



National
Multiple Sclerosis
Society

**MS Learn Online
Feature Presentation
Career Crossroads: Working with MS**

Sarah Keitt

Thank you

Sheila Becker

It makes me feel like I have something to contribute. It also gives me an opportunity to see people and interact and do something that's meaningful. Now that my children are grown, if I didn't have work, I don't know what I'd do.

Pamela Allen

(On phone) I'm looking at 9 o'clock. Unless that changes, let's go with that ...

I get grumpy when I'm not feeling like I'm being productive so maintaining a job allows me to feel like I'm still doing something useful.

Kathy Campbell

Work is a necessity to me – I'm single and so therefore I have to have a salary to survive.

Pamela Allen

I have 3 children 2 girls and a son, they are 12, 11 and 8 and it gives me the financial ability to take care of them.

Joel Kahn

The main reason that supplants all others is the emotional benefit, the emotional vibrancy that I get from work. I get a feeling of contribution and self worth.

Brian Lamers

(On phone) If it is a long-term investment, those are two good choices ...

You have to work. You have to do something with your life. You can't just sit on the couch, can't just sit there and say woe-is-me for having this disease. Work is gratifying; work is important.

Wayne Jackson

One of the things I've learned with MS is just that tomorrow's not promised to us. And we have no idea what's gonna be around the corner.

Brian Lamers

My MS affects me every day, when I get up, when I go through my day, when I go to bed. It's always affecting me. Because my choices that I make, every single minute of every day is based upon my MS.

Karen Jackson

If you have nothing else to focus on, then you can sit and think of all the yucky things happening in life. But if you have something else to divert you then you're gonna continue to focus elsewhere. So I do and work's important to me. It's important for me to get up every day because I can.

Sheila Becker

When I was first diagnosed and things were stopping work, I'd trip or something or I'd drop something, I'd end up in tears on the floor at home and it's like ok now what are you going to do, you have to get yourself up and say ok that felt better and now I'm going to carry on and take care of tomorrow.

Vanessa

Lately I've been learning a lot about what it takes to hold down a job while you have MS. Let me tell you, it ain't easy! But *not* having a job while you have MS, can be a whole lot worse.

Lately, I've been meeting some pretty amazing people lately who've continued to pursue their careers while managing their MS. Well, I think they're amazing. But actually they're ordinary people just like you ... who have MS. I've also learned a lot from some professionals who help people with MS find and keep their jobs.

So how is it that I became this treasure trove of knowledge? Well, it all started a few weeks ago when I got a call from my friend Claire.

Vanessa

She's had MS for about year or so. She's a graphic artist whose career is just beginning to take off. So far her symptoms have been minor, so she hasn't told anyone at work about her MS.

Dave

Claire, they've arrived for the meeting. I'll see you in the conference room ...

Vanessa

That was the day things started to fall apart for Claire.

Dave

So what do you think of the work so far?

Client 1

Overall it looks really good. However, I think I wanted this over here, and that this over here. Didn't we already discuss that?

Claire

You know, we did. We had that conversation, and I assure you that everything will be done.

Client 2

And I'm concerned about how it's all going to come together at the convention. We have a lot of pieces and parts that need to be pulled together in a very short period of time ...

Dave

Don't worry about it. Claire's the best we have. She's very energetic, she's focused. If she has to work 18 hours, we'll have this done they way you want it and it'll be done on time. I promise.

Again, let me assure you ...

Claire

I'll have those changes to you first thing ...

Client 1

Are you OK?

Client 2

What did she have for lunch?

Dave

Claire's the best we have. Don't be concerned about anything.

Client 2

Are you sure/

Dave

I'm certain.

Claire

Hi Vanessa I need to talk to you ...

Vanessa

... and that's how our regular meetings in our favorite coffee shop began.

Vanessa

Sorry it took so long to get here. I got hung up at a meeting.

Claire

I should be the one apologizing to you!

Vanessa

No girl, that's what friends are for. Plus, I'm looking forward to not being in that rush hour traffic. what's up?

Phillip Rumrill

MS has given Clare another full-time job and understanding how it does and does not affect her in the work place can be a very complicated task, one that people often need help to do.

Vanessa

Well, I'm glad you called. I find that when I have days like that, the best thing to do is cut your losses and take the rest of the day off.

Claire

Vanessa, this isn't just a run of the mill bad day here! I've got MS, remember? MS! And it's just going to get worse. At some point I've gotta come to terms with what that means to my job ... and my career.

Mary Hennessey

You may feel that's it's very overwhelming and severe and if you have somebody to bounce your ideas off of they can bring it back to "well let's look at this realistically and let's see what are some of the things that you can do and maybe it's not as bad as you think it is."

Wendy Richard

What Claire is doing is perfectly normal and very healthy. Before she gets to the stage where she is willing to make some definitive decisions on where she wants to go in her job and with her employer she has to start processing all of what is occurring and what is happening to her and how she feels about that.

Pamela Allen

It's ok to vent, I don't think that somebody should get stuck in that stage, but definitely vent and until you're feeling better about it because there's nothing any of us can do to change it.

Sheila Becker

Because it's not going to go away. But you can get through this. You just have to decide ok this is my little bag to carry and I'm going to make the best of it and I'm going to find ways to work around it and do what I can and don't worry about what I can't.

Pamela Allen

That's our choice to make the best of it or to cry about it every day. I choose not to cry about it and I know that may sound kind of harsh to some people but that's, . . .it is what it is.

Claire

I'm going to have to make some major decisions about my future soon.

Vanessa

Yes, you do. But before you do anything rash, you need to know what you're dealing. I'm a librarian, remember? I do research for a living. It's my thing. So let me help you out.

The first thing we need to do is get some basic information about MS ... how MS will affect your job ... and how your job will affect your MS.

Henry McFarland

Usually MS in the early stages is characterized by relapsing remitting disease. It means that a patient has an acute attack, it may last for a few weeks then that

patient gets better. Often times later in the disease there's a more insidious progression with some accumulation of disability.

Phillip Rumrill

So sort of keeping track of how MS is affecting you on an on-going basis because it changes sometimes from day to day. It's very important, I call it self monitoring.

Steve Nissen

I think it's important for you to just realize how your body reacts to stress, reacts to deadlines, reacts to having a set schedule.

Marion Levine

It's very important to keep doing what you're doing and doing it well. By doing something well you can get the benefits from work that you, that are kind of psychological benefits to working.

Kathy Campbell

I have more energy when I go out and interacting with people than I ever would if I sit at home and watch TV or anything. I'm one of those people who literally gets energy very much from other people

Mary Elizabeth McNary

Logistics are more tiring than the actual matter of the work. And that means that living here in Washington DC you can face a day of 104 degrees in the shade and a lot of humidity. So getting to the office can be dreadful

Sheila Becker

It's fine when I'm just sitting at my desk, working on my computer, answering phone calls, talking to my assistants, that's great. Where I notice it is if I get pulled into a big meeting or if I have to present. Anything that will cause a little stress or tension ... you know you gotta be "on" ... I notice that everything stops working as well as it should. I find that I trip a little bit more, my tongue gets tied a lot more, my mouth gets dry, in ways that it never did before the MS and so I really have to try very consciously – calm down, calm down, breath you know because the MS can get in the way a little bit.

Claire

I really do enjoy what I'm doing. I like all my co-workers, and I feel like my career is finally starting to take off.

Vanessa

And with that promotion you were telling me about, you'll finally be making some decent money.

Claire

And I can sure use it. I just found out Jenny will be needing braces. And without a husband's medical benefits to count on ... But I'm having these flare-ups, and with MS, it's just going to get worse. I just don't know how much longer I can keep this up.

Steve Nissen

Right when you've been diagnosed with MS you're going through a lot of different feelings and new and different symptoms and we can sometimes make decisions quickly. So please give it some time, learn how to manage your symptoms, learn how to manage your MS and then really look at how those symptoms are directly affecting your ability to work and you in the work place and then make that decision.

Marion Levine

I think that you should continue to work as long as you can.

Steve Nissen

For the financial benefits, for defining who you are.

Marion Levine

It's important for them to continue to work in order for them to feel like they are a part of the community.

Steve Nissen

There are definitely ways to manage some challenging symptoms that you may experience that is brought on by the MS and there are ways that you can tap into legal protections out there that will allow you to remain employed for as long as you possibly can.

Sarah Keitt

When I was first diagnosed, I had a number of people telling me, 'You really should think about not working. You should just rest. You should focus on your health.' And that was discouraging for me, at 30 years old you don't want to hear that you should consider disability. Even though at that time I was sick and I was in crisis, I didn't feel that I was anywhere near ready to retire or go on disability.

Karen Jackson

People are usually surprised when they hear that I'm still working. And they just assume that you're gonna go out on disability or you're just not working. We're not independently wealthy. I think work is just something that everyday people have to get up and go to work. Well, so do I. So, Yes, I'm constantly told, 'Oh, you know . . . Oh, You poor thing.' Well, No. There are a lot of people a lot more worse off than me. I can get up every day. It may take me a little longer. I may have to do things a little differently. But I can still do it. There are people that can't. So as long as you can, you do.

George Jackson

And I'm glad she's still working. I think it gives her something to do that keeps her challenged and focused. I think if she were to stop work when she could work would be probably like giving up to a degree. And I don't to ever want to see that happen. Always a positive approach is the best way to proceed. She's still functioning, and she's functioning very well.

Vanessa

OK... so here's the plan. We're gonna go online, do some research, talk to some people and get the information you need so you can do what you need to do. Here's how I think we should organize it ...

Claire

OK, wait a minute ... as researcher or drill sergeant?

Vanessa

Both! First thing you need to do is figure out what your legal rights are.

Claire

Wait a minute! There's no way I'm gonna get lawyers involved in this!

Vanessa

I don't think you need to, but there are laws out there to protect and help you, and you need to know about them.

Now have you told anyone at work about your MS?

Claire

No

Vanessa

Well, it may be getting to be time to disclose your little secret.

Claire

Why would I want to do that? And how would I go about doing it? How would people react?

Vanessa

That's what we've got to find out. We also need to figure out what can be done to make your job easier for you.

Claire

Accommodations?

Vanessa

Uh-huh. Then we're going to find out what resources are out there to help you out.

Then you'll be in a position to make some decisions about your career..

Claire

Vanessa, this sounds like a lot of work.

Vanessa

It's what you gotta do! But I'm gonna help you.

Claire

As researcher or drill sergeant?

Vanessa

Probably a little bit of both!

You look beat! Are you going to be all right getting home?

Claire

Yeah, I'll be fine.

Go home and get Jenny to order some Chinese for the two of you, and take it easy. You might want to think about taking tomorrow off. Take care of yourself!

I'll get started on this list. And then Saturday, we can get together and start working through this.