

**NATIONAL MULTIPLE SCLEROSIS SOCIETY  
MS LEARN ONLINE INTERNET PROGRAM**

**WHERE DO I BEGIN?  
NEWLY DIAGNOSED WITH MS**

>>**Rick Turner:** Welcome, and thank you for joining the National Multiple Sclerosis Society's MS Learn Online Internet program. I am Rick Turner, your host and medical correspondent.

To hear the words that you or a loved one has multiple sclerosis can conjure up different reactions and emotions. For many it is devastating. For a few it is a relief that it is not something even more serious.

>>**Mike:** When I was diagnosed, it was 1982, and I had just started a business with a partner six months prior to diagnosis, so there was some worry about being able to provide for my family and grow the business.

>>**Teresa:** When I was diagnosed, I did not know what my future would hold.

>>**Sarah:** When I was diagnosed, I felt that life as I knew it was coming to an end.

No matter the reaction, a diagnosis of multiple sclerosis is the beginning of adjusting to life with a chronic illness.

>>**Teresa:** Today my MS is still an unknown, but I know I will manage whatever it throws my way with the love and support of my husband, my family, and my friends.

>>**Sarah:** I thought that MS was a figurative death sentence, but now I know it is an inconvenient yet manageable condition that does not have to rule my life.

Today we will not be discussing the medical aspects of MS. Instead we would like to introduce to you three guests who have multiple sclerosis and have made some necessary adjustments to not let MS manage their lives but rather for them to manage their MS.

Joining us first today from Virginia is Sara. Thank you for being with us today, Sarah.

>>**Sarah:** Thank you, Rick. I am happy to be here.

>>**Rick Turner:** Why don't you get us started, Sarah, by telling us about your diagnosis and some of the emotions that you dealt with at that time. When did that happen?

>>**Sarah:** I was first diagnosed in 2000, and this was after about six months of unexplained symptoms including weakness and fatigue that progressed to numbness in my legs and losing the vision in my right eye. I was told that it was everything from heart failure to depression and neuroses before MRI, angiograms, and blood tests confirmed that it was MS. At the time, when I got the diagnosis, there was a sense of relief that I was not crazy and that I was not dying, but I did deal with some depression, anger, isolation, and most importantly fear with moving on with my life, not being able to plan ahead. I was very single, living alone in the city, and I just had no idea what was going to be happening to me and how I was going to be able to take care of myself.

>>**Rick Turner:** Well, let's hear from another guest now. From New Jersey we have Mike joining us. Mike, welcome to MS Learn Online.

>>**Mike:** Thanks, Rick. I am glad to be here.

>>**Rick Turner:** Glad you are joining us today. Tell us about your diagnosis with MS. I understand it was quite a while ago.

>>**Mike:** Yes. I was diagnosed in January of 1982. My original symptoms came about over the Christmas holidays of 1981. Slowly the right side of my body became paralyzed. It began with the leg, went up the leg and through the arm, and no, it was not too many Christmas spirits. I saw a neurologist who put me in a hospital, had a spinal tap, and was diagnosed.

>>**Rick Turner:** Also joining us today is Teresa from Washington State. Thanks for being here in the studio with us Teresa.

>>**Teresa:** My pleasure, Rick.

>>**Rick Turner:** How about you. What were some of the emotions you were dealing with at the time of your diagnosis and to whom did you turn for support and information?

>>**Teresa:** Well, Rick, I felt fear and anxiety about the future, grief for the life I felt I was losing, guilt for the potential of becoming a financial and physical burden, love fortunately for the support of my boyfriend and family, and then through my faith I also found peace. I also felt lucky because I already knew about the National MS Society. I went to their website immediately as soon as it was even an indication that this was a symptom. I ordered their Knowledge is Power series. I also stopped at the Greater Washington Chapter and picked up brochures. I read everything and anything I could find there and at the library. I wanted to know all about what I was going to be living with.

>>**Rick Turner:** So, did this diagnosis happen fairly recently?

>>**Teresa:** It has been six years now.

>>**Rick Turner:** Mike, I want to go back to you. You mentioned you were really curious at the time of that diagnosis to find out more about multiple sclerosis. Where did you turn, this was pre-internet we have to remember. Where did you turn for information and support at that time?

>>**Mike:** I first turned to the National Multiple Sclerosis Society. My neurologist recommended them to me. He said they would be able to tell me more about it now probably than he could as far as what was available and what treatments.

>>**Rick Turner:** Now, you mentioned there were lots of feelings of anger and this sort of thing at the time of your diagnosis. We sort of take for granted today the support network for people who are newly diagnosed. Did anything like that exist back then in 1982?

>>**Mike:** Actually, yes they did. There was a support group local to the Trenton area, and I am still involved with that group as we speak, and it was a very good place to meet people with MS, kind of depressing sometimes because I saw people that were much more disabled than I was, which was possible future for me; but it was also very uplifting because you got to see people dealing with it and realized that their lives did not end with the diagnosis of MS.

>>**Rick Turner:** Right, absolutely. Sarah, this is a very technological age in which we are living, but of course you cannot trust everything you find on the internet. So, where do you turn for reliable information that you can trust?

>>**Sarah:** Well, I am fairly lucky. I have medical health background so I am pretty good at interpreting things that I find on the internet or in print, but I highly recommend trustworthy sites like the National Multiple Sclerosis Society where all their information has been thoroughly vetted by a highly recommended and respected professional, and then sites like the National Institutes of Health that has excellent information about research and the disease in general. I think those are two of the best sites I would recommend for information. There are other places such as Web MD and some online support groups just for networking and talking with other people and just forming a community.

>>**Rick Turner:** Now Teresa, how about some of the other resources other than what Sarah just mentioned that you find helpful and valuable in trying to find out more about MS.

>>**Teresa:** Well, Rick, I like the disease modifying therapy sites for general information about MS.

>>**Rick Turner:** These are the Web sites of the drug manufacturers.

>>**Teresa:** Right.

>>**Rick Turner:** Okay.

>>**Teresa:** There is also the Demos Medical Publishing Web site where you can find information on books on MS or related topics, so it is a great way to check them out before going to the library to get them or getting them from them. Then I always go to my neurologist.

>>**Rick Turner:** There is a good answer for you. Go to the source. Sarah, I am going to go back to you for just a second. You say you are pretty savvy medically, and I am wondering what tips you can give people who are looking for reliable information on the internet to know when they have come across some information that maybe is not quite reliable. What should people look out for?

>>**Sarah:** First off, if it sounds too good to be true, it probably is. So when you are seeing all of these cures or fantastic diets or take this pill or theories of what is causing your MS, those are usually a good sign that they are not all that reliable. You want to look at who is providing the information. What are their credentials? Is there an MD or PhD behind it? Is there an academic qualification? Is it a link to a university or respected site? If you have any questions, bring it to you

neurologist, call your local chapter of the MS Society, print it out, and just take it with a grain of salt. Especially for people who are newly diagnosed, I would say limit your internet time if you can because it is real easy to scare yourself and get your head filled with all sorts of information that is not always reliable.

>>**Rick Turner:** Mike, you have been dealing with MS for over 20 years. How often have you come across bogus sites or bogus publications that advertise a cure for MS?

>>**Mike:** I am not so sure if have seen those sites because, while I work in the technology arena, I know that there is an awful lot of misinformation on the internet; and I feel much more comfortable with paper in hand, if you will, that I can sit down and read and digest at my leisure. I have seen over the years a number of different theories, bee venom and things like that, that just did not hold water, and those kinds of things are around internet or not.

>>**Rick Turner:** Teresa, you are nodding your head at the bee venom. So you have seen these same sorts of things.

>>**Teresa:** Well-meaning friends are always mailing me articles on the latest cure that they have read about in the paper. They are usually pretty scary.

>>**Rick Turner:** It is always good to take that information and go back to a reliable source, be it the National Multiple Sclerosis Society or your neurologist.

>>**Teresa:** Exactly.

>>**Rick Turner:** Let's shift gears for just a second, talk a little bit about identity because often these days we hear a lot about identity theft with regards to financial matters, but I want to twist it just a little bit and talk about your thoughts about identity theft in terms of multiple sclerosis, and it's potential of stealing a person's identity and sort of becoming your identity and replacing what was there. Sarah, I want to get your reaction to that notion.

>>**Sarah:** Sure. Losing my identity was a big part of adjusting to my diagnosis of MS. I was kind of leading a faced pace, working a couple of different jobs, when I was diagnosed, and I really had to stop, slow down, and re-prioritize my life. I was teaching at the time part time, and I found I could not teach any more because of my cognitive problems. Some creative things that I used to do, I used to play in a band, and I had trouble doing stage work on stage because I could not concentrate

and lead a band and all of that, and kind of left me with a void like what am I going to do with my life? Who am I now? What am I going to become. I just had to let go of things for a little while and let life come to me. I did not want to be a person with MS. I did not want that to shape what my life was going to be; and I found when I relaxed and just let life happen, I reinvented myself. I do not perform any more, but I still enjoy my music. I play music with my husband and with my children, and I think we all reinvent ourselves periodically through our lives whether or not we have MS. Yes, you can be sad about some of the things you have lost, but there is so much more that you can allow into your life, and you can become a stronger person, a more motivated person, and there is just different ways to focus your energy. While MS is still part of my identity, it is not my whole identity

>>**Rick Turner:** Okay. Teresa, what are your thoughts on this topic?

>>**Teresa:** You also cannot just be your MS. Some people when they are newly diagnosed, that is all they can see, cannot see the forest through the trees. You cannot do that either. You have to remember that you are still the unique person that you were. You are only, just as my nurse practitioner says, more special.

>>**Rick Turner:** Does it get easier with time?

>>**Teresa:** It does. I did not think it would, but actually it does.

>>**Rick Turner:** What are your thoughts, Mike? You have been dealing with this for a long time. Do you still think of yourself as a person with MS or how do you think of yourself?

>>**Mike:** I never gave my identity to MS. When I was diagnosed I just realized, alright, this is something I have to deal with it, and I will deal with it as best I can, and I will manage it as best I can, and I think I have been fairly successful with that.

>>**Rick Turner:** Not long ago we did a two-part series on positive relationships, and I encourage our listeners to visit those webcasts, which can be found on the MS Learn Online menu. Now let's hear from each of you regarding the impact of MS and your relationships. What impact did it have? Let's continue with you, Teresa. How did your diagnosis affect your marital relationship and your friendships?

>>**Teresa:** Some friends left.

>>**Rick Turner:** Really?

>>**Teresa:** Yes. They were not able to handle the disease or just me having an illness that they could not cope with. Others that I have met through and at the National MS Society are some of the closest friends I have ever had. But my best friend when I was diagnosed was my boyfriend, Pat, who told me that we have MS, and he proved that to me when he said “and in sickness and in health” on our wedding day.

>>**Rick Turner:** That is very sweet. Mike, you mentioned that you were diagnosed, and you and colleague were starting a new business at that time back in the early 1980s. Did MS impact that working relationship at all?

>>**Mike:** It did not really. I was able to adjust my lifestyle, stop burning the candles at both ends if you will, but we would good friends before we founded the business, and we had a good working relationship throughout. We were there to help each other. We knew that neither one of us could succeed, or the business could not succeed, with just one of us, and it did take two as a partnership to make it go. We were willing to make whatever adjustments we had to make to do that.

>>**Rick Turner:** Sarah, how has MS affected the relationship that you have with your children and your spouse?

>>**Sarah:** My spouse has actually never known me without MS. I met him a year after I was diagnosed, and he took my revelation that I have the disease in stride, and he has been wonderfully supportive with every decision I have made whether it has been to cut back at work or stop working when we had kids. As far as my relationship with my children, they are still too young to really understand. My oldest is two and my youngest is turning one next week; but my two year old does know that mommy takes shots everyday, and sometimes I have to go to the doctor a lot. I was in last week for a steroid treatment, so she knew that mommy had to go to the doctor everyday for a few days.

I have my own worries right now. Am I going to have enough energy for them? I worry, especially during the summer months when it is hard when it is really hard for me to be outside with them, am I going to have the energy and the strength and the physicality to be with them, but then I talk to other mothers who do not have MS, and they are just as tired and just worn out, and they have the same worries. I

think that is one thing to remember, is when we have these issues that are going in our head, you have to step back and say, what are other people without MS going through, especially with parenting. It is really easy to obsess about what you are not giving your children because you have MS; but when you talk to other parents, they have the same worries in just slightly different form.

>>**Rick Turner:** Right, well said. Teresa, what about your philosophy on disclosing your diagnosis?

>>**Teresa:** I have always been open about my MS. I want to spread the word about it. I want everybody to know about it. I will talk to anybody, everybody for as long as they want or as little as they want. If they keep asking me, I will keep telling them about it.

>>**Rick Turner:** Mike, you said you have not had very dramatic symptoms, at least that was my understanding of what you said. Has that always been the case, and if sometimes there were more symptoms, was disclosing an issue for you?

>>**Mike:** Disclosing has never really been an issue. I got out of the business in 1992, so I had a ten year track record of living with the disease, so when I took a job at Rutgers University, I did not disclose because it was not material to my condition, and I was not asking for any accommodations. Five years later I took a job as a vice president of information services, and prior to being hired I did disclose only because as the last question they asked before making me an offer, “Are there any potential deal breakers that you see”, and I said “Well, I have MS. It has not affected my life at all. I was diagnosed 15 years ago, but you should know this before you make me an offer,” and they did make the offer.

>>**Rick Turner:** Well, good. That was a win, win then.

>>**Mike:** Yes, it was.

>>**Rick Turner:** They got a good employee and they got a little education at the same time.

>>**Mike:** Absolutely.

>>**Rick Turner:** I want to stay with you, Mike, and talk a little bit about the importance of having a good doctor-patient relationship. What has been your

experience over the years, and how has it impacted how you have managed your MS?

>>**Mike:** Shortly after I was diagnosed, somebody gave me the book, *Anatomy of an Illness* by the late Norman Cousins, and I found this book very helpful. The book had a premise of humor and also building a partnership with your physician. Having been in the service industry, I became a very demanding consumer. If I was paying somebody for their services, I wanted to make sure I was getting my money's worth, and this book just reinforced how to go about that and how to build a relationship with your doctor as a partner in managing your own health. The doctor sees lots and lots of patients, but when I am with him I want him to be my partner for my health. It just seems to work very well. I have given up on some doctors that were not as attentive to my needs or willing to partner with me. They were rather dictatorial, and I found much better to work with doctors that I understand, and I respect their knowledge, but they are also willing to respect me as a partner in dealing with my symptoms and my disease.

>>**Rick Turner:** Was that a difficult thing to do, to switch doctors because you were not getting along with one or you did not like their style?

>>**Mike:** Not really, and again that is just because of my business background. In a business you are trying to satisfy your customers. I am the doctor's customer. I expect satisfaction, so if I did not feel I was getting my money's worth, it was not hard to go someplace else.

>>**Rick Turner:** Good for you. Sarah, what are your thoughts on this issue?

>>**Sarah:** It is really important that you are your own advocate. Only you know how you are feeling on a given day and what you need, and how MS is impacting your life. My symptoms are different than somebody else's symptoms, and what I can tolerate are different from what somebody else tolerates. You need a healthcare team that is going to listen to you. They might look at you and say you look great, your tests are normal, but they do not know how you are functioning on a day-to-day basis. If they do not listen, you switch. I too had to switch for different reasons. My neurologist who is wonderful went on sabbatical and has been for a couple of years, so I have been going around to a few different neurologists waiting for her to return, which is hopefully very soon. I am a pushy person when it comes to my health. I like to be in control but in a teamwork sense. So if you are having trouble with a neurologist, definitely see a different one or many

neurologists have nurse managers or case managers that can help you negotiate the system or really be an advocate with you if you feel like you are not being heard. Again, it is up to you to take responsibility for how you feel.

>>**Rick Turner:** Right. Great advice. Well, as we come near the end of our program, I would like for each of our guests to leave our listeners particularly those who have been recently diagnosed with multiple sclerosis with a message of hope and speaking from your own experience. Mike, what would you like to tell those who are newly diagnosed.

>>**Mike:** Over the years I have been diagnosed, I have met many MS people who still maintain an active lifestyle. I have been very fortunate in that I have been able to lead a pretty full life on my own. I am still an avid Harley Davidson rider, and all I can say is do as much as you possibly can. I did. You know I have had to slow down a little bit from my younger years, but learn to manage the disease and how it affects you. Pick a good care partner, doctor, to help you through this journey.

>>**Rick Turner:** And Sarah?

>>**Sarah:** I would like to say that there is life with MS. Some of the best things in my life have happened since I was diagnosed. I met and married my husband, the birth of my two children, and I think a lot of these things I let into my life because I made room for them after my diagnosis. It is hard to say that they would have happened had I not had my diagnosis, and I would not trade them for the world. I feel like I am living an active, vital, and important life right now and hope to continue that.

>>**Rick Turner:** So not only is there life after the diagnosis, it sounds like it has been the best of life so far for you.

>>**Sarah:** It has. This has probably been the best part of my life today. I have never been happier or more fulfilled, which is a little surprising, but yeah, I feel very hopeful and just full of life.

>>**Rick Turner:** And Teresa, your thoughts.

>>**Teresa:** Know that there will come a time when MS does not consume your every waking moment. That really takes a bit of time to accomplish that, but it really does happen. Also know that there will be a world free of MS.

>>**Rick Turner:** Well to Mike and Sarah and Teresa, thank you all for sharing your valuable thoughts and insights with us. We do appreciate it very much. Thanks again.

>>**Mike:** Rick, you are welcome. It has been my pleasure.

>>**Sarah:** It has been wonderful. Thank you.

>>**Teresa:** It has been fun, Rick. Thanks.

>>**Rick Turner:** The National MS Society is proud to be a source of information for you about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice consult a qualified physician. If you have a question that was not addressed, please e-mail us at [mslearnonline@nmss.org](mailto:mslearnonline@nmss.org). If you would like more information on multiple sclerosis, click on the resources link on your screen or call the chapter nearest you for an answer to your question. You can reach your chapter by calling 1-800-FIGHTMS. That is 1-800-344-4867. You may also want to check the National MS Society's Web site where you will find more information about today's topic and a menu of other web casts available to participate in.

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For the National Multiple Sclerosis Society I am Rick Turner wishing you health and happiness.