

What Is Progressive MS?

There are two kinds of progressive MS.

First, there is a relatively small group of people with MS whose disease is steadily progressive from the onset. They don't have attacks. Instead, they're slowly accumulating a little neurologic disability all the time. This is called "primary-progressive MS".

Second, there are people who go into a progressive phase. The generally accepted name for this is "secondary-progressive" MS. People in this group start out having acute attacks—they suddenly develop double vision or lose their ability to walk—but over a relatively short time, most of the deficit resolves or nearly resolves. They see normally again or they walk again, but sometimes with more weakness or balance problems than before. This is called "relapsing-remitting" MS, and it is the most common form of MS at diagnosis. At some point later on—five, 10, or 15 years later—many people with relapsing-remitting MS begin to accumulate disability in a slow fashion, whether or not they continue to have acute attacks and recoveries.

This is very confusing for people.

The secondary-progressive phase of relapsing-remitting MS is not inevitable, but it is common.

How does a physician tell who is who?

This can actually be tricky. Let's say a 40-year-old man comes to see me because he is having increasing difficulty with walking. He's not quite sure when the problems began. They've come on very slowly. He just knows he used to run marathons and now he can't. I examine him and find some evidence of spinal cord dysfunction. Then, on the next visit—or maybe it's the next—he suddenly tells me that he had an episode of double vision way back when he was in high school. No one could figure out what it was, but it went away in two or three weeks. Now, does he have primary-progressive or secondary-progressive MS? Suppose he never thought to tell me about the double-vision episode? But the distinction between primary-progressive and secondary-progressive is important. I may base my treatment recommendations on it.

You can see the pitfalls. Many peo-

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A 48-page overview of symptom management and coping strategies when progressive MS makes the road rougher. Download from our Web site (go to nationalmssociety.org, then click on "Library"), or call your chapter (1-800-FIGHT-MS) for a copy.



that a person should have had symptoms of progressive disease for at least a year, with documented increased worsening; that the MRI of their brain and spinal cord should reveal certain findings; and that the person have abnormalities in the spinal fluid that are typical of MS. These are the "oligoclonal bands" and certain alterations in immunoglobulin synthesis.

ple have selective recall or they don't talk to me about things they've decided aren't relevant.

It's even harder figuring out if a person who has relapsing-remitting MS has entered the more progressive phase. I can feel like I'm driving a car down an unfamiliar highway. It's difficult to predict where I'm going. On the other hand, if I check the rearview mirror, I can figure out where I've been. So, before I tell one of my patients that she or he is in the progressive phase, I follow them. I see them for six months or a year or more, to make sure I'm not seeing a prolonged relapse, which they will recover from. I need to make sure their accumulated deficits are not just the result of my seeing them at their best on one visit and at their worst the next.

My patients often ask me, "Am I progressive?" and I have to say, "I'm not sure yet." This is not easy.

The current diagnostic criteria, which an international panel struggled over, say

Beyond this, there is another cardinal feature of MS: The rate of progression varies from person to person. This shows up across all the natural history studies all over the world. But one of the patterns that is emerging from international studies is that the overall **tempo** of progression can be very similar, whether the person starts with relapsing or progressive disease. At a certain point the different disease courses seem to merge. If a person with relapsing disease reaches a certain level of disability, the variability of MS may even out. It becomes much more likely that this person will enter the progressive phase. ■

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