms-society.ie.

MS Ireland website and magazine

Keep up to date with news relating to MS by logging onto our website www.ms-society.ie and signing up to receive regular email updates. Members also receive our magazine, MSNews.

MS Information Line, 1850 233 233

The MS Information Line is an information and listening service for anyone needing immediate information or support on any aspect of MS. It is a confidential service

Regional Services

10 Regional offices around the country provide individuals and their families a home visit service where our trained staff can answer queries, offer advice and provide referrals, if necessary. Regional offices also provide a programme of activities for groups of people; newly diagnosed days, carers support groups, personal development sessions and a range of physiotherapy and exercise interventions.

Local Branch Network

MS Ireland has 41 voluntary Branches that provide information and support to the local MS community. Run by people affected by MS, the Branches offer many social opportunities to people with MS and their families to come together and share experiences.

MS Care Centre

The centre provides short-term respite care, therapy services, neurological assessments and social activities for residents. While staying at the Centre residents can speak to our many trained professionals including the MS nurse and the Physiotherapist.

Your neurologist, MS nurse, GP, physiotherapy and other health-care professionals are also a key source of information.

Useful organisations

Association of Occupational Therapists of Ireland

PO Box 11555
Ground Floor Office
Bow Bridge House
Bow Lane
Kilmainham
Dublin 8
Tel: 01 633 7222
Email: aoti@eircom.net / info@aoti.ie
www.aoti.ie

Irish Society of Chartered Physiotherapists

Royal College of Surgeons
123 St Stephen's Green
Dublin 2
Tel: 01 402 2148
Fax: 01 402 2160
Email: info@iscp.ie
www.iscp.ie or www.physicaltherapy.ie

Assist Ireland

Citizens Information Board
Ground Floor
Georges Quay House
43 Townsend St
Dublin 2
Ireland
Tel: 1890 277 478
Email: support@assistireland.ie
SMS text messaging: 086 383 7644

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.

Everybody Stretch: A Physical Activity Workbook for People with Various Levels of Multiple Sclerosis

by Jane Fowler, BPE. Published by MS Society of Canada. This book helps individuals design an exercise routine under the supervision of a health professional regardless of their level of disability. Available at http://www.ms-society.ie/uploads/File/everyone_stretch_canadianbooklet.pdf

MS and Fitness: Guide for people with multiple sclerosis

by Pierre Picard. Published by MS Society of Canada. This upbeat booklet aims to make fitness a part of everyone's lifestyle, providing examples of physical activity. Available at http://ms-society.ie/uploads/File/MSandFitness_canadianbooklet.pdf

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Suggestions for improvement in future editions are welcomed. Please send them to info@ms-society.ie

Multiple Sclerosis Ireland

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults, and we estimate that around 8,000 people in the Ireland have MS. MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body. For some people, MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

MS Ireland is the only national organisation providing information, support and advocacy services to those affected by MS, their families, employers, health professionals and others interested in MS.

- Individual and family support
- Living with MS programmes, activities and workshops
- Confidential Information Line, 1850 233 233
- Respite and therapy centre
- Advocacy and lobbying
- National Conferences
- Professional counselling
- 41 Voluntary Branches, nationwide
- MSnews magazine and e-newsletter
- Website www.ms-society.ie
- Information and research

You can help the work of MS Ireland by:

- becoming a member (open to anyone);
- making a donation or fundraising;
- offering your time as a volunteer.

Contact information

To learn more about our services or to make contact with local services, contact our national office:

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Tel: 01 678 1600

Fax: 01 678 1601

Email: info@ms-society.ie

Information Line: 1850 233 233

Web: www.ms-society.ie

