



MS Learn Online
Feature Presentation
Healthy Living with MS: Fitting MS into Your Daily Life
Special Guest: Clay Walker

Kate: Hi everyone, welcome to *MS Learn Online*. I'm Kate Milliken your host for the third installment of our special three-part series on healthy living with MS, featuring multi-platinum country music star, Clay Walker.

(Applause)

In the first two programs we talked about maintaining our physical and emotional health while living with MS. Now we're going to talk about putting it all together and really living with MS. Those of us with MS know at times just dealing with the disease can be a hand full. So how do we fit all the "stuff" associated with MS into our daily lives? That's what we're going to talk about today.

I'd like to start this segment out with a quote from Richard Cohen, a person with secondary-progressive MS. He says,

"But with any progressive disease like MS, the moment is going to come where you feel overtaken by it. It was time to stop running from it and start running with it. I just reached a point where I had to admit it was a part of me and part of who I am."

Let's take a look at how Clay Walker makes room for MS in his daily life.

Kate: So Clay, in my MS experiences I have found that there were moments where I have actually had to ask for help. I am curious at how you are at asking for help and if you have had to do this as well.

Clay: I've have been fortunate enough to have a really great doctor, relieving the anxiety of MS. The more you learn about, the less afraid it, that you are, so I have to say my doctor has been my support system as far as relieving my anxiety. My family, my wife Jessica is my biggest supporter. And once I start running with, that's the quote that Richard Cohen, I think that's, I've never looked back.

Kate: I think people don't ask for help because they don't want to know they have MS, so Dr. Kalb in your mind when do you think its best to tell family and friends that you have MS?

Dr. Kalb: I think its important to start letting the people close to you know pretty soon because the people who know you and love can tell something is going on even if you don't talk about. And their imaginations will fill in the gaps, so I think for those who live with you and are involved very much in your daily life you want to start to tell them pretty quickly. Once you start to tell people outside your very close circle you have to think about how you convey information about your self, how much information to convey, and you really want to be prepared to deal with different people's responses. One of the tricks is once that information is out there, you can't take it back, so I really encourage people to think about why they want another person to know, how much they want to know and how they are going to teach them about MS.

Kate: Clay, for you, what made you decide to go public?

Clay: Wow, probably because of what Dr. Kalb just said, is the fact that I didn't want something to become evident. If I ever reached a stage where it was physically evident that I had MS and someone thought I had something else and started filling in the blanks as the doctor said. I wanted to learn, so every concert I do it seems someone who comes through what we call a 'meet and greet' line asks me, "Clay what are you doing for MS?" "When did it affect you?" All these questions. And I'm like why don't we have a website that answers these specific questions about what is Clay

doing, and a lot the stuff that the folks are doing, and I decided to make our foundation all about MS, so that's why we started *Band Against MS* and I would say that it has helped a lot of people and there's a lot of heroes out there that are living with this disease and we wanted to acknowledge that so.

Kate: Let's go to the studio audience for Jo.

Jo: My MS affects my cognitive abilities, I know a lot of people have cognitive problems, and if it affects yours and if so if you've ever forgotten the words to your songs?

Clay: I don't forget words on stage, but sometimes I'll be trying to process a sentence, I can't think of the words I'm trying to say, but I think that you can't, we're so afraid of MS, a natural, or should I say normal mistake like that and say, oh gosh is MS kicking in?

Kate: Lets actually, I'd like to ask Dr. Kalb a follow to that in light of your tips for cognition function.

Dr. Kalb: I think that the most important things about cognitive function is to think about the ways your functioning in every day life, if you're noticing significant changes, and I don't mean the kinds of things that happen to every one of us, sometimes we can't remember something or we forget a word, but if you feel like your abilities at work or your abilities to function at home are changing, its important to get some help to figure out what the problem might be. The reason I emphasize this is because we that cognitive changes along with fatigue, the main reason people leave the work force early with MS, so the best advice is that if you pick changes in your own functioning, you want to notice it and take care of it before your boss does.

Clay: Do you think Dr. Kalb that stress or emotional pain has a great effect on our physical and thinking ability?

Dr. Kalb: I don't think any of us function as well, with or with out MS, if were under a lot of stress or great emotional pain. But I don't think that those things by themselves cause the kinds of symptoms or cognitive changes we see in MS.

Kate: Eric in the studio audience, hi.

Eric: I have a bit of a professional question for you. How does MS affect your relationship with your agents and talent managers and so forth? For example do they take that into account when they're planning your tour?

Clay: I think everybody around me had to take a step backwards and go, whoa! Think about this, think about the phone calls your family made, stuff that's going through my mind. I wonder what calls were made privately, Managers, agents, because there's a lot of people who depend on the income of what they make off me and we're a team. There's a lot of people, depending on me, therefore I have a double duty of taking care of myself, because you know band members that have been with me since I started, their entire families, their financial lives, managers, agents all these people...

Kate: Clay did you feel in the beginning when your agent your manager, they heard about it and they didn't know what was gonna happen, that there were some steps that they took?

Clay: Well not steps that they took but questions they wanted to ask. I heard Dr, Kalb talk about people leaving the work force and I understand that I really do, but only the truth will set you free, only the truth show, you know what, when I get on stage no ones going, I feel sorry for him , if I was debilitated by this disease tomorrow, I promise you I would look at my life and go, I've done everything I can do with this MS. So to gauge your own self, and you have to ask yourself tonight when you go to bed, Have I done everything? I'm gonna challenge you guys, have you done everything, and its not have you thought about it, that's half the battle, have you thought of everything, but have you done everything?

Kate: Next question for you Dr. Kalb, unfortunately we all know MS can progress to a different place and having to change the pattern of their life. What has been the reaction from people who are trying to accommodate accessories and things to help them in light of that?

Dr. Kalb: I think that everybody's reaction is very individual but to generalize a little bit, I think there people who feel that asking help or using

a mobility aid or another device to help them is somehow giving to MS. And so they struggle really hard to avoid that, thinking that the longer they avoid it the more they're putting MS off. And then I then there are other people approach this as a problem to be solve, a series of challenges to meet. And they look around for every single tool, every single they can find to make the job easier, just like if they were going to build a house they were going to use a tool chest full of things they need. So rather than seeing tools and devices as giving in to MS they see it as taking charge of MS. And I think that's when those when those tools and resources and mobility aids can be fabulous because they can make it possible for people to do the things they enjoy that they find satisfying and gives their life meaning.

Clay: Do you know what my biggest tool is? This!

Kate: Your smile!

Clay: People get happy even if you fake it a little bit. I'm telling you that tool right there, that one will carry you a long way. Because what is it about MS, MS makes us isolated, It makes us feel less than equal to the person standing in front or talking to. Do you know what people are attracted to? Happiness. If you be happy and find happiness, people will swarm you. But there's something about that energy that comes from people that can very healing and very gratifying, there's nothing debilitating about MS as far as your happiness.

Kate: And speaking of energy, Email question from Mary. Clay I've seen you numerous times in concert (Laughs) the thing that amazes me most is how much energy you put into each performance. How do you manage to put so much energy into a show?

Clay: I'm so happy to be there, MS made me grateful. Before I walk on stage I say thank you that I have this ability and this talent, and I go out there and I dance like it's the last time I'll ever get to do it.

Kate: Wow (claps) So um, I'm sure most the audience knows you have a new baby in the house (laughs) So how has parenting affected your MS symptoms?

Clay: That's the thing about MS, you have to have it, it can't have you. You know, If I was confident that I had accepted my role with MS, and MS's role in life, then I would have had another child. And its not because I think I'm gonna be Stretch Armstrong for the rest my life, so I just go on and I think that is the healthy approach, do I do, I am I in denial? Absolutely not. But one thing I am sure of is that is has not and it will never defeat me.

Kate: As we come to the close of this amazing series, I would like to end with a quote that I found on the National MS Society website that I think pretty much sums things up, quote:

“Wellness is a dynamic state of physical, emotional, spiritual, and social well-being that can be achieved even in the presence of a chronic illness or disability.”

Thank you Clay, for being so generous with your time, and being so open with us about how you live with your MS.

Clay: Kate you have been great, and I want to thank Dr. Kalb too.

Kate: I would like to thank Dr. Kalb as well.

Clay: And the audience!

Kate: And the audience I'd like to thank for your expertise

Clay: And can I thank Teva Neuroscience?

Kate: Lets thank Teva Neuroscience and the studio audience as we have already thanked, we've had a good time here.

Now if you haven't seen the first two installments dealing with physical and emotional health, or if you'd like to see them again, just click on the titles to the right of the screen. Take care, and make sure you join the movement against MS. Visit www.NationalMSSociety.org to learn how you can get involved.

And now we'd like to close with one of Clay's biggest hits, a song he wrote that we think is particularly fitting when we're talking about living well with MS ... "Live Until I Die."

Lyrics:

Livin right, livin in this little old town I grew
up in.

But I still held on to my dreams
Standin proud, standin tall
Standin smack dab in the middle of it all
I don't worry out things that I can't change.

And I don't wanna think about tomorrow
I don't need anything money can buy
I don't have to beg, steal, or borrow
I just wanna live until I die

And everything around me are
Things I dearly love
And every night I get on my knees and thank
The Lord above

That I don't have to think about tomorrow
I don't need anything money can buy
I don't have to beg, steal, or borrow
I just wanna live until I die

I don't have to beg, steal, or borrow
I just wanna live until I die