



Multiple sclerosis— related spasticity:

Answers for you
and your loved ones

Spasticity
A:nswers



As a patient with multiple sclerosis (MS), or support partner for a loved one who has MS, it is important to understand that the symptoms of MS can be life changing, but are often manageable. The information in this booklet can help. We hope you find it to be a useful resource that can help you take charge of your life and become an active participant in your, or a loved one's, treatment.

The following pages also contain thoughts from specialists Amos Katz, MD, Christopher Hughes, MD, PhD, and Gregory San Andres, OT, who are experts at diagnosing and treating the complications of MS.

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You or your loved one is living with multiple sclerosis (MS)

Living with MS presents many challenges. As you face these challenges, know that you are not alone. There is a wealth of medical and practical information available to help you through your journey.

MS causes sites of inflammation in the brain and spinal cord. As a result, your nerves may not function properly.

The symptoms of MS vary from person to person and over the course of the disease.¹ Attacks of MS can involve muscle weakness, trouble with balance, or fatigue. Additionally, some individuals may experience problems with vision. In this booklet we will talk about another symptom that people with MS often experience: spasticity.

This booklet is designed to help you and your loved ones understand and recognize spasticity. This information may

help you initiate a discussion with your physician about spasticity and what the options may be for treatment.

As you navigate through the maze of MS care, ***it is important to understand that the disease can cause many different symptoms, while other symptoms may be unrelated to the condition. Reviewing any new symptoms with your physician is the only way to determine their relevance to your disease.*** You need to speak out about your symptoms so you can receive the help you need and deserve.



What is spasticity?

Spasticity is a condition in which certain muscles are constantly contracting, causing an increase in muscle tone and leading to stiffness or tightness that may be painful.

When someone tries to move your limb for you, they experience resistance caused by the increased muscle tone. Characteristically, spasticity worsens with increasing attempts at movement. Spasticity can make even simple movements and tasks difficult or impossible—from buttoning a shirt to using the restroom without help.

When spasticity affects the arms, hands, or fingers, it is called *upper limb spasticity*.

For more information on spasticity, please visit

GoToSpasticityAnswers.com

or call

1-888-ULS-INFO (1-888-857-4636)

How do I know if I have spasticity?

*It is sometimes difficult to tell whether or not you have **spasticity**.* Spasticity can lead to a range of sensations, from mild muscle stiffness to severe, painful, and uncontrollable muscle spasms.^{2,3}

Symptoms of spasticity may include²:

- Increased muscle tone that may be experienced as discomfort, tightness, stiffness, or pain
- Rapid muscle contractions
- Muscle spasms
- Difficulty moving certain joints
- Heightened muscle contraction in response to muscle stretching

Some of the general symptoms listed above may be caused by a number of different health conditions. ***That's why it's important to talk to your specialist about all of the symptoms you're experiencing, including spasticity.***

Common signs of spasticity



*Flexed thumb and
flexed fingers*



*Wrist slightly flexed,
fingers curled*



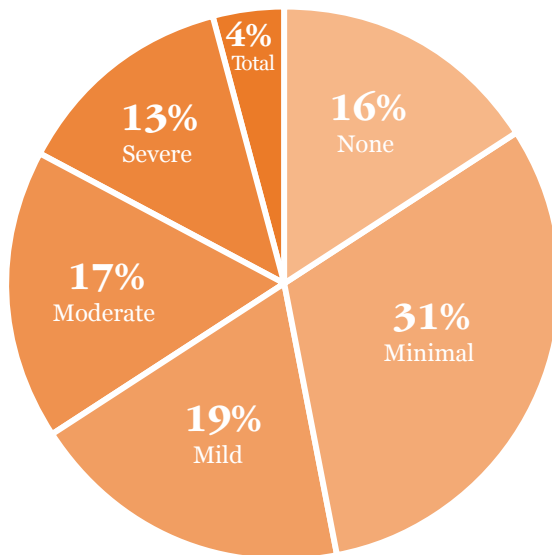
Flexed elbow



Clenched fist

Will I develop spasticity?

About 84% of individuals with MS develop at least some spasticity, according to a survey of 20,969 patients enrolled in the North American Research Committee on Multiple Sclerosis (NARCOMS) Patient Registry.⁴



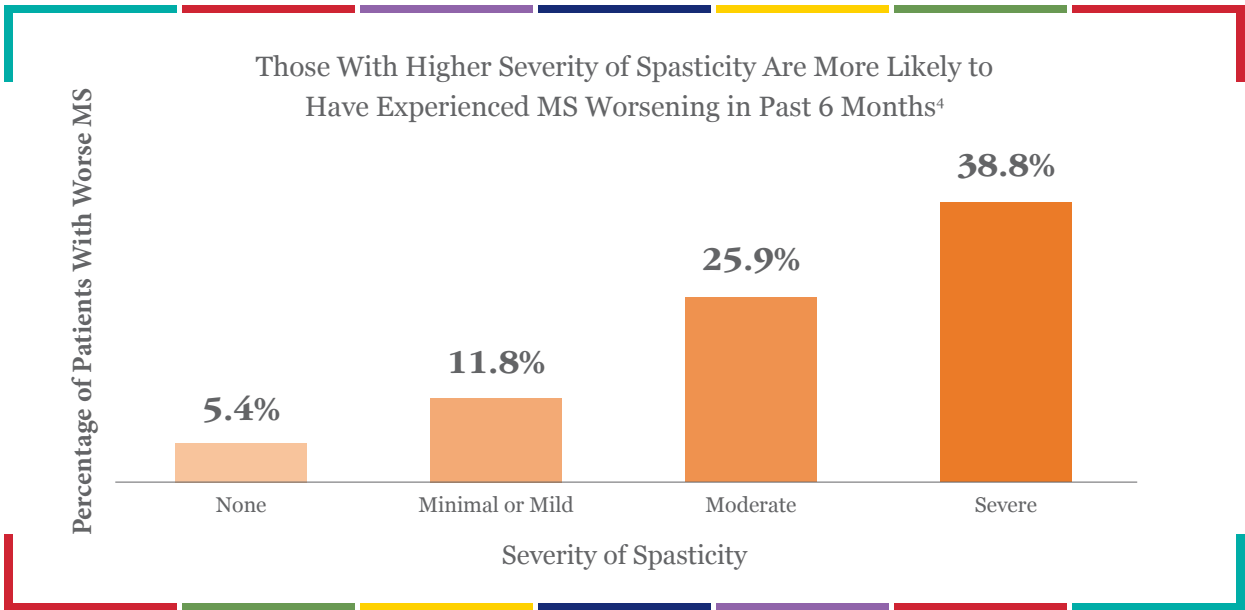
Percentage of individuals with multiple sclerosis experiencing various levels of spasticity (N = 20,969).⁴

- **None (16%):** No symptoms of spasticity
- **Minimal (31%):** I notice some problems with spasticity, but they do not interfere with my activities
- **Mild (19%):** Spasticity occasionally forces me to change some of my activities; ie, once a week or less
- **Moderate (17%):** Spasticity frequently affects some of my activities; ie, several times a week
- **Severe (13%):** Every day; spasticity problems force me to modify my daily activities
- **Total (4%):** Every day; spasticity problems prevent me from doing many of my daily activities

When does spasticity develop?

Although there is no set time frame in which spasticity occurs, *individuals who have had MS longer are more likely to show greater levels of spasticity.*⁴ Spasticity more commonly results from worsening of disease or having had a relapse within the previous 6 months, based on a study of 20,969 MS patients.⁴

The uncertain time frame for the development of spasticity can interfere with diagnosis. For this reason, it is very important that you tell your doctor about all your symptoms (or your loved one's symptoms, if you are a support partner).



Spasticity can cause different types of problems

Just as the severity of spasticity varies, so do the problems that you may experience as a result.⁵

You may have problems with the following^{5,6}:

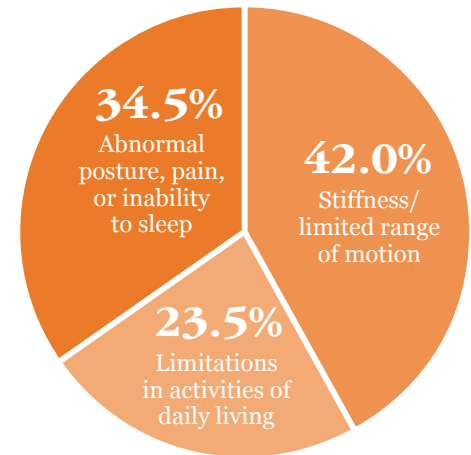
- Picking up objects
- Washing
- Sleeping
- Dressing
- Walking up and down stairs
- Preparing meals

Spasticity may interfere with rehabilitation,² such as your ability to do physical or occupational therapy.

Some people may experience⁵⁻⁹:

- Pain
- Depression
- Poor self-image
- Dependence on caregivers
- Increased medical costs
- Skin problems

Because each individual may be affected differently by spasticity, it is important to be specific when discussing your particular problems with your specialist.



Percentage of 810 people with spasticity who identified each aspect of their condition as having the most significant impact on their quality of life.⁵

Why haven't I heard of spasticity?

You may not have heard much about spasticity. ***Spasticity often develops during the later stages of MS and may not be recognized as a significant issue until it has been present for many months.*** Therefore, it may not have been discussed with you.

Be informed about spasticity so you can be your own advocate in your care. As with most conditions, education and information are your best tools.

Family members and support partners should also know about spasticity. The stiffness and tightness of hands, wrists, and arms can limit a loved one's recovery progress and chance for more independent living. You may be the first person to notice symptoms in your loved one and start the discussion with his or her doctor. Being an informed advocate for your loved one's recovery can give him or her the best chance of maintaining or recovering as much independence as possible.

It is important to speak to your doctor if you feel you or your loved one has symptoms or difficulties that are not being addressed.

Thoughts from a neurologist, *Amos Katz, MD*



Amos Katz, MD, is a Clinical Assistant Professor of Neurology at Robert Wood Johnson Medical School in New Brunswick, New Jersey. Dr. Katz is also the Medical Director of the Linda Cardinale MS Center at CentraState Medical Center in New Jersey. He is certified in both neurology and psychiatry, and has a special interest in spasticity.

Spasticity in the MS patient can be difficult to detect because it typically develops gradually. Loss of strength, reduced range of motion, and pain may be signs that you are developing spasticity.

Spasticity is one of the factors that can affect employment in patients with MS.^{4,10} Because MS tends to begin when individuals are in their 20s, 30s, or 40s, it has the potential to affect many years of work. In addition to spasticity, disease progression, symptom duration, disability, and functional limitations can also have an effect on employment in MS patients.^{4,10}

Spasticity can also be a source of embarrassment for people with MS. For instance, upper limb spasticity may make it difficult to hold a glass, and patients may avoid going out to restaurants for fear of dropping their drinks.

Because doctors do not always test for spasticity, it is important to be your own advocate. Tell your doctor about the problems you are experiencing—they may or may not be due to spasticity. Your doctor may be able to help figure out whether your problems are due to spasticity, or can refer you to a doctor who is specially trained to understand and diagnose spasticity.

Spasticity can also affect you at work

Individuals with greater levels of spasticity are less likely to be employed than those with no or minimal spasticity, based on a survey of 20,969 patients.⁴

Various factors, such as MS progression, underlie both spasticity and reduced employment. Additional studies are needed to help better understand the role of spasticity in employment.



Tell your doctor about the problems you are experiencing. Your problems may or may not be due to spasticity. Your doctor may be able to determine if your problems are caused by spasticity and treat you accordingly. You may also be referred to a specialist who treats spasticity.

Why is detection of spasticity important?

Spasticity is associated with impairments, activity limitations (disability), reliance on caregivers, restriction of participation, and reduced quality of life.¹¹

Spasticity is also associated with an increased risk of falls.¹²

For people with MS, spasticity may cause feelings of embarrassment, dependence, and stress that may influence social and emotional relationships.¹³

Spasticity can progress if left untreated.

- Treating spasticity early in its course may help avoid the development of functional problems, as well as loss of activity and participation¹⁴
- Treating spasticity may help avoid the development of complications later on¹⁵
- It should be noted, however, that not all spasticity requires treatment

Who treats spasticity?

A number of health problems can occur at the same time in MS, making it difficult to recognize spasticity. Many different types of medical specialists have expertise in evaluating and treating spasticity.¹⁶⁻¹⁸ ***These specialists often work together as part of the spasticity rehabilitation team.***

- Physiatrists are doctors who specialize in physical medicine and rehabilitation (PM&R). Physiatrists are nerve, muscle, and bone experts who treat injuries or illnesses that affect how you move. They aim to restore maximum function lost through injury, illness, or disabling conditions
- Neurologists are doctors who specialize in diagnosing, treating, and managing disorders of the brain and nervous system
- Physical therapists are professionals who guide you through rehabilitation exercises, and occupational therapists are professionals who help adapt your environment to meet your needs

Learning about the specialties of these and other medical professionals may seem confusing, but may ***help you and your loved one match your treatment needs with the right treatment providers.***

The first step in finding out whether or not you have spasticity is to talk to your doctor. ***You may need to initiate this discussion instead of waiting for someone to bring it up.***

Tests for spasticity: thoughts from a neurologist, *Christopher Hughes, MD, PhD*



Christopher Hughes, MD, PhD, is a neurologist at the Southern Maine Medical Center in Biddeford, Maine. Dr. Hughes holds MD and PhD degrees from the University of Illinois at Chicago. He has treated MS patients for 20 years and is a specialist in the treatment of spasticity. Dr. Hughes is a nationally respected speaker on issues related to multiple sclerosis.

If you suspect you may have spasticity, your doctor may recommend several different tests to help make the diagnosis.

Physical tests help evaluate nerve activity or shortening of muscles due to spasticity. Your doctor will observe your movements and feel the muscles in your affected limb(s), observe your range of motion, and look for signs of spastic “catching” and rapid muscle tightening.¹⁹ Rating scales can be used to quantify spasticity, muscle tone, and your response to treatment. The Ashworth Scale is a commonly used measure in which muscle tone is rated from 0 to 4.²⁰

Functional tests measure your ability to move your limbs and perform daily tasks such as grasping objects, dressing, washing hands, dialing a phone, and walking.²¹ Functional tests may also help assess pain.

There is no single “best” test for spasticity, and no single test measures everything about the condition.²² Many doctors choose more than one test, and their choices may vary depending on the pattern of spasticity presented by each person.



What type of treatment is right for my spasticity?

Whether your spasticity has just appeared or whether you have been dealing with the symptoms for some time, ***there may be a treatment option that can help you.***

The main types of treatment for spasticity are physical and occupational therapy, injection therapy, oral medications, intrathecal (the fluid surrounding the spinal cord) therapy, orthotics, and surgery.^{2,3}



Thoughts on occupational therapy in MS from *Gregory San Andres, OT*



Gregory San Andres, OT, is the Senior Occupational Therapist at CentraState Medical Center and is the Clinical Specialist at the NeuroRehabilitation Center and Multiple Sclerosis Center in Freehold, New Jersey. He holds national board certification in occupational therapy and is a multiple sclerosis certified specialist. Mr. San Andres is also an active member of the clinical advisory committee for the National Multiple Sclerosis Society, New Jersey Metro Chapter.

Education is an important first step in helping MS patients with their spasticity. Spasticity may fluctuate over the course of a day and can be exacerbated by environmental triggers such as cold temperatures and humidity. Behaviors such as poor posture and tight clothing can make spasticity worse, as can medical conditions such as urinary tract infections, viral infections, and constipation.

Even though we usually think of spasticity as being detrimental, it may actually help certain patients perform one or more activities. However, spasticity can also lead to permanent and irreversible fixed limitations of joint mobility, called *contractures*, and reduced range of motion. So it is typically important to address the increased muscle

tone through a rehabilitation program that involves physical and/or occupational therapy.

Stretching is a fundamental aspect of physical and occupational therapy for spasticity.

Different types of stretching exercises may be recommended depending on each individual's particular needs.²³ Many patients are able to perform stretches on their own; whereas, others must rely on family or support partners. Splints, braces, or casts may be used to align joints and prevent muscles from shortening. Stretching can be combined with yoga, massage, tai chi, meditation therapy, or breathing exercises to promote relaxation. Strengthening exercises are also typically useful for spastic muscles, as well as their nonspastic counterparts.

What should I do if I think I may have spasticity?

If you think you may have spasticity, ***it is important to learn as much as possible about the condition.*** For more information, you may want to visit the Spasticity Answers website or call the upper limb spasticity hotline at the number listed below.

For more information, visit the Spasticity Answers website at

GoToSpasticityAnswers.com

or call

1-888-ULS-INFO (1-888-857-4636)

It is important to determine the effects of spasticity on your activities of daily living, so speaking with an occupational therapist and your physician is recommended to create a collaborative treatment plan individualized to your needs and lifestyle.

It is also important to explore and discuss your goals for treatment, along with available treatment options, with your specialist. The following pages may help you prepare for a discussion with your specialist about spasticity.

How can I prepare for a discussion about spasticity treatment with my specialist?

There are numerous factors to consider when you and your specialist begin to explore treatment for spasticity. These include¹⁵:

- Where you feel you are experiencing symptoms of spasticity
- How consistent your spasticity symptoms are
- The severity of your condition
- How much care and support are available to you
- How much your symptoms of spasticity are affecting your life



Questions to consider when discussing your symptoms with your specialist:

- What are my *specific* symptoms?
- What symptoms bother me the most?
- What activities am I having trouble with?

Some patients and support partners find it helpful to make a written list of issues they wish to discuss with their specialist.

Answers to the following questions may be worth sharing with your specialist:

Are you experiencing muscle stiffness or tightening in the upper limb?

☐ Yes ☐ No

When did you first notice the symptoms?

Describe how your activities of daily living have been affected by your symptoms:

If applicable, the level of muscle stiffness you are experiencing is:

☐ Mild ☐ Moderate ☐ Severe

Have you had any of the following treatments for your muscle stiffness?

- ☐ Oral medications
- ☐ Physical/occupational therapy
- ☐ Injection therapy
- ☐ Intrathecal medication
- ☐ Surgery

How would you rate the effect of your treatment?

Please rate on a scale from 1 to 5 (1 = poor; 5 = very good).

What do you wish?

Prepare for a meaningful discussion with your specialist by considering the wishes below that are expressed by many people with spasticity.

- ☐ Have less muscle tightness and stiffness
- ☐ Unclench my hand
- ☐ Be less dependent on others for help
- ☐ Button my shirt or tie my shoes without help
- ☐ Carry items such as a purse, grocery bag, or laundry basket
- ☐ Open my hands to wash them
- ☐ Feel less embarrassed about my arm position
- ☐ Lift a cup and hold it steady while drinking
- ☐ Raise my arm to reach into a cabinet or style my hair
- ☐ Put on clothing without help



Your specialist may have different treatment ideas than you do about what your treatment should accomplish.¹⁵ For this reason, it is always important to communicate with your specialist so you, your support partner, and your entire healthcare team all understand what is expected of treatment.

Resources

Your specialist is the best source of information about your condition, related spasticity, and treatment. In addition, there are many organizations that offer support, education, and services for patients and support partners. Some of these may have local chapters in your area.

Can Do MS

1-800-367-3101
www.mscando.org

MSWorld

www.msworld.org

Multiple Sclerosis Association of America

1-800-532-7667
www.msaa.com

National Multiple Sclerosis Society

1-800-344-4867
www.nationalmssociety.org

Paralyzed Veterans of America

1-800-424-8200
www.pva.org

The organizations listed are provided as potential resources for patients and support partners; they are not endorsed by Allergan.

For more information on MS-related spasticity, please visit

GoToSpasticityAnswers.com

or call

1-888-ULS-INFO (1-888-857-4636)

This website allows you to create your own specialist discussion guide and access information that is relevant for you.



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Note pages for patient use:

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

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For more information about spasticity, visit
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