



**National
Multiple Sclerosis
Society**

**MS Learn Online
Feature Presentation
Moving Forward with a Diagnosis of Primary-Progressive MS
Rosalind Kalb, PhD**

Tom>> Welcome to MS Learn Online, I'm Tom Kimball.

Tracey>> and I'm Tracey Kimball. Trust me, getting a diagnosis of MS brings with it a host of emotions and concerns. When someone realizes their course of MS is primary progressive, it can feel overwhelming.

Tom>> National MS Society's Dr. Rosalind Kalb talks to correspondent Rick Sommers about a common question most everyone asks upon getting the diagnosis of MS ... "Why me?"

>>**Kate Milliken:** Dr. Kalb, the question, "Why me?" probably crosses the mind of anybody that's diagnosed with Primary-Progressive MS. What are some of the recommendations for coping with the "Why me?" especially for people who can't get past it?

>>**Roz Kalb:** I think the "Why me?" question is very common for anybody who is given a surprise in their life, confronted with a challenge that is unpredictable and difficult. I think the question takes on special meaning for people who are diagnosed with Primary-Progressive MS. It's difficult enough to be diagnosed with a chronic,

unpredictable illness like MS, but this particular disease course, PPMS, doesn't have the same treatment options that the other ones do. It has a lot of unanswered questions about it that the relapsing forms don't have. So many people with PPMS have been heard to say they feel like orphans in the MS world, and we don't have good answers for them about why PPMS and why they got this particular form of the disease.

But I think as for anyone who is given a challenge like this, who asks, "Why me?" the first steps are to get as educated as you can about what's happening, what do we know and what don't we know about PPMS? What are the important treatment strategies that are available? And what are the resources that a person can tap to meet its challenges? The only way to get beyond the "Why did this happen to me?" is to begin to focus on, okay, what are the problems I'm actually having and what steps do I need to take to keep those problems from interfering with my everyday life?

I think that the first step in that is actually a grieving process. You've been given a diagnosis of something that you didn't expect and it's pretty unpleasant, and it doesn't fit in with the picture you have of who you are. So, first you have to grieve over that loss of your old self image. Then you have to start to incorporate bit-by-bit this new diagnosis of PPMS into your picture of who you are. Make space for it in your life, but not give it more space than it actually needs. And you do that by addressing the particular symptoms you're having and working with your healthcare team to meet any challenges that come along.

>> **Kate Milliken:** If there are no approved treatments for Primary-Progressive MS, and I've been diagnosed, why would I go to a doctor?

>> **Roz Kalb:** That's a very important question and I'm very glad you asked it, because I think we all need to remember that treatment is a big word, right? What we have at the present time is no approved

disease-modifying medication for PPMS, but that's not the same as saying there is no treatment for it.

Treatment involves taking care of the whole person. So, we don't have a medication to slow progression yet, or stop it in its tracks, but we have lots of important symptomatic management strategies which people need to use to the hilt. And that involves working with a neurologist and a pretty broad range of healthcare professionals to make sure, for example, that if one's having trouble with walking, that somebody is looking at what's the source of the problem with walking? Is it a balance problem? Is it a sensory loss in the feet or legs? Is it a vision problem that's getting in the way of getting around? Work with the healthcare team to figure out what's causing the problem and get the help that one needs.

>>**Roz Kalb:** For example, problems with mobility are very common in Primary-Progressive MS, so it's important to engage all the members of the healthcare team who might be able to help manage that symptom.

So, for example, the neurologist needs to determine what's causing the problem with mobility, and make sure that anything that may be contributing to it is being addressed. The rehabilitation team gets involved. The physiatrist or the physical therapist might recommend that a particular walking device would be helpful, either an ambulation aid or a brace of some kind. The physical therapist might also work on mobility training. If the person is having trouble getting around at home and at work, the occupational therapist can get involved to help people manage their workspace in such a way that they can get around more easily and conserve energy. So, it's not that there's nothing that can be done, it's that it's working on individual symptoms and engaging the right health professional to work on it with you.

Same thing with the mental health professional. Anybody living with PPMS might experience some mood changes, some depression.

[Know that] depression is very common in all forms of MS. It can happen in PPMS as well. It would be important to engage the mental health professional to help diagnose and treat that.

So, we don't have medications, but we have lots of things to do that are important treatment strategies in managing PPMS.

Tracey>> Well if the first step you take to moving forward is education, then you're in the right place. I still feel that education helps me cope with this disease.

Tom>> Yes and even if disease modifying therapies aren't right for you, Dr. Kalb listed a host of treatment options people with primary-progressive MS can use.

Tracey>> And remember, you can get support from your doctor, the National MS Society and your family and friends as you move forward with your diagnosis. You are not alone!

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