



National
Multiple Sclerosis
Society

MS Learn Online Feature Presentation

Personal Insights & Tools for Coping with MS Featuring: Cathy-Lee Benbow

Coping

Stephen: I didn't go to work for the rest of the week, just kind of adjusted. I slept a lot, a lot of tears, a lot of kind of -- a lot of emotion just overall.

Holly: Coping with MS and keeping it part of my life but not my entire life has been a roller coaster ride.

Vito: There are things I can control in life and things I can't. The only thing I can control about this whole journey with MS is my attitude. So, that is why I try to control my attitude. I try to keep a good attitude, an open attitude, and not let MS control my life. I know I've got limitations because of MS, and I pick up accommodations and tools to help me get around it, and that's the way I have to approach it. I keep looking at things from the brighter side and try to move forward.

>>**Kate Milliken:** Hello, I'm Kate Milliken, and welcome to MS Learn Online. Hearing the experiences of others can often bring new insights and hope to those of us who are living with MS. Throughout this video we will hear from a number of people who candidly share with us how they go about coping with this disease. In addition to these people living with MS, we'll chat with Cathy-Lee Benbow, manager of adult mental health services at the London Health Sciences Centre in London, Ontario. Cathy will help us explore some coping techniques and strategies to help work through the challenges of living with MS. Cathy-Lee, welcome to MS Learn Online.

>>**Cathy-Lee Benbow:** Thank you.

>>**Kate Milliken:** Cathy-Lee, Stephen talks about having to stay home from work and having to adjust in terms of time. Can you talk about the importance of that time and to give yourself time to adjust?

>>**Cathy-Lee Benbow:** What I love about Stephen's choice in words is that he mentions adjustment, not acceptance. And this is where I have a bit of an issue with semantics. Patients would sometimes say to me, "I should be getting over this quicker, Cathy-Lee. I should just be accepting what's happening and moving on." And I would say to them, "Sometimes I have a hard time with that word, because 'accept' to me sounds like someone came and knocked on your door and said, 'Would you mind having this chronic neurological condition with this much uncertainty, and we're not quite sure how it's going to affect you, but would you just take it and roll with it?'"

>>**Kate Milliken:** Yes, passive.

>>**Cathy-Lee Benbow:** Yes. "Adjustment," to me, is a word that makes more sense to me, and I would share with clients that "adjust" to me, sounds like Stephen is acknowledging the challenge he is currently dealing with, taking some time to process it, and figuring out how he is going to adjust to that change and keep on going, which sounds much more active, involved, and gives, I think, more of a sense of control over the changes people are experiencing. So, I like his choice of words.

>>**Kate Milliken:** Stephen talks about adjusting, Holly talks about calling her MS experience a roller-coaster ride. So, how would you make that ride smoother?

>>**Cathy-Lee Benbow:** How you make the ride smoother, I've learned over 25 years working with people with MS, many, many strategies that people use. I think the first step is educating yourself, which we've talked about already, identifying where your supports are. I would often meet with clients and patients after an exacerbation, so certainly during that exacerbation when they needed support from their healthcare provider, we were there. But I would often ask them to come back in after the exacerbation had resolved and we would talk about what went well and what didn't go so well during managing that last exacerbation. So that people could identify the next time the roller coaster took a dip, who they might put in place, what strategies they might begin to use already before the dip gets into its lowest point.

But, again, really important to acknowledge that, yes, it will be a roller coaster, let's not deny it. So, let's look at planning and adjusting to how we are going to manage that

roller coaster as best as possible. It will not eliminate the roller coaster, it will just hopefully make the ride a little easier.

>>Kate Milliken: And no matter where you are on your own roller coaster, you always have your attitude that is with you, and Vito talks about controlling his attitude. So, any advice on how to put your attitude in a good place to ride along with your MS?

>>Cathy-Lee Benbow: I think, again, acknowledging that you will have times where you feel more good about your attitude than others. So, can someone always keep a very positive, upbeat attitude about the challenges they meet in life? Definitely not, so we need to challenge people's expectations.

I would often explore with people, though, what was their definition of managing as good an attitude as possible? So, people would say, "I would know I'm keeping my attitude up if I am maintaining my community social activities." Okay, how will we help you to keep doing that during this time of challenge and change? So, there are those outside supports we use to maintain as good an attitude as possible. But recognizing we will have times when we just don't have the best of attitudes, but maybe that's a trigger for us to take up some of those other strategies that help us cope as best as possible.

>>Kate Milliken: Cathy-Lee, thank you so much. Your experience is obvious and helpful. So, thanks so much for being here.

>>Cathy-Lee Benbow: Thank you.

>>Kate Milliken: If you would like to get more information on multiple sclerosis, go to nationalmssociety.org. This is Kate Milliken for MS Learn Online. Thank you for joining us.

Cheryl: You can't run from it, you can't hide from it. You have to face it, and when you do, it's not like you're inviting the Intruder, but you're facing it, you're dealing with it. And it helps you. You make friends with it to a degree, and it shows you what you need to know. It's speaking a language to you that you need to learn.

Donna: With MS, don't let the disease define you. Don't define yourself as an MS victim. You're not a victim, you are a person who is experiencing this condition.

Trevis: It's our responsibility to ourselves not to just go and close the door and sit down in the recliner and let life pass us by. We still have an immense amount to give back to our communities and take back from our communities. And so I believe that people who live with MS can live an exceptionally full life; in some cases an even fuller life than we did before MS. It's all up to what we take back from this disease.