

The Primary Progressive Experience



Two words come to mind when I think of the 37 years I've lived with primary progressive multiple sclerosis: loneliness and guilt.

It can feel like the ugly stepchild of all MS diagnosis. We are patted on the head and told how great we are, but could we step aside to make way for the relapsing-remitting crowd?

[According to the National MS Society](#), primary progressive MS is “characterized by worsening neurologic function (accumulation of disability) from the onset of symptoms, without early relapses or remissions.”

Some of the loneliness I've felt was self-imposed, but not all of it. It is estimated that only [10 to 15%](#) of people diagnosed with MS have the primary progressive form.

I remember going to support groups when I was first diagnosed, but after a while, I stopped. This was before the internet, everything was in person. There didn't seem to be anyone who was remotely experiencing the same problems as me. I know it's not a competition, but it was hard to relate to someone whose symptoms would remit for months or even years at a time while mine never went away and were slowly getting worse. I know there's more to it than that, but those groups were not for me, and in spite of living in a large metropolitan area, I couldn't find a group for those living with progressive MS.

I have now joined several online support groups, and while I appreciate the ease in being able to connect with fellow MS'ers, I still can't help but feel a sense of isolation within the community. I sometimes have pangs when I hear someone with the relapsing remitting form

describe their symptoms. Rather than turning away, I am continuing to learn and also educating and informing people — putting my years of experience with the disease to good use.

There were no disease modifying drugs available when I was first diagnosed. But when Betaseron was introduced, I jumped at the chance to enroll in the lottery. It was a medication approved for those with relapsing-remitting MS, but my healthcare provider thought it was worth a try. We injected the medication for years until I took time off to have children. I've since tried several other medications, all for those with relapsing-remitting MS — only because that was all there was. It was our only hope. Over 20 different treatments have been approved for MS **[but only one, Ocrevus, is approved for the primary progressive form.](#)**

It's hard to read that without feeling like you've been left behind.

Then there's the guilt. When you have the progressive form of this disease, you not only wonder why you have MS, but why yours is more severe. Was it something you did or didn't do, your diet, your lifestyle choices? What are you doing that's different from those with the relapsing remitting form? Friends and family hear accounts of other people with MS who went from not being able to get out of bed to running marathons. Why can't you do that? Support group testimonials describe the success people are having with diet and exercise and try as you might, you aren't having those same results. Doctors and researchers don't know why people get one form or the other, but it's still hard to keep from wondering. I know everyone living with MS has had some kind of varying thoughts like these.

Receiving an MS diagnosis is difficult, to say the least, and being told you've got the progressive form is particularly tough. Educating yourself and learning all you can is very important, along with finding a good neurologist and healthcare team to support you. Finding a good online support group can be helpful as well.

It's important to understand that everyone's variation of this disease is different. Your path is your own and you need to do all you can to live your best life. You didn't get the progressive form because of something you did or didn't do, it just happened. We are not quitters, we just need to fight that much harder.

Editor's Note: Read about the latest in progressive MS research on **[the Society website.](#)**