



National
Multiple Sclerosis
Society

**MS Learn Online
Feature Presentation
A Conversation with Clay Walker: Part 2**

Tom

Welcome back to part two of A Conversation with Clay Walker, I'm Tom Kimball

Tracey

and I'm Tracey Kimball and I'm excited to continue our program with Clay Walker, Dr. Patricia O'Looney and correspondent Kate Milliken

Tom

In this web-cast, they discuss treatment choices and therapy options

>>**Clay Walker:** [Video] "I know that I'm doing everything in my power to help myself, and that is taking the drug therapy that I'm on, staying physically active, exercising when I can, and overall just having a good attitude."

>>**Kate Milliken:** Long-term analysis of the disease-modifying therapies indicate that they are effective in delaying disability progression in people with relapsing MS. So, I feel like people in this world, day-to-day life, are used to waking up and having a headache or a cold, and taking a pill and then the next day they feel better. And with MS, this is a different deal. Why is it so important to hang in with the therapy for the long-term?

>>**Dr. Patricia O'Looney:** Well, it's so important Kate, because obviously I can talk about evidence and data, but that's exactly what it is. We are to the point now that we have accumulated -- you know, when the drugs were first approved in the '90s, most of the neurologist community were not sure about the impact of the therapies on the disease progress. But now we can

look at 10-year, 15-year data and see that those patients who are on therapies really have shown a slowing down of the progression of the disease. And so it really is making a positive impact on the disease itself.

But it is difficult, going back to the unpredictability of the disease. Someone is on a therapy and because the therapies do not stop an attack or exacerbation, they generally reduce the numbers and they reduce the severity. So, some individual who is on a therapy and they have an attack, they'll get discouraged. "Why am I going through these injections for if I'm still having an exacerbation?" I guess the point is, you're taking that insurance that the relapses are not going to be very severe, and you really are taking a proactive role in trying to slow progression.

But that's where the discouragement comes through, because you're on an injection and may still have a relapse. But the data clearly shows it's not quite as severe.

>>**Kate Milliken:** And I feel, Clay, that in light of you, you've made it so clear that it's something that you feel that your dedication and commitment to, your daily injection, has made a total difference.

>>**Clay Walker:** I know, it's made my hair grow like crazy.

>>**Kate Milliken:** Awesome.

>>**Clay Walker:** I do think it's important. I just got an epiphany when you were talking.

>>**Kate Milliken:** Do we need a guitar?

>>**Dr. Patricia O'Looney:** Or a harp, I don't know!

>>**Clay Walker:** That it's hard to shed an old school of thought, but we're in 2000s. Times have changed rapidly. I mean, the growth that has taken place in technology and in every facet of our world that we live in today has been light years ahead of where it was in the 1900s. And I think one of the, I guess the mystiques out there, is that for so long there was nothing you could do about multiple sclerosis, nothing at all. I mean, you got diagnosed and they sent you home to rest.

>>**Kate Milliken:** That's such an important point, I think.

>>**Clay Walker:** And the thing now, even the mindset of -- you know, if you talk to a general practitioner who is say, 60, 70 years old, they probably still don't know what is happening in the world of multiple sclerosis. But in the last 15 years, it has been -- it's light years where we've come, and to promote that and to get it out there. I also believe that MS is on the back burner because there is only half a million people in the United States living with it, so it's not like -- it's not as prevalent as cancer or AIDS or breast cancer, or some of the other diseases. So, you're not hearing about it all the time. But we are at a stage right now that it's super important to promote where we are. It's light years ahead of where we were 20 or 15 years ago.

>>**Kate Milliken:** I think even on a personal level, too. I mean, I remember when I got diagnosed and people sobbed in the telephone and said this is a death sentence for poor Kate, and it's over. And being able to say, "No, you've got to believe me. This is a totally different deal than it was 20 years ago."

Now, in light of how far we've come with the medicine, what are the dangers when you stop taking your medication?

>>**Dr. Patricia O'Looney:** Well, again, it's going back to the unpredictability. I mean, obviously, when you're stopping your medication, you're really going into uncharted territory. We really don't know, but guesses are, since the therapies do help slow progression, stopping therapies would probably just do the opposite or may have the disease pick up again. Because it is an ongoing disease process. So, the idea here is to try to slow the disease process, control the inflammation, and the best way to do that is to stay on therapies.

>>**Kate Milliken:** We have a question, actually, from the Web, from Ursula for Clay. "Clay, how do you stay so upbeat about having MS? How do you handle the ups and downs of this unpredictable disease? P.S. I'm a big fan and I can't wait to see you live Thursday and Friday in Vegas."

>>**Clay Walker:** All right, Ursula! I've always been an upbeat person. Getting diagnosed with multiple sclerosis was the darkest day of my life. I mean, I laid in bed and I shook all night, because I had this spinal tap. I make jokes about it now, but that was the darkest moment of my life.

But MS did something for me that is almost indescribable. It made me even more upbeat, because I had something to feel good about. I was like, you know, this is a challenge and I've often joked around to my friends, but I'm very serious. I go, "You know what? When they put me in the grave, I want to make sure this body is used up. I don't want to leave this world without any scars on me."

So, I have an attitude of I want to live every day to its fullest. And when I got MS, I realized how important it was to walk with my kids. I realized how important it was to go out there on stage every single night and give a thousand percent, because who knows how much longer I have to do that.

But I don't look at it so much from a perspective of the fear of losing my abilities; I look at it now like I'm blessed to know that I'm probably not going to lose my abilities, so I should appreciate that and live every day and smile. And also talk to people that have MS and share that hope. And, also, I'm not selling hope to them. You can look at me and see that 12 years later I'm still mobile and I'm still here.

>>**Kate Milliken:** And you'll probably end up having hair still on your head. Okay, let's go to the audience and look for Allison. Hi, Allison.

>>**Allison:** Hi. I was diagnosed with relapsing-remitting MS 14 years ago, and I've been very, very fortunate. I've been on Avonex for six and a half years, and I've been trying to eat right and exercise right, and live the right kind of life of low stress. But besides all of that, what more do you, Clay and the doctor, recommend that I can keep doing? Because I'm at a point now where I feel I've hit a plateau. I feel a little discouraged, had a couple of relapses, but I've talked to my doctor. She says stay the course. What more can I do to stay enthusiastic and get that enthusiasm back like I had five years ago?

>>**Clay Walker:** If I can start, and you guys can finish. I feel that stress and anxiety are uncharted waters for doctors. I think that they know that stress and anxiety can keep women from getting pregnant. I think that we know that it has some effect. I believe it's one of the greatest effects that there is. Fear of the unknown, fear of what multiple sclerosis is going to do to you.

You know, there's something that I read very early on and it was talking about see yourself as whole. And when I get a little discouraged or get a

little fear in me about something, I immediately see myself running, I mean, literally jogging or running, and I go, you know what, that's the me that I'm going to be. And you have to see it to be it.

So, whenever you start feeling these pressures and this wall that you're hitting, you do have to dig deep inside of yourself and you are the only person who can save yourself. And you have to see -- you know, look at a picture of yourself doing something. Surely you have one or two pictures that you really liked of yourself. Look back there and remember what put that smile on your face, and then go, "That's what I'm going to think about every time I get this bad, sick feeling in my stomach. I'm going to go to that."

>>**Kate Milliken:** Patricia?

>>**Dr. Patricia O'Looney:** Well, I'm not sure how much -- that's beautiful! I'm not sure how I can -- did you get this on tape? It's beautiful. Yes, I often say stress is not a neutral factor. We do know that stress does influence the immune system, so we try to deal with stress. And stress means different things to different folks. Some people -- a stressful event may mean a high level to one person, but another person may deal with it better. So, I think -- it sounds like you're doing everything right. You're on a medication --

>>**Clay Walker:** And you look great.

>>**Kate Milliken:** You do look great.

>>**Dr. Patricia O'Looney:** -- you do look great. Your doctor is watching you closely. Because obviously the benefit having options is that under a doctor's care, he obviously would do imaging or MRIs every once in a while. And if they do see activity increasing, then he or she may sit down with you and say, well, maybe we should try another option. Maybe we should try another therapy. But everything seems to be doing well, so the best of luck.

>>**Clay Walker:** Can I be an audience member and ask Dr. O'Looney a question?

>>**Kate Milliken:** Sure.

>>**Clay Walker:** This will be the hardest question you answer of the night.

>>**Patricia O'Looney:** All right. Okay.

>>**Clay Walker:** I know that it will be, because obviously there are patients here who are on different medications, and if someone has been on a medication for a while and they have two or three relapses, when do you decide as a doctor -- remember, that we as patients are trusting you unconditionally. We know nothing about this disease. When do you tell that person it's time for us to go to a different medication? When do you do that?

>>**Dr. Patricia O'Looney:** Well, that's a difficult question, Clay, and I think every physician has their own opinion. A lot of it is experienced with the drugs --

>>**Clay Walker:** Okay, I'm your patient, let's role play. I'm your patient, forget about anybody else here, but I'm your patient and I come in and I've been on a therapy for four or five years. I've had six relapses in five years. What are you going to do?

>>**Dr. Patricia O'Looney:** Well, it depends upon if the relapses have any residual deficit, meaning that you're not recovering completely.

>>**Clay Walker:** Exactly.

>>**Dr. Patricia O'Looney:** From each relapse.

>>**Clay Walker:** There's a noticeable difference. If you get a scale from 1 to 10 --

>>**Kate Milliken:** It's a decline.

>>**Dr. Patricia O'Looney:** Right.

>>**Clay Walker:** -- and I'm a 2 on a scale from 1 to 20, and all of a sudden I'm a 4, what do you say?

>>**Dr. Patricia O'Looney:** So, the relapses are increasing in number, if there is activity on the brain, which is the MRI, separate from the relapses. So, it's a different area. So, suppose you have activity, lesions occurring

along the optic nerve or something, which indicates some more damage taking place.

>>**Clay Walker:** In layman's terms, how long are you waiting?

>>**Dr. Patricia O'Looney:** Probably -- it depends on how long I've seen you, but probably maybe a year. A year, two years, watch you and see you, see how you're doing. But probably then would recommend maybe one of the other therapies.

>>**Clay Walker:** That's a big question that I see, and a lot of times people get on the medication and all of a sudden it doesn't work for them, and they put so much faith into this doctor and into this therapy. They go, "I'm done; it didn't work."

>>**Dr. Patricia O'Looney:** Oh, no, that's a good point. I'm glad you led me down that path, then. Because you should allow yourself at least a year, year and a half, two years to see how the therapy is working. Because sometimes there might be a slow impact, the therapy finally -- I don't want to say kicks in, but --

>>**Clay Walker:** I was on a different therapy when I first started for two years, three relapses. Bam! I was like that's not for me. Copaxone, all of a sudden that therapy was like this, and I'm saying if somebody is on one, they may find that another one will keep them in remission. I'm saying don't lose hope.

Tracey

Celebrity or not I always find it so interesting to hear from another person with MS.

Tom

Yes, and Dr. O'Looney had lots of valuable information to share.

There's one more segment of this Conversation with Clay Walker

Tracey

So please feel free to check it out

