



more  
TO **MS**<sup>TM</sup>

## Are you experiencing *invisible* MS symptoms?

There are a wide variety of symptoms people living with MS experience that are not always visible to others.

Learn more about these *invisible* symptoms of MS, how they can affect you, and how you can talk to your doctor about it.

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To find out more about MS  
and MS symptoms visit

**MoretoMS.eu** 



# How MS affects your central nervous system (CNS)

MS is an autoimmune disease in which  
your own immune cells attack your CNS<sup>1</sup>



The CNS includes your brain, spinal cord, and optic nerves. It communicates by sending signals through nerve cells, also called neurons.<sup>1,2</sup>



Neurons help you process and respond to the world around you. They can also be damaged by MS.<sup>1,2</sup>



Myelin is a substance that forms a protective layer over neurons. This helps neurons send signals quickly and effectively.<sup>3</sup>



In MS, for unknown reasons, immune cells attack myelin, damaging or destroying it and causing inflammation.<sup>4</sup>



When myelin is damaged or destroyed, it becomes harder for neurons to communicate quickly and effectively.<sup>1,3</sup>

# MS can cause a variety of symptoms

People living with MS can experience  
a variety of symptoms, including<sup>5,6</sup>:

Vision problems

Difficulty thinking

Fatigue

Emotional  
changes

Bladder and/  
or bowel  
problems

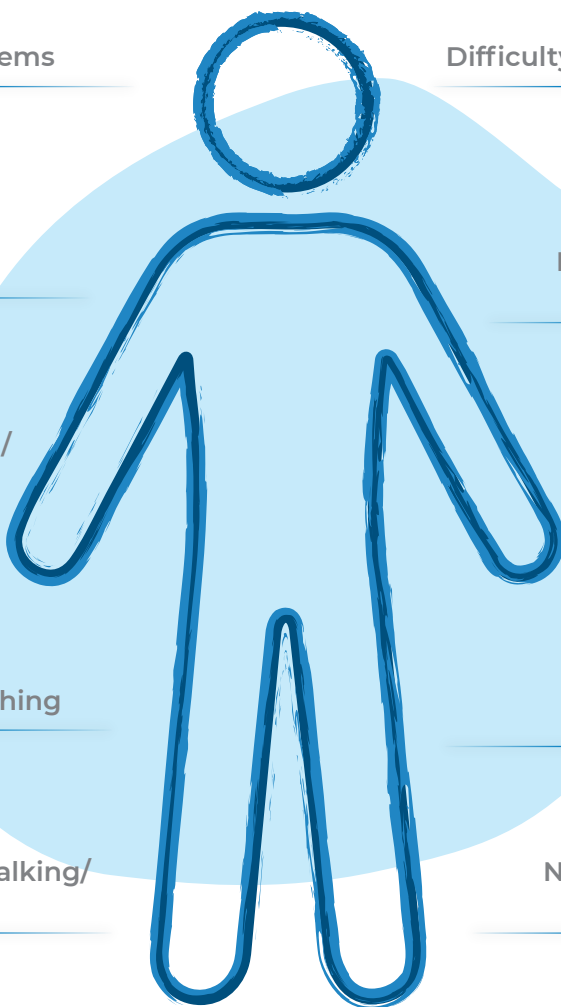
Tremor

Pain and itching

Spasticity

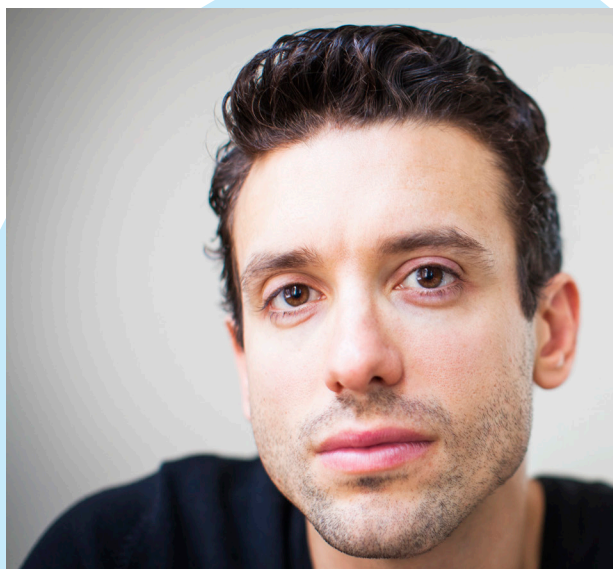
Difficulty walking/  
gait issues

Numbness/  
tingling



# How can MS symptoms affect your life?

MS symptoms can impact your life in a variety of ways including<sup>7,8</sup>:



**Feeling limited** when carrying out intense activities



Having to reduce **daily work activities**



**Feeling fatigued** or exhausted



**Functioning** at work, around the house, helping your children and leisure activities



Imposing a **practical, emotional and financial** strain



**Feeling frustrated**

# MS can cause a variety of symptoms

Many people with MS experience  
*invisible* symptoms



**These are symptoms that can't necessarily be seen by others. (such as fatigue, cognitive problems, pain and bowel and bladder dysfunction)**

***Invisible* symptoms** of MS can significantly impact your life and are just as **important** to how you feel as the 'visible' symptoms.<sup>9-11</sup>

They can be difficult to talk about and you may feel like your *invisible* symptoms are being ignored, questioned or misunderstood by the people around you.<sup>10,11</sup>

**It is important to talk** openly and honestly about all of your MS symptoms to avoid misunderstandings that can put a strain on your emotional well-being and your relationships.



# How do people describe their *invisible* MS symptoms?

*Invisible* MS symptoms can be hard for others to understand



***Invisible*** MS symptoms aren't always easy to explain to others. They affect everyone differently, and people living with MS have unique ways to describe it. Below are some examples.

Others explain their MS symptoms in their own words...

“MS fatigue makes me feel like I'm wearing a suit of lead.”

**Elsbeth, 37,**  
diagnosed with  
Relapsing-Remitting Multiple  
Sclerosis (RRMS)  
about 3 years ago

“I feel like I'm in a fog.”

**Leann, 39,**  
diagnosed with RRMS  
about 11 years ago

# How to adjust to life with MS symptoms?

MS symptoms  
can cause life adjustments



MS symptoms may change how you are able to spend your time. At first, you may want to just push through them but you may find that you need to plan for and prioritise certain activities. Or you may have to simplify or stop activities.

What one person with MS says about pushing through MS symptoms...

“There have been times when I know I’ve pushed myself a little harder than maybe I should have and then for the next several days I notice I’m more tired and need to rest more.”

...and about learning to plan around MS symptoms.

“One thing that I learned pretty quickly after getting my diagnosis is that you really need to pick and choose what is your priority.”

Elsbeth, 37, diagnosed with RRMS about 3 years ago



**If you find yourself living life around your MS symptoms, it's important to discuss this with your doctor.**

# Remember, if you're experiencing MS symptoms...

## Your healthcare team is there to help!

It all starts with a conversation. Here are some suggestions\* to help you talk to your doctor about your MS symptoms at your next visit.



- Talk about whether physical or mental symptoms has made certain activities harder for you, such as cooking, working or visiting friends



- Write down questions about MS symptoms that you would like to discuss at your next visit to your doctor



- Talk to friends, family, and other people living with MS about your MS symptoms and how it affects you



- Check out other resources for people living with MS

Randy, 38, was diagnosed with RRMS about 8 years ago. He was initially hesitant to talk about his *invisible* MS symptoms with his doctor...

**“The first couple of years, even though I was starting to notice fatigue a little bit more, I wouldn't talk about it. I was just hoping it would go away.”**

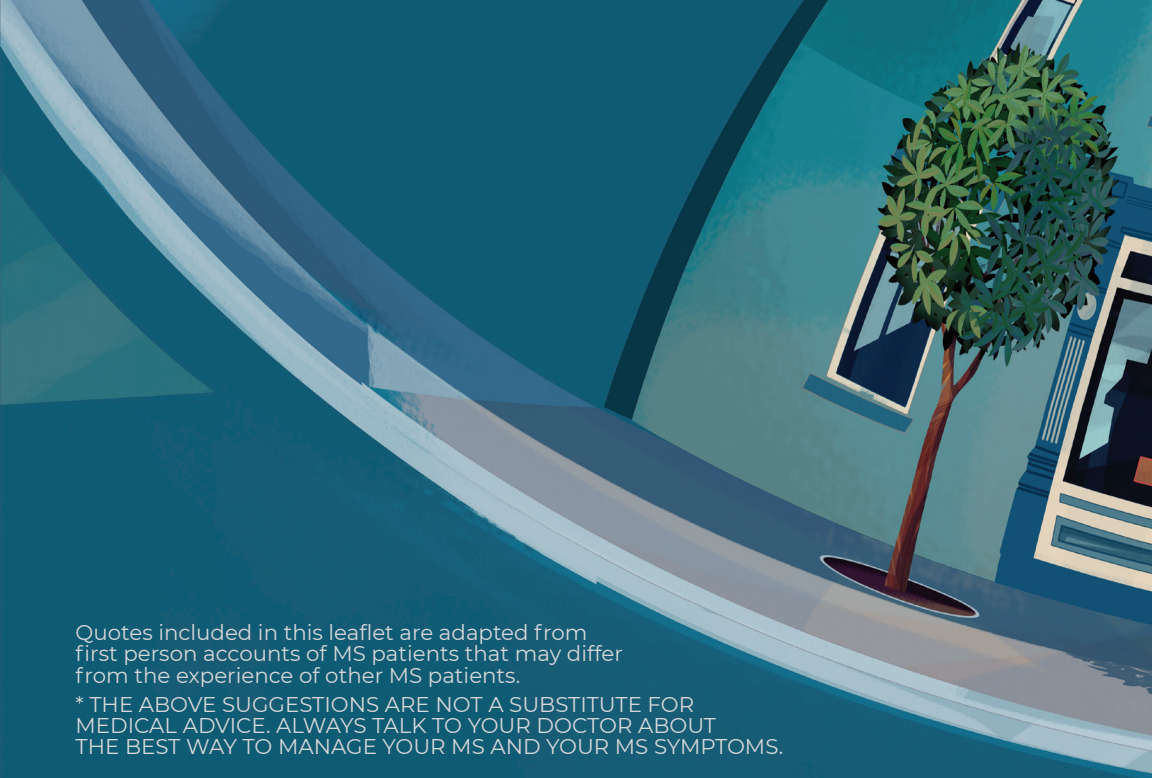
...but after speaking up, he and his doctor now talk about it regularly.

**“Now my doctor actually has that on his list. So he brings it up every time I come into the office.”**

To find out more about MS and MS symptoms visit **MoretoMS.eu**







Quotes included in this leaflet are adapted from first person accounts of MS patients that may differ from the experience of other MS patients.

\* THE ABOVE SUGGESTIONS ARE NOT A SUBSTITUTE FOR MEDICAL ADVICE. ALWAYS TALK TO YOUR DOCTOR ABOUT THE BEST WAY TO MANAGE YOUR MS AND YOUR MS SYMPTOMS.

1. National MS Society/What is MS. Accessed September 25, 2020. <https://www.nationalmssociety.org/What-is-MS>.
2. National Institutes of Health/Know your brain/"Making Connections" Accessed August 24, 2020 <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Know-Your-Brain>.
3. National MS Society/What is MS/Definition of MS/Myelin. Accessed August 24, 2020. <https://www.nationalmssociety.org/What-is-MS/Definition-of-MS/Myelin>
4. National Institutes of Health/Hope Through Research/glossary. Accessed August 24, 2020. [https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Multiple-Sclerosis-Hope-Through-Research#3215\\_3](https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Multiple-Sclerosis-Hope-Through-Research#3215_3)
5. National MS Society/ Symptoms and Diagnosis/MS Symptoms. Accessed June 29, 2020. <https://www.nationalmssociety.org/Symptoms-and-Diagnosis/MS-Symptoms>.
6. Giovannoni G, Butzkueven H, Dhib-Jalbut S, et al. Brain health: time matters in multiple sclerosis. *Mult Scler Relat Disord*. 2016; 9 Suppl 1:S5-S48. doi:10.1016/j.msard.2016.07.003.
7. Ysraelit MC, Fiol MP, Gaitán MI, Correale J. Quality of Life Assessment in Multiple Sclerosis: Different Perception between Patients and Neurologists. *Front Neurol*. 2018; 8: 729. Published 2018 Jan 11. doi:10.3389/fneur.2017.00729
8. Mortensen G, Rasmussen PV. The impact of quality of life on treatment preferences in multiple sclerosis patients. *Patient Prefer Adherence*. 2017; 11: 1789-1796. Published 2017 Oct 19. doi:10.2147/PPA.S142373
9. Kister I, Bacon TE, Chamot E, et al. Natural history of multiple sclerosis symptoms. *Int J MS Care*. 2013; 15(3): 146-158. doi:10.7224/1537-2073.2012-053.
10. Parker L-S, Topcu G, De Boos D et al. The notion of "invisibility" in people's experiences of the symptoms of multiple sclerosis: a systematic meta-synthesis. *Disability and Rehabilitation*. 2020; 1-15. doi:10.1080/09638288.2020.1741698
11. Green R, Cutter G, Friendly M, et al. Which symptoms contribute the most to patients' perception of health in multiple sclerosis? *Multiple Scler J Exp Transl Clin*. 2017; 3(3): 1-6.

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