



National
Multiple Sclerosis
Society

MS Learn Online
Feature Presentation
Career Crossroads: My Little Secret

Vanessa

Hey, Claire ... how you doin'?

Claire

Ugghhh! I'm trying to write out what I'm gonna say to my boss about my MS.

Vanessa

I see you're making wonderful progress!

Claire

I feel like I'm opening a pandora's box here. Once the word's out, there's no turning back. How do I go about telling him? What do I even tell him about my condition? I have no idea how he'll react. And what about my co-workers? Are they going to treat me like some kind of freak, or something? Vanessa, I don't even know what to ask for.

Vanessa

OK, OK ... let's take this one step at a time. First, you know you're not the first one to be going through this. Let me show you what I've found out.

Phillip Rumrill

Your employer does have the right to know that you are a person with a disability. Very important distinction between disability and multiple sclerosis. Multiple sclerosis is a diagnosis.

Marion Levine

You do not have to say that you have MS. You can say that you have a neurological impairment that limits some of your activities and you get very tired at times.

Phillip Rumrill

Not all people with MS are people with disabilities under the ADA and so having the diagnosis doesn't really tell the employer anything at all about the functional aspects of your ability to do the job.

Wendy Richard

And it's important to know first of all that you do not have to disclose that you have a disability on the job unless you're seeking some type of accommodation.

Vanessa

Now this brings up an important question: Are you to a point where you feel you can no longer do your job without an accommodation?

Steve Nissen

I think it's very important for Claire to realize that maybe once people are starting to recognize that sometimes going on,

Client 1

Didn't we already discuss that?

Steve Nissen

... that possibly her supervisor or the employers are also recognizing that something is going on.

Dave

I'm just as much concerned as the customer is ...

Steve Nissen

There's no question that this a very stressful time for her. She's dealing with these particularly challenging symptoms, she's really seeing the impact that these symptoms are having on her ability to follow her job duties through. And if she's noticing that, most likely some other people at work are also noticing that.

Client 2

What did she have for lunch?

Claire

Yeah ... I think it's time. But who needs to know about this?

Wendy Richard

It's important for you to remember that once you disclose your disability to your employer if you choose to do so, that is confidential information shared between you, your employer and possibly your representative from human resources who may need to know about subsequent accommodations that will need to be made. That is not public information for everyone else on your team, in your department or for the corporate newsletter. That is private, confidential information. If you choose to tell one of your other co-workers you certainly can do so. But of course know that you may be opening yourself up that the rest of the department may then find out.

Claire

I'm just so worried about how my boss will react to this.

Steve Nissen

I think probably one of the ultimate fears of disclosing is that that person is going to be fired, or they're going to be pigeon holed into a dead end job that they can no longer move up.

Charles Goldman

The disadvantages to disclosing are not legal disadvantages but they're more societal disadvantages

Phillip Rumrill

Whenever you give somebody a label that they don't understand very well or one that affects people differently you're engaging their existing biases about that very label.

Charles Goldman

For me to tell you something I can't do is hard. For me to admit it in public I'm going to fall asleep if you don't help me, I can't remember what you're saying, my God it doesn't feel good and when my boss hears that – gee you know is Chuck going to be good enough to be my star anymore? So there are some disadvantages and they're attitudinal.

Phillip Rumrill

Other times employers will start seeing the dollar signs. Safety issues, health care costs, things of that nature – what if you go out on long term disability what are the costs going to be of that.

Vanessa

I understand why you're worried. There are some disadvantages to disclosing ... but, in addition to getting the accommodations that you need, there are some advantages, too.

Steve Nissen

There are several advantages to disclosing to an employer. One it may just reduce your own stress, keeping this secret can be very stressful and obviously we're always looking to manage the stress that we do have in our lives.

Marion Levine

And if you disclose well you'll feel better. Which it makes it easier for you to do your job and to keep your job so that since MS is a progressive disease that strikes unpredictably it's kind of an insurance policy for yourself to be honest with your employer.

Wendy Richard

Another advantage is – it can open up lines of communication that were previously not there and help to clarify some possible misconceptions.

Vanessa

Wayne Jackson is a Project Manager for Charles Schwab and Company. He conducts training sessions for their online educational service.

Vanessa

Pam Allen is an associate project manager for Biogen IDEC. When Wayne disclosed to Charles Schwab and Pam disclosed to a previous employer, they had very different, but not uncommon reactions to their disclosure.

Wayne Jackson

I don't think they knew how to react to someone with MS. Because it was so new to them. Not only was the condition new to me, but it was new to them.

Pamela Allen

you know my past employer, I have no idea what he was concerned about. I really don't, because one day he didn't know I had MS, the next day he did know that I have MS.

Wayne Jackson

They didn't know if they could touch me. They didn't know if they could give me additional work. There was just a lot of uncertainty. And that uncertainty was across the board.

Pamela Allen

He just treated me much differently kinda like from one day to the next. After he found out I had MS he doubted my ability.

Wayne Jackson

I found myself being a walking billboard because I always had something in my backpack or my briefcase. Because if there was something that they were unaware of or were unsure of, I would pull out a brochure,

Pamela Allen

I felt like I had 2 choices, I could either stay there and continue to fight every uphill battle that came my way with this job or I could find another job and I chose to find another job.

Wayne Jackson

I'm a Project Manager with the live-on-line component, where I am -- I play a central role in delivering workshops through the virtual channels, what we call Live-On-Line. And I love what I do. I've been in several different capacities with Charles Schwab.

Pamela Allen

I guess what my current employer would be most concerned with, I'm talking about my immediate manager is very compassionate. I think she would be most concerned with my health. Um, how I would be doing physically, more so whether or not I'm going to be able to do a particular job. I think she would be most concerned about me as a person.

Wayne Jackson

And one of the things that I like is -- my immediate boss who is in San Francisco, she's that much more attentive to -- how am I feeling?. Do I need anything? Is there anything I am not receiving now that I can receive. And the great thing about that is -- if I ever need it -- a wheelchair, or a bigger desk or a larger office -- Gina has set it up so that I'm that much more at ease and comfortable, just ask her.

Claire

OK ... So I've decided to go through with this, and I know that there is a down side to disclosure ... how so I go about telling him in as positive a light as possible.

Vanessa

Well you hit on the key word: Positive. You also want to make sure you give it some thought and planning. You don't want to just drop it on him during a coffee break. What I've found in my research is that some employers are OK with just a verbal disclosure. Others will want it in writing. Either way, you need to plan what you're going to say.

Steve Nissen

I would say almost come up with a disclosure script. Practice it. Usually a disclosure script is comprised of 4 different parts. One is disclosing the MS or the medical condition,

Phillip Rumrill

Sometimes people with MS, we've talked to a lot of folks who will say things like I have this nerve thing it comes and goes. Well guess what folks, MS is a nerve thing, it does come and go and you haven't sold away your privacy when you've shared it in that fashion

Marion Levine

I tell my clients to keep it simple and not to give more information than is needed. And what they need to know is that you have an impairment or you have a disability and it's under control ... now.

Phillip Rumrill

Your employer can ask for written documentation of the disability and that documentation does not need to include your diagnosis. That documentation, we recommend, be a one or two sentence line from a health care provider, social worker, psychologist, rehabilitation counselor, nurse, physical therapist, occupational therapist ... these are the people who can certify disability status.

Vanessa

So let's hear the first section.

Claire

I have recently been diagnosed with MS ... no that's not right ... I have recently been diagnosed with a medical condition that is affecting some of my mental and physical functions.

Vanessa

I think you need to be more specific about your mental and physical functions. We don't want him to think you now have an IQ of 35 and you about to pass out at any moment.

Claire

I have recently been diagnosed with a medical condition that affects my memory and balance.

Vanessa

I think we're off to a good start ...

Steve Nissen

The second component would be describing the way that the MS is directly affecting her.

Charles Goldman

You remember last year I did this for you well I had MS but it wasn't a problem, now all of a sudden it's a problem, I don't want it to be a problem. So I want to continue to do and I think I can and emphasize the positive.

Steve Nissen

Obviously with MS there are so much variability from person to person that it's important to relate your MS, to relate Clare's MS to her symptoms and how they are affecting her at work.

Claire

I am proud of the award winning work that I have been able to produce for the agency. I want to continue to do what I do best ... developing creative and innovative design solutions for our clients. My memory and balance issues are beginning to interfere with my ability to be as effective as I want to be.

Vanessa

You're on a roll, girl!

Steve Nissen

The third component is providing the accommodations or suggest the accommodations to the employer.

Charles Goldman

See if you know what your company's policy is say you know boss I would thinking about flexi place or I was thinking about our telecommuting policy or

maybe work at home and I found this. And the boss may say gee I didn't even know we had that, can we do that? Well but your job requires you to be here. Well I can be here if you need me.

Claire

I just don't know what kinds of accommodations I should ask for.

Vanessa

Well that's something we'll need to investigate. Let's set that issue aside for now, and move on.

Steve Nissen

The fourth component of that disclosure script is finishing on a positive note. With these accommodations I know I'm going to be able to continue to excel in my job, I know I'm going to be able to perform and to meet the deadlines that I need to meet.

Charles Goldman

Rather than saying under the ADA I'm entitled to reasonable accommodation. Your boss is going to say oh my God there's a lawsuit waiting to happen get her out of here. You want to create, you want to build on the positives and you want build with your successes.

Joel Kahn

I think there is the course of action of making sure they understand it is in their beneficial, their financial and productive interest to make you as productive as possible because of the cost of bringing in a new person, of training a new person.

Claire

... and I'm looking forward to working with you to find the best solutions that will maximize the contribution that I can make to our company.

Vanessa

I think we're almost there. The only part we need to deal with now is this part about accommodations, which we'll work on next time.

Hey Claire! What's going on?

Claire

This is so hard, Vanessa! I feel like I'm "coming out", or something. I have no idea how people are going to react ... or how I'm going to respond to them.

Vanessa

I can't answer that. All I know is that, while you're feeling very alone right now, know that a lot of other people have gone down this road before you, and it would be good to learn from their experience.

Wayne Jackson

And it's funny because when people look at me and they'll go, 'He doesn't look like he has MS.' And I want to say to them, 'What am I supposed to look like? Am I supposed to have a wheelchair? Am I supposed to have crutches? A cane?'

Joel Kahn

I kept telling people that I had a pinched nerve and that story was wearing thin. And so I think because I had just been promoted and had been in a scooter I said I have nothing to lose and so I just went ahead and told them. Things have been very positive since.

Sheila Becker

I finally decided it was time for me to tell my manager about it. And I sat down and told him and his response was oh wow what can we do to make your job easier, how can we do to help, the fear ended up being all on my side and really none from theirs. They were very, very accommodating and accepting, which was a really pleasant surprise for me.

Sarah Keitt

One of the advantages of letting my employer know that I had MS is that I could ask for things that would help me do my job better, and help me to be more productive.

Wayne Jackson

I'd say the negative feedback along with other things in life, it's far behind me. And it's taught me how to adapt to that type of reaction and change.