



**MS Learn Online
Feature Presentation
The Emotional Side of Living with Primary-Progressive MS
Dorothy Northrop, MSW, ACSW**

Tom>> Hi I'm Tom Kimball

Tracey>> and I'm Tracey Kimball welcome to MS Learn Online. People living with primary-progressive MS often experience a full range of emotional issues while living with this difficult disease.

Tom>> And the person with the disease is not the only one who might be affected by primary-progressive MS. Family members and friends often face emotional challenges as well.

Tracey>> Dorothy Northrop, Vice President of Research and Clinical Operations for the National Multiple Sclerosis Society joins correspondent Rick Sommers to discuss these issues. Ms. Northrop begins by talking about a feeling that many people with primary-progressive MS have ... that they're the "orphans" of the MS world.

>>Dorothy Northrop: I think that I can understand why people with primary-progressive MS would feel that way about being orphans of the MS world, because all of the treatments that are currently available for MS that have been approved are focused the relapsing-remitting course of the disease.

I think also just the general materials that we have on MS, because they're generically written, many of them, I think that sometimes they look at them and say, "You know, they're not speaking to my particular issues and my particular needs; they're different."

I think the good news is that I think things are changing. I think the research world is beginning to really have interest in advanced MS. And I also think just our materials are going to be much more targeted as we go along.

So, I think that things will be better in the future. But I do think that right now I can certainly understand why they may feel that things just aren't out there for them.

>>**Rick Sommers:** What are some strategies in dealing with the immensity of emotions somebody living with primary-progressive MS can adopt to help them cope?

>>**Dorothy Northrop:** Well, there is no question that a diagnosis of primary-progressive MS is going to generate a lot of different feelings, a range of feelings -- disappointment, sadness, anger, apprehension about the future. And I think the most thing someone with primary-progressive MS can do is to talk about those feelings. I think it's very important to get them out and share them. It's a grieving process, and I think to find those that you can comfortably share those feelings and talk about them, it's going to help to get past those feelings.

So, I think you need to find family or friends or a counselor, a clergy person, another person with MS, anyone that you feel comfortable talking about this. I think the trick is not to get stuck there, because there's a lot that needs to be done when you have a diagnosis as well. You want to go forward and manage your symptoms and find ways to be independent, to find ways to keep control of your life. And if you find that you're kind of

stuck with that stress and that sadness, it's very hard to get the energy to go forward.

So, it's difficult, but I think if people can move past that, I think that they can then start to incorporate the disease into their life and begin to make plans for the future. And I think sometimes talking to others who have been through that journey is always very helpful, too.

>>**Rick Sommers:** Talk to me about how MS impacts not just an individual but an entire family, and what are some of the coping mechanisms and strategies that a family might use to deal with this?

>>**Dorothy Northrop:** Well, we always call MS a family disease, and it is indeed. I think the challenge is that within our families we're very different people, so you have people that are different ages, different personalities, different temperaments. They have different life goals, they have different coping styles. So, even though we're one family, everyone is going to be impacted by MS in a different way, and they're going to respond to having MS in the family in a different way.

So, I think the first thing that families really need to do and the most important is to really sit down and talk to each other, and really learn where each one is. What is the impact of this disease for them, and where do they see themselves fitting in, in terms of going forward as a family and as a family unit?

So, it's a matter of kind of finding the place where you can balance the needs of the disease with the family. And it does take a while to get there, but I think if families talk about it and work it out together, I think they can definitely go forward and be able to be very happily set as a family.

>>**Rick Sommers:** Along those lines, roles and responsibilities within the family unit dealing with primary-progressive MS are likely to shift and begin to feel somewhat unbalanced. What are some of the ways that you have tried to keep the balance in relationships that you've dealt with?

>>**Dorothy Northrop:** Well, it is a problem for those with primary-progressive MS, when you're trying to figure out how you go forward when some roles and responsibilities may have to shift. And it's naturally going to be a stressful time, because we have rhythms and routines of our family, and when these get kind of shaken up a little bit, it takes a little while to get through that.

I always strongly recommend that families again sit down together and talk about what are the tasks and responsibilities that we need to do as a family, let's say over a period of a week. And I like to think of people starting from a blank slate. Let's just look at what all has to be done within our family, and then begin to see where there are certain people that could pick something up pretty easily.

Or you might do a little shifting. Perhaps someone with primary-progressive MS can't go get the children from school anymore so easily, but perhaps they can take over the checkbook, for example. So, you kind of start to work this out to see how it shifts. And I think this is an ongoing process, because things change, people change. You may have a youngster who goes off to school and then you have to rearrange again. Look to family and friends who are often trying to find a way to help, and sometimes they can pick up some of those very specific tasks that are very time limited but are going to be a terrific help to the family.

And then I think, also, families have to think about when they need to pay for a service. Is there so much stress in getting the housework done, for example, that maybe this is something where we should invest in the dollars and get someone to come in and do it because it's going to lessen our stress overall. It will be worth it to us.

It is a matter of piecing together, and I think the bottom line is to really -- to share and to work it out as a family, and then I think this is usually a very successful process.

>>>>**Rick Sommers:** So, how can a person who has been diagnosed with primary-progressive MS develop a healthy support system? Are there tricks? Are there tools?

>>**Dorothy Northrop:** Well, certainly a person with primary-progressive MS wants a healthy support system around them. And many of them will have a support system there when they get the diagnosis of primary-progressive MS. They have their family, they have their friends. And I think the first thing they need to do is maintain and nourish those relationships. It's so easy when you're involved with trying to manage a disease and do all the things that come with that, that you can sometimes let those relationships kind of falter a bit. They take energy, but it's a priority to keep those around you in your support system. So, you need to kind of spend some time doing that.

I think you also want to look at your healthcare professionals as your support system, and really bring them into your circle and make sure that you're using them optimally, so that you're getting all the clinical care you need, because that's very important in terms of support. And this is probably the time when it's most helpful to reach out to those who have similar challenges, to go out and find those that truly understand what you're going through because they're going through it, too.

And, so, whether it's through support groups or chat lines or conference calls or peer mentoring, any way that one can get connected with someone else that they can truly talk to when they get it, I think this is always very helpful for a person that's dealing with a difficult diagnosis.

I think the biggest challenge for caregivers is that they sometimes feel guilty looking after their own needs, and looking for their own support. They somehow feel like they really need to be focused on their loved one with MS. But MS is a marathon, not a sprint, we always say that. You can be talking about many, many years, and so you want caregivers to continue to nourish the relationships and friendships they have. They need to find time to reenergize themselves, whatever that is. And they shouldn't feel

guilty about that, because that's the fuel that's going to help them to go back and really care for their loved one and have the energy that's needed.

So, with caregivers, I think it's more giving them the permission and saying, you know, you really need to do this, if you're going to be the best that you can be for your loved one.

Tracey>> It really is important to pay attention to the emotional side of living with primary-progressive MS. Having a support system in place certainly helps to deal with the day to day issues that come up.

Tom>> I particularly liked her acknowledging the importance that family members can play in providing that support.

Tracey>> Yes, please check the menu for additional programs that specifically address issues regarding primary-progressive MS.

Tom>> See you next time!