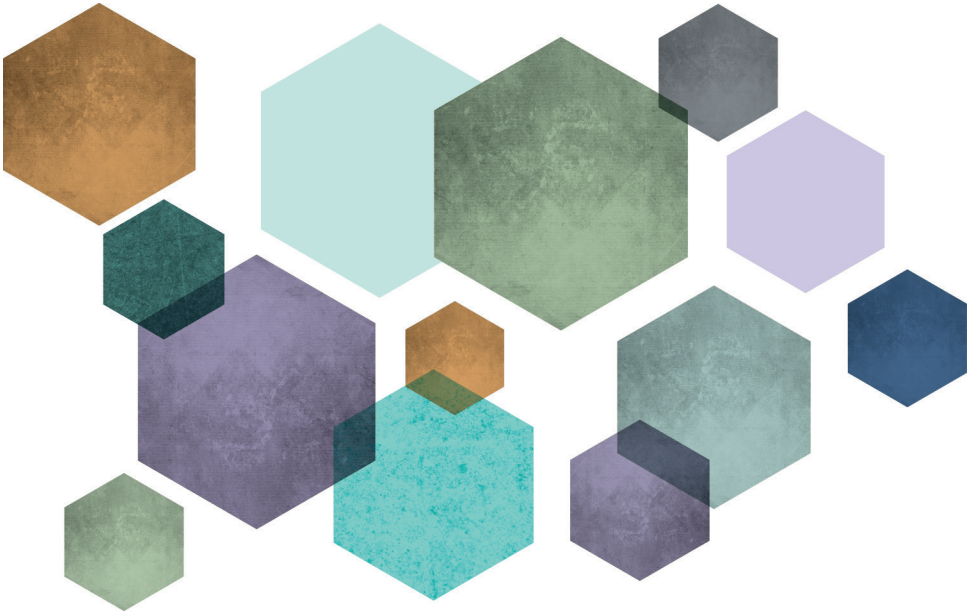
Managing spasticity and spasms

A guide for people with MS



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Introduction

As many as **9 out of 10** people with MS will be affected by muscle spasms or spasticity at some point in their life. Most will only experience occasional symptoms. However, **1 in 5** people report that spasticity and spasms frequently affect their activities and **1 in 8** describe their symptoms as severe.

"My leg spasms used to wake me and my partner up, they were so violent. Getting treatment has made a huge difference."

If you have muscles that feel stiff, heavy or difficult to move, or you experience sudden or painful tightening of your muscles, then this book will explain why this happens. This book also explores how you can manage these MS symptoms yourself and with the help of your health professional team.

Often, muscle spasms and spasticity are triggered or made worse by other factors, such as infection or a change in routine. By working through the spasticity questionnaire and diary in this book, you can identify your personal trigger factors. You and your health team can then work together to reduce the impact that spasticity and spasms have on your life.

1. What causes spasticity and spasms in MS?

Spasticity is when your muscles feel stiff, heavy and hard to move. When spasticity is severe, it can be very hard to bend or move that limb at all. Your arms or legs may be stiff and difficult for you or someone else to move.

You may have spasticity in your neck or torso as well. These might make you twist or arch your spine or make your rib area feel tight or painful.

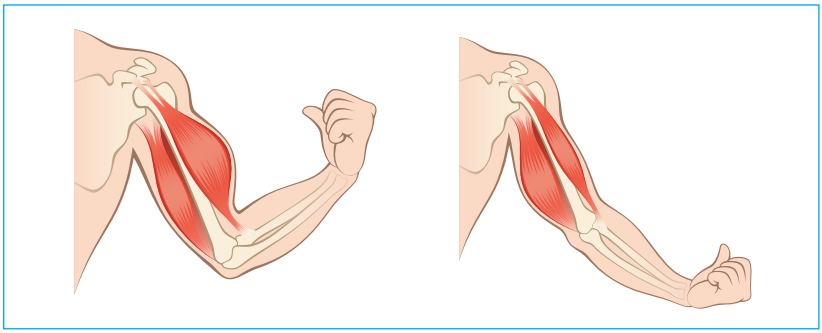
A spasm is a sudden stiffening or contraction of a muscle. It can affect any muscle in your body, but most commonly the limbs or torso. Spasms can cause your limbs to kick out, your legs clamp together or jerk towards your body.

"I'm always unsteady in the mornings, until I've had a chance to stretch out my stiff legs."

Both spasticity and spasms can range from mild to severe, and vary over time. They can be painful, affect your movement, and cause falls.

Spasticity and spasms are caused by an increase in muscle tone or tension in that muscle. Normally, your brain coordinates smooth movement in your arms and legs by tightening and relaxing muscles in pairs.

For example, in the arm, the biceps must relax and the triceps must tighten, in order to straighten the arm.



If the nerve pathways between the brain and muscles are damaged by MS, your muscle might remain short and tight instead of relaxing, or tighten in an uncontrolled way. In the arm example, this might mean that the biceps muscle stays tight and prevents the triceps from straightening your arm.

2. What can I do for myself, if I have spasticity or spasms?

If you experience mild or occasional problems with spasticity or spasms, you can try the following ideas yourself.

Movement and stretching

It is important to keep your muscles, ligaments and joints as flexible as possible. You can do this by regular stretching, movement or massage. If you can't move your own limbs, then passive movement, where your limbs are moved by your carer, physiotherapist or an automated exercise machine, may help.

Consult a physiotherapist for advice on the best way to maintain your flexibility. They will be able to teach you specific stretches that you can incorporate into your daily routine, or suggest exercise classes, such as yoga or Pilates, that you could join. The aim would be to gently explore your full range of motion and release tension in the muscles throughout your body.

For more resources on exercise in MS, visit www.mstrust.org.uk/exercise.

Posture

Poor posture can lead to muscle and joint pain, and can also make spasticity and spasms worse. Try to maintain good posture, whether you are standing, sitting or lying down, avoiding strain or tension where possible.

Physiotherapists and occupational therapists can advise you on posture, help you find adapted seating and aids to improve your posture in sleep, at work or when relaxing.

For more resources on posture in MS, visit www.mstrust.org.uk/posture.

Know your trigger factors

Many people with spasticity or spasms find that they worsen in response to certain factors. These might include tight clothing, pressure sores, an infection or extremes of temperature. If you can learn what tends to set off a spasm, or worsen spasticity, then you may be able to avoid your triggers.

Chapter 4 of this book describes common trigger factors in MS, and explains how to recognise your personal triggers.

When should I speak to a health professional?

Spasticity and spasms can be distressing and interfere with your daily life. There is no need to delay consulting a health professional, or struggle alone with spasticity or spasms. Your MS health team need to know the challenges you face, and the severity of your regular symptoms, in order to understand how well controlled your MS is.

If spasticity remains untreated, you can end up with the affected muscle becoming permanently tight and shortened. This is called a contracture, and can cause pain and poor mobility. A contracture may require surgery to release it.

However, having spoken to your health team, the decision about whether to seek treatment is up to you. Your health team will work with you to decide what to do next and to make a treatment plan. This might include using drugs (described in Chapter 3), physiotherapy or other options. A combination approach is often appropriate.

3. How are spasticity and spasms treated?

Health professionals treating spasticity and spasms will be aiming to reduce the stiffness in your muscles, whilst not reducing their strength. If you remove all of the spasticity from a limb, the muscles may be too weak to work properly. For instance, if you have spasticity in your leg, the stiffness may help to keep it rigid enough to help you walk. If all of the stiffness is removed, the muscles might be too weak to hold you up or allow you to transfer between positions.

Drug treatments

There are several medications for spasticity.

Baclofen

Pregabalin

Clonazepam

Tizanidine

Gabapentin

Dantrolene

Diazepam

You can find more information on these drugs at www.mstrust.org.uk/a-z.

Clinical guidelines suggest that the first options to try should be baclofen or gabapentin, or a combination of both. Treatment usually starts with a low dose and gradually increases until a level is reached that helps you best.

All medications come with a risk of side effects. For spasticity medication, side effects may include increased fatigue, dizziness or muscle weakness. You may need to explore with your team which drug and dosage schedule works best for you.

TIP

The time of day that you take your medication can make a big difference. For instance if you struggle to get up, washed and dressed, taking your medication 10-20 minutes before you get out of bed may ease the effort of your morning routine. If you need some stiffness in your legs to help you get out of bed safely, you may prefer to take your treatment after you have got up.

Alternatively, if you are troubled by spasms at night, then taking your medication in the evening may improve your sleep. The side effects may wear off by the morning so you don't notice them.

Cannabis-based treatments

Sativex is a cannabis-based mouth spray that is licensed for the treatment of MS spasticity. It can be prescribed by a specialist doctor anywhere in the UK. In some regions you may find it harder to access, if prescribing services are not yet ready. If no improvement is seen within 4 weeks, treatment will be stopped, as only around half of people respond to Sativex.

Cannabis oils containing the cannabinoid CBD can be sold legally in the UK, providing they do not make any claims for medical benefit. There have been few clinical trials in MS, although anecdotal reports suggest that some people with MS find CBD oils beneficial for their spasticity or spasms.

Botulinum toxin

If spasticity affects only part of your body botulinum toxin may be helpful. Botulinum toxin is injected into specific muscles and temporarily weakens them for about three months. During this period

your health care professional can advise you on splinting, moving and stretching exercises that you can do to reduce the effects of spasticity in the longer-term.

Intrathecal baclofen

Intrathecal baclofen therapy involves having surgery to place a small pump in your abdomen. The pump delivers baclofen through a fine tube (called a catheter) into the fluid space around your spinal cord (called the intrathecal space). The pump uses much smaller doses of baclofen than when you it take it as tablets and so causes fewer side effects.

"My baclofen pump has been a godsend. I have better relief and hardly notice any side effects."

Phenol

Treatment with phenol is usually only used if you have severe spasticity that hasn't responded to other treatments. Phenol is given via a lumbar puncture into the space around the spinal cord. This is an irreversible, destructive treatment that permanently stops nerve messages. Phenol treatment can greatly reduce spasticity in your legs without the risks of surgery. However, phenol treatment may also reduce the ability to move your legs, skin sensation, affect sexual function and alter how your bladder and bowel work.

If your doctor is considering treatment with phenol, you will already be aware of these symptoms and may have a urethral or suprapubic catheter, a skin management programme to avoid pressure ulcers or be using suppositories regularly.

Surgery

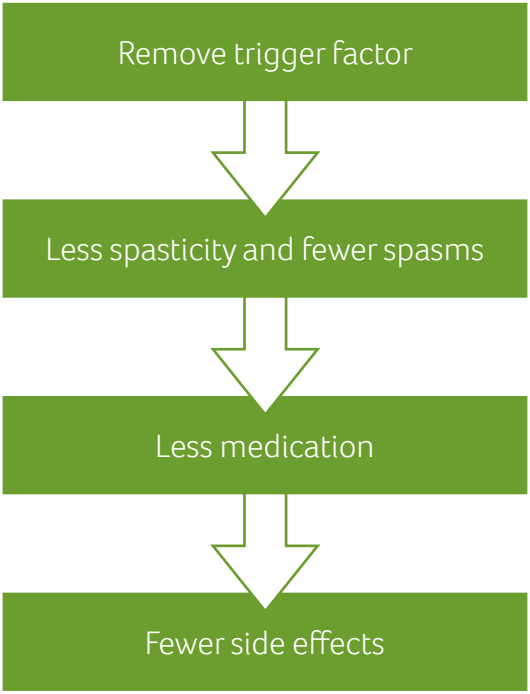
Surgery is rarely performed to reduce spasticity. If you have contractures, your neurologist may recommend surgery once the spasticity has been effectively treated with oral medication or intrathecal baclofen.

4. What can make muscle spasms and spasticity worse?

Stiffness and spasms can be dramatically worsened by trigger factors. If the trigger factor is managed appropriately then your symptoms of stiffness and spasms will ease without needing any medication.

"My partner finds that his leg spasms come on as he gets more tired throughout the day. He has to rest!"

If the trigger factor is not managed appropriately then this can lead to worsening of your symptoms, unnecessary medication changes or secondary problems such as contractures.



How do I identify what my trigger factor is?

The following pages present a list of known trigger factors for spasticity or spasms. If your spasticity or spasms have worsened, read through the list to identify whether any of these factors have changed recently.

Where you have noticed a change in your normal function or routine, tick the relevant box. There is space at the bottom of each section where you can make notes on the details, either for your own information or to discuss with your health team.

TIP

If you have difficulty identifying your trigger factors then you may find it helpful to fill in the stiffness and spasms diary in Chapter 5 first.

Bladder problems

A urinary tract infection (UTI) is one of the most common causes of worsening spasms/stiffness and may require antibiotic treatment. Once the UTI is treated, you should find that your spasticity or spasms improve, if this is a trigger factor for you.

If you have been going to the toilet more often than normal, you have pain when passing urine or notice an unpleasant smell from your urine, you may have a urinary tract infection. However, it is possible to have an infection without any symptoms.

It is always worthwhile taking a sample of urine to your MS nurse or GP practice for testing if your spasticity or spasms have worsened.

If you have a catheter and notice any change in colour or smell from your urine, take a sample of urine to your GP for testing. If your catheter is causing pain or is blocking then contact your district nurse or continence nurse.

Going to the toilet to pass urine but needing to go back again shortly after, or difficulty starting a flow of urine may mean that your bladder isn't emptying properly. This can irritate your bladder and make you more at risk of infection.

Pain in the lower abdomen or recurrent UTIs could indicate problems with your bladder or kidneys and may require further investigation. You should see your GP for further assessment, and they can refer you to a specialist continence service if necessary.

Have you noticed anything from this list recently?

- More frequent visits to the toilet ☐
- Pain when passing urine ☐
- Unpleasant smell from urine ☐
- Change in colour of urine ☐
- Painful catheter ☐
- Blocked catheter ☐
- Difficulty starting urine flow ☐
- Needing to go again after passing urine ☐
- Pain in the lower abdomen ☐
- Recurrent UTIs ☐

Bowel problems

A change in your normal bowel routine is another common cause of worsening spasms or stiffness. If you have more difficulty moving your bowels, are moving them less often than normal, or your stools are hard and difficult to pass, this can indicate that you are constipated.

Constipation with episodes of diarrhoea may indicate that you are extremely constipated and have a full bowel, known as an impacted bowel. This may need urgent attention and you should see your GP for further management.

Any other bowel problem such as an upset stomach or irritable bowel syndrome can also impact on your stiffness and spasms. Your GP can help with appropriate treatment.

Have you noticed anything from this list recently?

- Difficulty moving bowels ☐
- Pain passing stools ☐
- Change in stool consistency ☐
- Change in frequency or routine ☐
- Bowel urgency ☐
- Bowel accidents ☐
- Diarrhoea ☐
- Impacted bowel ☐
- Irritable bowel syndrome ☐
- Constipation ☐

Skin problems

Anything rubbing on your skin can cause irritation, redness or blistering. This in turn can be a trigger for your stiffness or spasms to worsen. Think about whether you've worn tight clothing, if new shoes are causing friction, if you have sunburn or you've noticed rubbing from a leg splint or urinary catheter. You might also have had a skin rash as a side effect of medication, or experienced a burn.

It's important that the cause of the irritation is dealt with or you may risk developing an infection. If you're unable to manage this problem yourself, then see your GP for further advice.

If you have trouble moving or changing position, you may be at risk of pressure sores. Excessive pressure on the skin affects your circulation and can lead to skin damage and breakdown, also known as pressure sores. It's a good idea for you or a carer to check your skin on a daily basis, and see your GP at the first sign of skin damage.

If you develop a pressure sore, you will most likely need regular treatment from your district nurse or practice nurse. A tissue viability nurse, physiotherapist or occupational therapist will be able to advise you on how to avoid developing pressure sores.

"When the pressure sore on my father's foot finally healed, we all noticed he was getting fewer spasms."

Have you noticed anything from this list recently?

- Skin irritation ☐
- Tight clothing ☐
- New shoes ☐
- Burns ☐
- Sunburn ☐
- Rashes ☐
- Blisters ☐
- Pressure sores ☐
- Skin damage ☐

Infections

Any infection will aggravate your stiffness and spasms until the infection has settled. Common types of infection are urinary tract infections, chest infections, infected wounds or sores in the mouth or teeth, and common illnesses such as a cold, flu or tummy bug. If you suspect you have an infection you should see your GP or dentist for appropriate treatment.

Some people can experience a worsening of their symptoms after the flu vaccination. This is generally a short-term effect and your symptoms should settle down in time. If you are concerned then see your GP for further advice.

"I hate getting a cough. I feel that it brings on the dreaded MS hug and spasms around my ribs."

Have you noticed anything from this list recently?

- Cold ☐
- Cough ☐
- Chest infection ☐
- Recent vaccination ☐
- Tooth pain ☐
- Gum infection ☐
- Infected toe or fingernail ☐
- Tummy bug ☐
- Eye infection ☐
- Insect bite ☐

Pain

If you have difficulty changing your position when lying or sitting you may experience discomfort where you have too much pressure on certain parts of your body. If this is causing worsening of your symptoms then contact your local physiotherapist or occupational therapist for advice on how you can use simple props to help you change position or be more comfortable in your home furniture or wheelchair.

"I have a complicated arrangement of cushions under my legs in bed, which means I can generally sleep without pain or spasms."

Any new or unexplained pain should always be checked out by your GP. They can prescribe appropriate pain medication and refer you for further investigation if required. If you have nerve pain or unusual skin sensations, your GP may refer you to your MS nurse or neurologist for further advice.

If you have a new joint or muscle pain you can consult a physiotherapist, either through referring yourself directly or via your GP.

Have you noticed anything from this list recently?

- New or unexplained pain ☐
- Unusual skin sensations ☐
- Numbness ☐
- Nerve pain ☐
- Muscle pain ☐
- Joint pain ☐
- Headaches ☐

Other possible trigger factors

Being overtired can temporarily worsen your symptoms. This may be due to physical tiredness, mental exhaustion or difficulty sleeping. Your symptoms should generally ease as your energy levels improve. You could speak to your MS nurse, local physiotherapist or occupational therapist for help to pace your activities and manage your fatigue.

Being too hot or too cold can cause your stiffness and spasms to temporarily worsen. Try to keep your temperature as constant as you can. The spasms and stiffness should ease once you become more comfortable.

"Cold weather is the worst for my spasms! I find that a hot water bottle or heated blanket helps ease them."

If you are feeling stressed or anxious about something, then your symptoms may worsen. Sometimes just being aware of your feelings can help, but you may benefit from speaking to someone about the things that are bothering you. Your GP can refer you for counselling if required, or you can talk to family and friends.

"I find stress is the worst thing for my spasms. I do deep breathing and take medication to help."

Have you noticed anything from this list recently?

- Fatigue ☐
- Less sleep than usual ☐
- Insomnia ☐
- Low energy levels ☐
- Increased physical activity ☐
- Too hot ☐
- Too cold ☐
- Stress at work ☐
- Emotional troubles ☐
- Anxiety ☐
- Depression ☐
- Family troubles ☐

5. Stiffness and spasms diary

Using a stiffness/spasms diary for a week can help you identify what causes your symptoms to worsen.

How do I fill in the diary?

The day is divided into 6 sections – on awakening, morning, lunchtime, afternoon, evening and bedtime.

Use this scale to note how troubled you are by your stiffness/spasms – there is a box in each section for you to write down your score.

1 = not at all troubled

2 = a little troubled

3 = moderately troubled

4 = extremely troubled

If you are troubled by stiffness and spasms, write down in the space provided what you were doing at the time, how you were feeling or anything you think might be relevant – this will help you identify what triggered your stiffness or spasms. As much information as possible will help.

At the end of the week review the diary to see if you can identify a pattern.

What do I do once I've completed my diary?

Read the list of trigger factors and make notes on what applies to you. Try to take the actions suggested in the booklet.

If you are still unable to identify what is aggravating your symptoms, contact your MS nurse or physiotherapist for further advice.

Extra copies of the diary can be downloaded from the MS Trust website at www.mstrust.org.uk/trigger-diary.

Note how troubled you are by your stiffness/spasms throughout the day. Write down your score in each box.

	Monday	Tuesday	Wednesday
On awakening			
Morning			
Lunchtime			
Afternoon			
Evening			
Bedtime			

1 = not at all troubled
2 = a little troubled
3 = moderately troubled
4 = extremely troubled

Thursday	Friday	Saturday	Sunday

Is there a pattern?
What was happening when your spasticity or spasms were troublesome?

About the author

MS Trust Information Team

The MS Trust is a UK charity for people with MS, their family and friends. We have a personalised enquiry service and provide extensive information through our website, social media and printed publications.

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