Managing Multiple Sclerosis

Whether you are newly diagnosed with MS or have been living with MS for years, navigating this complex disease can feel challenging. Asking the right questions during your conversation will help you know what to expect and how to better navigate your condition. Familiarize yourself with these common terms before your appointment to help facilitate your discussion.

**Vocabulary to Know**
Your doctor might mention these common terms. Here’s what they mean.

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tr>
<td>Myelin</td>
<td>The fatty covering that insulates nerve fibers, helping them send signals to one another rapidly and effectively.</td>
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<td>Demyelination</td>
<td>The process by which the myelin surrounding nerve fibers is damaged, so nerve signaling is impaired, leading to a variety of MS symptoms.</td>
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<td>Central Nervous System</td>
<td>Consists of the brain, spinal cord, and optic nerve. Only myelin in the central nervous system is damaged in MS (not the peripheral nervous system, which are the nerves located outside of the brain and spinal cord).</td>
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<td>Magnetic Resonance Imaging (MRI)</td>
<td>An essential imaging test that uses magnetic fields and radio waves (not radiation) for both diagnosing and monitoring MS (tracking the course of a person’s disease is especially important for making treatment decisions).</td>
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<td>Relapse</td>
<td>The appearance of new neurological symptoms or a worsening of prior symptoms that lasts for at least 24 hours and is separated from the previous relapse by at least 30 days. Also referred to as an MS attack, exacerbation, or flare.</td>
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<td>Gadolinium-Enhancing Lesion</td>
<td>An area of active inflammation, as seen on a brain or spinal cord MRI, which signals that the myelin sheath is being attacked by a person’s immune system.</td>
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<td>Silent Lesion</td>
<td>Areas or spots visualized on an MRI that represent MS-related demyelination but cause no symptoms to the patient.</td>
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<td>Disease-Modifying Medications</td>
<td>These medications, while not curable, can decrease the number and severity of relapses and slow the overall progression of MS. There are currently fifteen medications approved for treating MS.</td>
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<td>Uhthoff Phenomenon</td>
<td>The temporary worsening of one or more MS symptoms when the body’s core temperature is increased, such as from a fever, exercise, or hot/humid weather.</td>
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<td>Paresthesia</td>
<td>A common sensory symptom of MS that describes abnormal sensations like “pins and needles,” numbness, tingling, burning, or itching.</td>
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<td>Spasticity</td>
<td>A common “motor” or movement symptom of MS that describes muscle tightness, stiffness, and/or painful spasms.</td>
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Questions to Ask
These questions will help you start a conversation with your doctor about how to best manage your MS.

About Symptoms
- Why does someone else I know with MS have different symptoms than me?
- Why do my MS symptoms get worse in the summer or when I take a hot shower?
- Is it true that exercise can help ease MS-related fatigue?
- Are my symptoms permanent or will they go away at some point?
- What should I do if I develop new neurological symptoms—call my doctor or go to the hospital?

About Causes & Risk Factors
- If I have MS, are my children at a higher risk for developing it?
- Is MS contagious?
- I heard vitamin D deficiency may be associated with MS development and/or disease progression. Should I be taking Vitamin D?
- Besides stress, are there other factors that may trigger an MS relapse?

About Diagnosis
- Is a spinal tap required to make a diagnosis of MS?
- Is there a blood test that can diagnose MS?
- What are the different types of MS and what does that mean for my disease management?
- I’ve already been diagnosed with MS. Why do I still need periodic MRIs?

About Treatment
- How does my MS health care team know if my disease-modifying medication is working?
- If I do not like to give myself an injection, are there other MS drug options available?
About Treatment (continued)

- Are there complementary and alternative medicines available to treat my MS?
- Am I able to receive vaccinations, like the flu shot, while taking an MS disease-modifying medication?

About Coping

- What should I do when people tell me I look wonderful, but I don't feel wonderful—in other words, how can I manage my “invisible” MS symptoms?
- Who can assist me with any financial concerns I have related to my MS care?
- Will my MS be fatal?
- I feel like so much is out of my control. How can I take a proactive stance in my MS health?

About Living With MS

- Is there a specific diet, like the ketogenic or Swank diet, that will prevent an MS relapse or ease my symptoms?
- Does having MS mean I will require a wheelchair at some point in time?
- Can I become pregnant with MS?
- How do I talk to my children about MS?
- Do I still need to see a primary care doctor, even though I’m seeing my neurologist regularly?