# Secondary Progressive MS or Relapse?

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## Could It Be Secondary Progressive MS, or Just a Relapse?

Many are familiar with relapsing remitting multiple sclerosis (RRMS), the form of the disease characterized by periods of relapse where symptoms flare up, followed by complete recovery. Most of us are diagnosed with this form of MS when symptoms first present, but 65 percent of us will go on to develop secondary progressive MS (SPMS) within 15 years of the initial diagnosis. But how many of us even understand what this is?

Most neurologists agree that SPMS is a sustained build of disability independent of relapses. The disease progresses, so disability gets worse — with no periods of recovery following relapses. There is no medication or treatment for SPMS, so once you have it you're essentially on your own.

How do we know when we have it then? How do we know the difference between a particularly nasty relapse that's hanging around a long time and disease progression? You'd think a neurologist would be able to help there wouldn't you? Not necessarily!

### My Experience

In my experience it's not guaranteed that a neurologist will know as much about MS as you do, so make sure you see an MS specialist; someone who knows what to look for a how to treat you.

A few years ago my balance and mobility got steadily worse over a period of about six months. It was about a year after my second child was born and I'd gone back to work way too early — the stress was full on.

I was still injecting myself once a week with beta interferon, but I found I felt awful for five out of seven days. I went to see my neurologist and pointed out that I hadn't had a clear relapse in six months, but my mobility had taken a nose dive and I was scared I had SPMS. He peered at me over his glasses, agreed it didn't sound good, and threw me onto the MS scrapheap!

Beta interferon doesn't work for SPMS, so what was the point of continuing with medication that was making me feel worse? There were no other treatment options available to me and I disengaged with the health care team looking after me.

What was the point in dragging myself to appointments when there was nothing they could do except prescribe various drugs to manage my symptoms?

This went on for few more years until I realized other MSers I know were getting far better care. They all seemed to have the same neurologist, an MS specialist and the MS lead in my area.

I kicked up a stink and demanded an appointment with the one man who seemed to know what he was taking about!

## Seeing a Specialist

I eventually got an appointment to see him and he was concerned I'd been diagnosed with SPMS without an MRI to investigate. I got the results a few weeks later and the letter stated that I had "two enhancing lesions suggestive of current inflammatory activity."

He went on to recommend these lesions be treated by a five-day course of steroids (as per protocol) followed by going back onto disease-modifying therapies (DMTs).

If this is "as per protocol" why didn't the previous, useless neurologist suggest steroids when I went to him years before? Perhaps my balance and mobility issues were due to a huge relapse and not progression?

Could they have treated it then and could my worsening disability have been avoided? These questions make me start twitching with anger if I'm not careful, so it's best that I keep calm and count to 10!

## Relapse or Secondary Progressive MS?

I'm on day four of the five-day course of steroids and am writing this while looking at myself from the ceiling! I'd forgotten how strong they can be and I feel like I'm on hardcore drugs!

Despite the lack of sleep and crazy thoughts I do actually feel better. My bladder function has improved dramatically and I feel stronger on my legs. I don't know if it will help in the long run but I'm encouraged that there's something that can be done for me and I don't have the dreaded SPMS label anymore.

I think the message in this sorry tale is that you need to get a second opinion from an MS specialist before you presume you have SPMS.

Not all of us go on to develop it, and even if your symptoms seem to be getting worse there are treatments available that might be able to help. Demand to see the best in your area and constantly chase them. Stay in control of your own health care and ask for MRIs.

It's so hard to figure out when you're having an actual relapse, so it's a good idea to keep a diary of when symptoms seem to be flaring up. That way you can discuss these with your specialist to make sure you get the best care possible.