



National
Multiple Sclerosis
Society

MS Learn Online Feature Presentation

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

Educating Others about MS

Donna: I don't have a problem educating people first about MS and then asking for help. And I've done that many times.

Holly: Educating about MS is kind of a continual thing. I have pamphlets that I give to people sometimes when they have a lot of questions.

Kathi: It's just to realize that everybody goes through a different experience and that for people to be understanding of the different experience, it comes down to education and talking about it.

Donna: You have to be persistent with it, because so many people don't really understand what it is. So, I find I have to be patient first, when I come to people who don't know what it is.

>>**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:** Since I personally was diagnosed with MS, I found that telling people I had MS, they just thought it was the worst, and I found that one reason why is they really didn't know what MS was. So, what are some tips you would give for people who are newly diagnosed on how to educate them and people around them about MS?

>>**Cathy-Lee Benbow:** I think the most important thing to do, first, is to educate yourself so that you truly understand what the illness is and what it can and will mean for your life. And I will say to people, at first you need the answers to questions that you have. So, I would never send newly-diagnosed people off to vast resources about MS and tell them to wade in and learn what they wanted to learn. I would get people to begin to focus initially on what are your immediate questions? And that could be everything from, "Can I still have children?" to, "Will I not be walking this time next year?"

Certainly early on in diagnosis, because there is so much emotional turmoil for the individual and their immediate family, to open up yourself to all the reactions of your larger social circle can be a bit overwhelming. So, I think taking it slowly and approaching as you do disclose it in the same way as I would with patients as they were told they had multiple sclerosis: "Can I tell you a little bit about the illness," and, "Do you have any other questions?"

Because I used to joke with people, it's a lot like having the sex talk with your kids. You don't start a huge anatomy discussion. When you first get a question, answer that question and don't say anything else, and often that's enough. "Where do babies come from?" "They came from Mommy's tummy." No further questions. You don't have to get out the anatomical chart and explain all the workings of reproduction.

So, same sort of things with, "I have MS," have a small little bit of information and a pamphlet to share with the person in person, and then, "Do you have any other questions?" You may not have the answer. You know, "That's a really good question. I don't know, but my healthcare provider did provide me with this Internet site or further booklets. Let's go find that answer together." So, then the journey of learning becomes not about you as the patient alone, but you with those key people in your life beginning to learn about life with MS.

>>**Kate Milliken:** I think one of the hardest things about having MS and educating others is there is such an element of unpredictability and individualism. So, it almost

seems that sometimes you say, "I don't know; I don't know what's going to happen," it almost seems like a copout, and I think that is hard.

>>**Cathy-Lee Benbow:** Yes, it is. And I would often say to patients that on the day of diagnosis, we not only give them a diagnosis, we gave them uncertainty. And then it was very key that people began to explore how they coped with and managed uncertainty at other times in their life around any other challenges. That would be often how I would suggest they share it with others as well. This is an uncertain illness, and I've been told by my healthcare professional there will be times we will not have answers, and it's important for us to consider how we might begin moving forward dealing with the fact that from time to time there won't be a pat answer. And it's not about a copout; it's about the reality of life with this illness, so how do we live with uncertainty?

>>**Kate Milliken:** I also think with MS there is such an element of knowledge is power, because the people that don't know a lot about MS make assumptions that are very scary.

>>**Cathy-Lee Benbow:** For sure. Yes, and I think that the more educated a person can be about their own individual experience with MS, but also about others. Because you will run into someone that says, "Oh, that's what my cousin had and it was a terrible experience," to educate back, "You know, I've had MS for 15 years and I'm still working full time and I have three children." That's an opportunity as well to put a different face on life with MS, because it is so individual. So, you are educating life is a lifelong journey of learning and certainly life with MS is the same.

>>**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. Thank you for joining us.