

An illustration of a park at night. Two people, a man and a woman, are walking away from the viewer on a path. The man is wearing a hat and a long coat, and the woman is wearing a long coat. They are walking towards a city skyline in the background. There are trees on the left and right sides of the path. Streetlights are visible along the path, casting a warm glow. The sky is dark blue with some clouds. The overall mood is peaceful and serene.

healthline

# Navigating Your MS Care:

How to Find and  
Work with a Doctor

Jackie Zimmerman



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## How to Find and Work with a Doctor

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*This e-book was medically reviewed by  
Nancy Hammond, MD.*

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# Introduction

**Whether you're newly diagnosed with multiple sclerosis (MS) or a veteran like myself, you may at times feel overwhelmed, uncertain, or frustrated. But you don't have to navigate MS on your own. This guide is here to help.**

When I was diagnosed with relapsing-remitting multiple sclerosis over 13 years ago, resources simply weren't available like they are today. I had to learn a lot through trial and error. Though I now consider myself to be well-educated about MS, being chronically ill, and navigating healthcare, I'm still learning. We can learn together and support each other through our massive online community — and through websites, blogs, and resources like this e-book.

One of the most difficult things I've experienced throughout this journey is how to communicate with my doctor and how to be heard as a patient and, more importantly, as a person. Though I've seen over eight neurologists since my diagnosis, I've received great treatment from only two of them, and felt like a partner in my own care with just one of them.

In my interactions with providers, I've felt a strong, invisible barrier between them and myself. For many of us with MS, that barrier can lead to an overall sense of defeat. I believe the No. 1 culprit preventing effective partnerships between doctors and patients is communication. With better communication, we can be partners in our own health and receive the best quality care.

I wish I could sit beside you at every appointment to help advocate for you. Since that's not possible, I'll instead help you create a folder full of resources, checklists, and discussion guides to bring to your appointments. It'll be like I'm right there with you, cheering you on. You can even print out my picture and put it in there if that helps!

You've got this,



**JACKIE ZIMMERMAN**

*Veteran MS patient and advocate*

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# Symptom Guide

You are unique. You are so unique that your life with MS could, and probably does, look very different than mine. One of the most complicated parts of MS is the difficulty in identifying symptoms because each and every one of us presents differently.

MS isn't like high blood pressure, which is diagnosed through a single test and treated directly. We as patients, and MS as a disease, are much, much more complicated.

When it comes to MS symptoms, there are some that present more often and are considered [to be common](#). These include:

**walking problems**

**vision impairment**

(blurred vision or double vision)

**numbness or tingling**

**muscle weakness**

**fatigue**

**muscle pain and stiffness**

**trouble urinating or constipation**

**dysarthria**

(slurred or slowed speech)

**dysphagia**

(difficulty swallowing)

**Lhermitte's sign**

(an intense burst of pain like an electric shock that runs down your back into your arms and legs when you move your neck)

**nystagmus**

(repetitive and uncontrolled eye movements. You may notice that things seem to be wiggling or moving.)

**Uhthoff's phenomenon**

(worsening of MS symptoms caused by an increase in internal temperature often associated with exercise or sitting in the sun)

These symptoms are arguably the easiest to identify because many of them are physical and have visible consequences.

However, it's important to remember that MS is a disease of the central nervous system, which means it could affect anything your brain controls. Movement, sensations, cognitive function, and speech can all be affected by MS, which is what makes each case of MS so unique.

So, what about MS symptoms that aren't considered common? Here is a list of uncommon MS-related symptoms that are worth keeping on your radar. If you experience any of these symptoms, bring them up with your doctor. You can also learn more about other uncommon MS symptoms [here](#).

**Cognitive functions:** People with MS can have trouble with memory, concentration, and finding the right words.

**Depression:** Depression isn't uncommon among people with MS. However, diagnosis can be difficult because it's not a visible ailment. [Clinical depression is more frequently diagnosed among people with MS](#) than it is among many other groups.

**Lack of symptoms:** It's possible for people with MS to be asymptomatic, showing little to zero signs of MS in their daily life. However, even without symptoms, they may still have lesions in the brain, which can be causing what's called [silent damage or inflammation](#). The best way to track silent symptoms is through regular MRI scans.

**Light sensitivity:** People with MS can experience an increased sensitivity to natural and fluorescent lighting. Sometimes, light sensitivity can be related to an MS medication.

**Loss of hearing:** Hearing loss can happen during a relapse, or it can be generally associated with damage to the hearing nerve pathways in the brain or brainstem.

**Headaches and migraine:** Though headaches aren't considered a common MS symptom, [some studies](#) show that people with MS often experience them. Migraine and chronic migraine are the most common types of headaches that people with MS experience, though they may experience other types as well. Worsening or new headaches may indicate an MS attack.



Sometimes it's hard to determine if neurological symptoms, such as vision problems, are due to MS or migraine with aura. Aura is a series of vision symptoms that can happen before a migraine attack.

People experiencing a migraine with aura may see sparks and bright or zig-zag lights. The migraine attack that follows an aura may or may not be painful, and the aura usually resolves itself in 5 to 60 minutes. An MS relapse, during which symptoms like vision issues may appear, will often last longer than 24 hours.

**Pseudobulbar affect:** This condition is characterized by episodes of uncontrollable and sometimes inappropriate crying or laughing. Some people with this condition will experience emotions normally, but they'll have an exaggerated response to them. Other times, the response won't match the emotion — for example, crying uncontrollably when the person isn't sad.

**Raynaud disease:** When under stress or in cold temperatures, the skin on your hands, feet, or other affected areas will turn blue or white.

**Seizures:** Seizures are estimated to happen in only [2 to 5 percent of people with MS, which is about the same risk as people without MS.](#)

**Sensitivity to the sun:** While sunlight-related fatigue is common, it's less common for people with MS to feel just as severely fatigued after they've been in indirect sunlight.

## Sharing changes in symptoms

Keep in mind that if you notice a change in your symptoms, you should report these changes to your doctor — even if what you're experiencing is considered common for people with MS. What's common for the general MS population may not be for you, and it may indicate changes to your MS. Consider what's typical for you day to day, and use this as your baseline. Make a note whenever something happens outside of that baseline.

## Is this MS, or not?

Even now, so many years after my diagnosis, I find myself playing the game of “Is this an MS symptom or just a ‘being alive’ symptom?” As a patient, I struggle to identify what’s a symptom or change in my MS, what’s a side effect of aging or activity, and what’s a random fluke.

I’ve gotten better at identifying my reoccurring symptoms now that I’ve been tracking them for over a decade, but I still find myself running things past my doctor regularly. Sometimes I feel silly asking things like, “This finger is always cold — is that related to MS?” But I’ve learned that MS rears its head in so many different forms that even the smallest thing can be helpful for my doctor to know. Remember, your doctor will use *your* symptoms to treat you, not the symptoms that are considered common.



# How to find the right doctor for you

There may be many reasons you need to find a new neurologist. Perhaps you're newly diagnosed, you've moved, your insurance has changed, or your doctor is no longer practicing medicine. Whatever the reason, finding a healthcare provider can be overwhelming and even discouraging at times. But there are plenty of steps you can take that may make the process a bit easier.

## Step One:

### *Find a doctor you'd like to see*

Although you may already know of amazing doctors in your area, your choices might be limited by your insurance network. Though there are many different ways to find a doctor, no matter which route you take, always check that the doctor takes your insurance before you make your first appointment. Not all doctors in the same practice take the same insurance plans, so be sure to ask about the specific doctor you're interested in seeing.

### Here are some ways you can go about finding a doctor:

- **Get a recommendation.**

One of the most reliable sources for doctor recommendations is someone you know and trust, whether that be another patient or doctor. If you can, ask your friends about their experiences — both positive and negative — with local neurologists.

If you live in a rural area where it may be difficult to find another patient or doctor to ask for a referral, the National Multiple Sclerosis Society (NMSS) has a wonderful program called the MS Navigators. You can connect with a Navigator who will help you find nearby resources like support groups, doctors, financial assistance, and more. Contact them by phone at **(800) 344-4867**, option **#1**, email at [contactUSNMSS@nmss.org](mailto:contactUSNMSS@nmss.org), or live chat on [www.nationalMSsociety.org](http://www.nationalMSsociety.org).

If you don't have access to the internet, NMSS also offers a phone support program called MS Friends that will connect you to other patients or caregivers who also have experience with MS. These conversations are one on one, and they're confidential, so you're free to talk about anything. Call **(866) 673-7436**, from 9 a.m. to midnight EST, seven days a week.

***Tip:** Don't always take the insurance company's website as truth. When you find a doctor you'd like to see, call their office to make sure they take your insurance. Insurance companies' websites aren't always regularly updated.*

***Tip:** It can take weeks to get a new referral processed. Be sure to give your PCP enough time to push it through.*

- **Get a list of providers from your insurance company**

Check your insurance company's website, where you can search for local doctors that accept your plan. Take note of any MS specialists or if there are any local MS treatment centers. MS treatment centers are the ideal place to get care for patients like us because they only treat MS. Most are able to let you see your neurologist (who will be an MS specialist), get MRIs or other testing, and even get infusions in the same place.

- **Get a referral**

If your insurance is an HMO, you'll need a referral from your primary care physician (PCP) to see a new specialist like a neurologist. It's important to start the referral process before you make your appointment, as some offices won't let you make an appointment without the referral in hand. When you go to your first appointment with your new doctor, bring a hard copy of the referral. Don't risk losing your appointment because your referral got lost in the mail or online.



## Step Two:

### ***Do your research***

Use the internet to your advantage, and research the doctor online before you make an appointment. Find out their medical background, and see if anyone has shared positive experiences or complaints about the care they deliver. Look into the reputation of the hospital that your doctor is affiliated with, and consider if you'd want to stay there if you had to be admitted. You can never have too much information when picking a new provider.

## Step Three:

### ***Make the appointment***

Remember that your doctor is just one part of the equation. As you make your first appointment, consider the experience as a whole. Are the staff friendly and willing to help? Do they show any flexibility in scheduling? You'll put yourself in the best position if all the staff are equally engaged and committed to providing excellent care. This includes both the doctor who is treating you, and the office staff who are completing the paperwork and making the phone calls.

*Tip: If you can, accept the first available date they offer — even if you're not currently experiencing symptoms. It's best to meet your doctor before you're in a relapse.*

## Step Four:

### *Interview your new doctor*

Just getting to this point could have taken you months, and you may feel a lot of pressure to like the doctor you're seeing. Be open and honest with yourself. I encourage you to use this first appointment to interview your doctor to confirm they're a good fit for you. Initial appointments are often scheduled in longer time blocks than checkups, so this is your chance to ask lots of questions.

I've provided a list of questions in the next section that'll help you with this first appointment. Feel free to print this out and bring it with you so you remember what you want to ask. You can also use the extra space provided to add in questions of your own.

## Step Five:

### *Consider your feelings*

Bottom line: How did you feel talking to this doctor? What are you willing to compromise on, if anything? Everyone is different and has their own priorities. Personal red flags that let me know a doctor isn't right for me include feeling belittled, having my care neglected or my time disrespected, and being met with an elitist attitude. These may be similar to your own red flags, or they may be different. Take some time to think about what matters to you.

Finally, when it comes to picking a new doctor, trust your gut, but also look at the available facts. Don't be afraid to ask questions and remember: ***You're interviewing them.***

# Questions to consider while looking for a doctor

1. Has someone I trust recommended this doctor to me?
2. Is the doctor an MS specialist?
3. Are they in-network with my insurance company?
4. Do I need a referral?
5. When is the first available appointment?
6. What do I do if I need to see the doctor before my scheduled appointment?
7. Was the office staff accommodating when I made the appointment?
8. Had the doctor reviewed my file before I arrived?
9. How did I feel after meeting the doctor?



**Notes or extra questions**

# Questions to ask at your first appointment

## General

1. What is your neurological specialty? If it's not MS, have you done any extra training in treatment of MS?  
How many patients with MS do you currently treat?

*Note: A teaching hospital usually means that when your doctor visits, they may have a group of students with them. Some people find that having a group of people listening to their discussion is uncomfortable. If you prefer a one-on-one visit with your doctor, consider asking specifically not to have students in your visits or looking into another hospital.*

2. Is this a teaching hospital?
3. Will you be my only doctor, or will I see other doctors in this practice?
4. Are there any other specialists I should be seeing (e.g., speech, physical or occupational therapists, or a neuropsychologist)?

## Doctor Approach

1. What is your approach to treating MS?
  - a. Do you host clinical trials?
  - b. Do you recommend any herbs, vitamins, or other supplements?
  - c. Do you have any suggestions to try to combat this disease that don't involve a prescription (e.g., vitamins, exercise, diet, massage, yoga)?
2. How do you typically treat an MS flare?
3. Do you think my current therapy is the right one for me at this time?
4. What do you recommend for my personal treatment plan?



## Scheduling

1. How long will it take to get a call back if I leave a message? Do you or a nurse call me back?
2. Do I have to call the office to get ahold of you or is there an online portal available?
3. Do you do virtual visits if I can't make it into the office?
4. How long does it typically take to get an appointment?
5. If I have a problem, can I be seen quickly?

## Communication

1. What are your procedures for handling issues that come up in between appointments?
2. How do I get in contact with you if I am experiencing a flare up?

# How to work effectively with your doctor

Being prepared for your appointments will help you make good use of your time with your doctor. You may find it useful to bring the following to each appointment as you share updates with your doctor.

- a record of your daily habits (see health diary)
- a list of your symptoms (see daily symptom tracker)
- a list of all of your medications, including vitamins, supplements, herbal teas, and anything else you might be taking (see medication tracker)
- a list of any other conditions or ailments you may have
- a friend or relative, if possible. They can provide more support, help you remember what you want to ask the doctor, and take notes.
- a list of questions you want to ask your doctor (see doctor discussion guides)
- results of any recent tests
- a copy of your medical records for your first appointment. Don't assume the doctor has received your medical records even if they were sent. With MS, it's particularly important for your doctor to be able to see the pictures of the MRI. Most imaging facilities will give you a copy on a CD.

## Health diary

Tracking your daily habits is a great way to collect data to share with your doctor that may help them treat your MS. There are so many different things you could track in a day: your sleep, your diet, your medication, your symptoms, your menstrual cycles, and more.

The suggestions below are meant to give you an idea of what may be helpful for you or your doctor to know. If you feel overwhelmed at all the possibilities, try focusing on just one or two things that feel important to you. Any information you're able to provide will be very helpful to your doctor.

**For the techies:** There are many helpful apps designed to assist people with MS in tracking this type of information. [This](#) is a great list to reference if you're looking for an app.



Sleep tracker

Date	Time I went to bed	Time I woke up	Total hours of sleep	Sleep quality worst (1) - best (5)

Notes

Exercise tracker

Date	Type of exercise	Length of time	Did I overheat?	Fatigue level	
				Before	After

*Mood tracker*

Date	Today I feel	I feel this way because

*Symptom tracker*

Many doctors will ask you to fill out the Multiple Sclerosis Impact Scale at your appointments. This scale provides a list of questions about your symptoms over the last two weeks. If you have access to the internet, try searching online for the scale and printing it out ahead of time. It’s helpful to track your symptoms daily so you’re prepared to answer these questions when you go to your appointments.

Medication tracker

At each appointment, the office staff will ask for an updated list of your medications. Keep the medication tracker up to date, and print it for your doctor to put in your file.

Name of medication	Dosage	X per day	How do you take it?	When did you start?	Purpose	Doctor who prescribed it
medication	100mg	3x	oral	2009	blood pressure	Dr. Jones

Notes



## Doctor discussion guides

These guides are meant to help you communicate effectively with your doctor. Print them out, and bring them to your appointment to help you remember what you want to ask. Feel free to use the extra space to add your own questions.

### *For recently diagnosed patients*

1. Are you sure I have MS? Can you help me understand how the test results determined this?

*There's no single diagnostic test for MS, so doctors use many different tests to diagnose the disease. These may include blood tests, spinal fluid tests, MRIs, and evoked potential tests. If you're not sure which tests you've already taken, ask your doctor to explain, and see if they recommend taking any others.*

2. What is your neurological specialty?

*This question is important, and it can provide you good insight, so be sure to ask it.*

3. What type of MS do I have?

*There are four types of MS: clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), primary progressive MS (PPMS), and secondary progressive MS (SPMS).*

4. What's the prognosis for this type of MS?
- Different types of MS can have very different outcomes, so it's important to understand the differences. Remember, no two cases of MS are the same.

- 5.** What symptoms are typical for this type of MS?

## Quick Notes

[illegible]

6. What types of treatment do you recommend?  
*There are many different ways to treat MS, including oral medication, injectables, infusions, diet, and supplements. Your doctor can help you understand which treatment is right for you and why.*
7. Are there treatments for [specific symptoms you're experiencing]?
8. Do you have any suggestions to try to combat this disease that don't involve a prescription (e.g., exercise, diet, massage, yoga, biofeedback, reflexology)?
9. Are there other specialists I should see (e.g., speech, physical, or occupational therapists, a neuropsychologist)?

- 10.** Do you recommend taking any herbs, vitamins, or other supplements?

*Not all people with MS treat their symptoms with medication, and some supplement medication with other types of treatment. There are many [natural remedies](#) that may help you manage your symptoms.*

## Quick Notes

[illegible]

- 11.** What about taking large doses of vitamin D? Could that help my MS?

Research continually shows that low vitamin D levels can affect disease activity. Ask about your level and if you should be taking a supplement.

- 12.** What are MS flares? Can they be prevented? How do you treat flares?

- 13.** What should I do if I experience new symptoms or if my current symptoms worsen?



***For MS veterans***  
***Information to share***

- In the past two weeks, I've been feeling:
- The symptoms I've been experiencing the most are:
- I've been feeling the effects of MS most when I:
- I'm here today to talk about:
- I'm concerned about:

## Quick Notes

## Questions to ask

1. Based on test results, how would you say I'm doing?
2. Do you see any worsening or progression of my MS?
3. Do I need to get any tests (e.g., blood work, MRIs, EMGs, neuropsychological testing)?
4. Do you think my current therapy is still the right one for me?
5. Can you tell me about new therapy options and why they may or may not be right for me?

6. Will I be able to continue working? What do I do if I can't? Can anyone on staff help me navigate the process of applying for disability or other government assistance? If not, where can I go to get help?

### *For new prescriptions*

1. Could this symptom be treated effectively without medication?
2. Is there a medication — in addition to the one I've just been prescribed — that I could or should take on an as-needed basis for this symptom to help with breakthrough symptoms?
3. Is this medication taken orally, by injection, or intravenously? If it's available in multiple delivery methods, what are the pros and cons of each method?
4. How long will I need to be on this medication? How often should I take it, and in what dosage?
5. How will I feel on this medication? What are the possible side effects?
6. What should I do if I start experiencing side effects?

7. How will I know if the medication is working or not?
8. What should I do if I forget to take my medication?  
Are there risks if I don't take it, or if I miss a dose?
9. Are there any over-the-counter drugs (e.g., vitamins, herbal supplements, pain relievers, cold remedies) that I should avoid while taking this medication?
10. Can I drink alcohol while on this medication?
11. Does insurance typically cover the cost of this medication? If not, is there financial assistance available for this medication?
12. Do you have any samples or coupons for this medication?
13. Would you prescribe this medication to a friend or loved one? Why or why not? If you would with some reservations, what would they be?

**Notes or extra questions**



# Where to find more information

The Multiple Sclerosis Association of American has this great article about the [importance of a positive doctor-patient relationship](#). If you're feeling like [your doctor isn't showing you the compassion you're looking for](#), or [isn't listening to you](#), Healthline has some great articles about the [doctor-patient relationship](#), too.

NMSS has [this quick guide](#) about how to make the most of your appointments. Be sure to review the list of patient rights and responsibilities at the bottom of the page.

Dr. Aaron Boster is a neurologist who hosts an amazing [YouTube channel](#) for people with MS, helping them to understand the disease and navigate their lives. In [this video](#), he explains that with all the advancements in treatments for MS, the way that doctors see patients still needs some work.

He also has a [series about decoding the neurological exam](#) that you receive at every appointment. Learning what your doctors are looking for may help facilitate the discussion about this exam.

**Notes or extra questions**

# About the Author

Jackie Zimmerman has been in the patient advocacy game for over a decade and has established herself as an authority on chronic illness, patient-centric healthcare, and patient community building.

She began as a blogger shortly after her multiple sclerosis diagnosis in 2006 and later continued to (over)share her battle with ulcerative colitis (UC) in 2009. In navigating her way around having UC, she saw a massive hole in support for women living with inflammatory bowel disease and ostomies. In 2012, Jackie founded Girls With Guts, a nonprofit that offers education and support for women around the globe.

Jackie has had the privilege of giving keynote speeches and presentations, traveling to the Hill, sitting on various advisory boards, and partaking in countless other opportunities all in the name of improving healthcare and sharing the patient experience.

By day, she's an [online marketing consultant](#), a chronic overcommitter, a wife to Adam, a pet mom to four fur babies, and a roller derby athlete.

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