The Confident Patient: Managing Progression



The Confident Patient:

A Doctor Discussion Guide for MS Progression

When something feels different

Living with MS means always adjusting. Some changes may be more obvious or hard to miss. Others may build more slowly – you're more tired than usual, your balance is off, or daily tasks take more effort than they used to.

MS progression can feel confusing, frustrating...even scary. It's easy to second-guess or brush it off. But if something feels different, it's worth bringing up.

Even small <u>changes</u> can offer important clues. The more your care team knows, the better they can support where you are right now.



The impact of progression

In MS, progression means certain symptoms may be sticking around longer – or gradually getting worse over time. It might affect how you move, think, or feel. And it doesn't always follow a relapse or show up on an MRI.

That's why it's important to pay attention to how MS is showing up in your everyday life.

You're the one who sees what's getting harder, what takes more energy, or what doesn't feel the way it used to.

Sharing those insights can help your care team better understand what's happening to inform next steps.



Questions to ask your neurologist

Preparing for your <u>next appointment</u>? It's a good time to get clear on what's changed and what you want to ask.

Whether your symptoms feel different, tougher to manage, or more persistent, bringing them up can help your care team figure out if your MS is progressing and what to do next.

Not sure where to start? These questions can help guide an honest conversation.

Not sure where to start? This list can help you feel more confident jumpstarting the conversation.

Is this progression:

- I haven't had a relapse, but I'm feeling worse could this still be progression?
- Are these changes likely to get worse if we don't act now?
- Could my symptoms be progression even if they come and go?
- How can we tell the difference between a flare, everyday ups and downs, and progression?

What to track:

- What changes in walking, thinking, or energy should I log?
- Can we use walking tests, memory checks, or other tools to measure where I'm at?
- Are there patterns that would help you like symptoms at certain times of day or after activity?
- How will we compare today's results with past visits to see my trend?

Treatment options:

- My symptoms are harder to manage even though I'm on treatment – what's our next step?
- Could a <u>different medication</u> or dose help slow progression?
- What non-medication options like PT, OT, or mobility aids – could help me stay more independent?
- How do we decide when it's time to make a change,
 and what would that process look like?

Coming prepared and bringing questions like these can help lead to more meaningful conversations and ensure your care keeps up with where you are now.



Symptom Check-in

What's changed?

MS symptoms can ebb and flow – but when something starts to linger more than usual, it may be time to take a closer look. Let's see how you've been feeling lately.

In the last month, have you experienced any of the following?

- □ New or increased fatigue
- ☐ Trouble with walking, balancing, or falling
- □ Changes in speech
- ☐ Muscle tightness or spasms
- □ Vision changes
- □ Numbness, tingling, or pain
- ☐ Trouble focusing or remembering things
- ☐ Mood swings, anxiety, or depression
- □ Bladder or bowel changes

The Check-up



What to say at your next appointment

Describing progression can feel challenging. Here are some ways to share what you've been noticing:

"This symptom feels more constant than before – is that something we should watch? It's taking me longer to recover after activity. Could that be progression? <u>Tasks</u> that used to feel easy now feel harder. Can we talk about that? Based on what I've been tracking, I'm wondering if it's time to reassess my treatment."

Remember: Your voice is one of your greatest tools. Trust it – and speak up when it matters.

