



**MS Learn Online
Feature Presentation**

**MS and Employment
Featuring: Steve Nissen, MS, CRC**

Susan: I am currently employed. And they have been very supportive.

Cheryl: The fatigue definitely affects employment or work. It's difficult getting through the day when you're so tired.

Trevis: Let's face it, in American society, we are what we do. In a cocktail party here, you meet someone and the first thing you ask is, "So, what do you do?" So, when that is taken away from us -- and don't get me wrong, I didn't give up my career as a corporate chef and traveling around the world easily. I did not give that up; multiple sclerosis took that from me and I was angry about that.

Walt: You lose your self-esteem. You start thinking like you're not the person -- maybe you weren't doing your job very well and then that was what you lost the job for. And not realizing the impact that MS has had on it, you really need to think back and say, "I really couldn't do that anymore because MS has affected me that way."

Mike: I retired four and a half years ago, when I was 56

Donna: I had to do a little bit of creative thinking there and a little of talking to myself and finding out what I really did want, what my strengths are and what I could still do physically even with the MS, not in spite of it.

>>Tracey Kimball: Hello. I'm Tracey Kimball and welcome to MS Learn Online. As a complex and unpredictable disease, MS can have a significant impact on a

person's ability to work. Understanding disclosure, workplace accommodations and available resources will help you navigate your career decisions while living with MS.

Joining us to discuss employment issues for people with multiple sclerosis is Steve Nissen. Steve is the Senior Director of Employment and Community Programs at the National Capital Chapter of the National MS Society in Washington DC.

Steve, thank you for joining us on MS Learn Online. Our work, our jobs, our careers are an important part of our lives. In many ways they can define who we are. But what happens when a person's career -- when a person with MS's career enters the scene?

>>**Steve Nissen:** Thank you so much for having me.

>>**Tracey Kimball:** How can one's employment be impacted by multiple sclerosis?

>>**Steve Nissen:** What we know in regard to employment issues for people that are living with MS is that definitely your employment can be affected. A person may have concerns about disclosing within the workplace. Do I need to tell my employer? Or, if I'm looking to change jobs, disclosing to a prospective employer?

As a person may experience new or different symptoms, those symptoms may directly affect their ability to perform the work that they had been performing. So, they may need to look at ways to accommodate those symptoms on the job, looking at modifications that can be made to allow a person to successfully continue to work, to work effectively, to work efficiently, and still be able to perform the essential functions of their particular job.

At some point a person may ultimately decide to leave the workforce as symptoms progress and maybe can no longer perform their particular job. They may consider making a career change or possibly ultimately deciding to leave the workforce.

DISCLOSURE

Holly: Disclosing to employer is something that is really personal and everyone has to do it their own way

Cheryl: I told only the people at work that I needed to tell.

Kathi: I think it depends on your employer and the relationship that you have with the employer, and the type of job that you have.

Stephen: I have disclosed that I have MS to my employer. As soon as I got the diagnosis I went in, because it was obviously a pretty sudden shock to me and I didn't go to work for the remainder of week, just kind of adjusting to the news.

Walt: I'd get very educated and I'd talk to somebody who knows about the Americans with Disabilities Act.

>>**Tracey Kimball:** You mentioned disclosure earlier and it's such an important issue to understand. What do people with MS need to know about disclosing their condition to employers?

>>**Steve Nissen:** That's a very good question and it's a very tricky question. Because, really, no two people are the same. When it comes to disclosure in the workplace, it's kind of a legal side of disclosure and then a practical side.

Part of the legal side of disclosure is in order to request some type of an accommodation, some sort of modification or change on the worksite to allow you to perform your essential job functions, a person would need to disclose.

The practical side is that oftentimes with MS, given the unpredictability of the symptoms that a person could experience, the unknown of their ability to perform their job for a long period of time, from a practical perspective, some people might choose to disclose even when they don't need any types of accommodations. They may feel like, that they would want to disclose just in case their condition changes over time so they may need to request that accommodation.

So, it really is a personal decision to make. I think what is important when it comes to considering disclosure in the workplace is to plan ahead. Figure out what's going on that might lead you to be thinking that you would want to disclose and, if so, part of the process is figuring out who is the right person, when is the right time, and what would you actually say.

WORK PLACE ACCOMMODATIONS

Kathi: I was far more productive working 24 hours a week than I was working 40.

Walt: I got a program from them that's called "Naturally Speaking," and you can speak to your computer and it will write for me and you can do e-mails and stuff.

Vito: They ended up getting me a mobility scooter without me asking for it, which was a great benefit. Then they also had ergonomics people come and check out my situation, set up my work station, get me a special chair.

Susan: I had to ask for an office, which was kind of unheard of at this place, because noises tend to bother me. Background noise bothers me. It affects my concentration

Mike: And the thing that as probably the most significant was I needed them to write down exactly what the expectation was that they wanted from me and when they needed it. I needed to know to help me prioritize, because it was very difficult for me to multi-task.

Cheryl: I came up with suggestions that would keep me employed and still doing the job. For instance, I can do this part of the job but can I do it sitting down?

Cermit: At work we didn't have a handrail up the stairs, and they put the handrail in for me. Other things, they wanted to put my office on an upstairs thing, I said, "No, I want it on the ground floor and I want it near a bathroom." They said, "Okay, we can deal with all that." I've not asked for anything I would call major. It's all been simple and easy things, so there has been no reason to say no.

Kathi: I would contact the National MS Society, too, because they have a wonderful brochure on explaining MS to your employer and what accommodations can be made.

>>Tracey Kimball: What type of accommodations are common or even reasonable for a person with MS to ask for?

>>Steve Nissen: There are a host of different types of accommodations that a person with a disability, specially a person with MS, may be able to request from their employer. Many of these things can be practical things. For instance, someone who may be experiencing fatigue may be able to request just a flexible work schedule, taking a break during the day. Telecommuting we have found has been a great way to accommodate people. If you can work from home part of the time can be really beneficial to assist a person in working productively and working efficiently.

Mobility difficulties in the workplace, making sure that you're physically placed in the area that is close to where you need to visit often. So, if you need to go to the workroom on a regular basis, or to the front desk, making sure that your desk is located in an area that will hopefully minimize your need to walk far.

For people who may experience cognitive symptoms, some of the built-in accommodation, the accessibility features that are built into computers nowadays, the reminders, to-do lists, can be practical things that people can definitely utilize; making sure that your desk is located maybe within a part of the office that doesn't have as many distractions.

So, really, there are a lot of very creative but practical things that people can do in order to work effectively on their job.

LEGAL PROTECTIONS

Kathi: As long as you are doing the job that you're assigned, you can't be fired without the American Disabilities Act coming into play.

Walt: talk to somebody first that knows about the impacts, the disease, that knows the employment situation. I would even say talk to an attorney.

>>**Tracey Kimball:** Are there employment laws that people with MS should be aware of?

>>**Steve Nissen:** Definitely, there are several legal protections that a person with MS, I would encourage people to get informed about and possibly need to tap into at some point of your life working with MS.

The Americans with Disabilities Act is one of the prime pieces of legislation that is designed to protect against discrimination of people with disabilities within the workplace. It is the ADA that does address disclosure and would give the opportunity for that person to request a reasonable accommodation. The ADA does require that a person is still able to perform the essential functions of their job, but they have the right to request a reasonable accommodation.

Another legal protection that a person with MS may tap into is the Family and Medical Leave Act. What this is is job protected leave without pay. If a person may be going through the diagnosis process, or they're going through an exacerbation and

a flare-up, maybe they have utilized their personal time off. If the employer follows the Family and Medical Leave Act, that person would be able to request, it's usually up to 12 weeks' leave without pay. During that time your job is protected.

Two other legal protections that I think are very important for people to be familiar with deal with some of the insurance protections. HIPAA, which is the Health Insurance Portability and Accountability Act, there are a lot of different components to that law, but oftentimes for people with MS, what they're paying most close attention to deals with preexisting condition clauses. So, if a person is going from a group medical insurance plan, maybe thinking about changing jobs, and they move from a group plan to a group plan, as long as there is not a significant break in coverage in that person's coverage, that new group insurance policy cannot impose a preexisting condition. Sixty-three days is kind of the magic number for that.

And COBRA is another law that deals with medical insurance. If a person chooses to leave the workforce, then their previous employer can offer to that individual to stay on their employer's group policy. In that situation, the full cost does fall on the employee. And sometimes HIPAA and COBRA can kind of dovetail together, that a person can utilize COBRA to tide them over until their new benefits kick in.

RESOURCES

Walt: I work with the Department of Vocational Rehabilitation for the State. They'll know any contacts you need with the ADA. The National MS Society has great resources that you can tap into that -- they'll tell you how to get information about the ADA.

Trevis: a lot of rehab facilities through universities and research institutions can help you as well.

>>Tracey Kimball: Finally, what resources are available for people with MS regarding employment?

>>Steve Nissen: I think tapping into the resources is so important in terms of to get educated and to get informed about the potential impact that your MS can have within the workplace. The National MS Society is obviously a great source of good information. We have a variety of different brochures and publications dealing specifically with workplace issues and employment concerns, disclosure tools on our website. So, definitely turn to your local chapter.

The Job Accommodation Network is another amazing, federally-funded resource. You can call a JAN consultant at 1-800-526-7234. Their website is actually, it is askjan.org.

One more great resource are what is called the ADA Centers. Their website is www.adata.org, and their phone number toll free, 1-800-949-4232. Again, a slew of information when it comes to legal protections, the ADA, and can be a very good source of information as well.

>>**Tracey Kimball:** Thank you Steve for joining us.

>>**Steve Nissen:** Thank you so much for having me.

>> **Tracey Kimball:** If you would like to get more information on employment issues go to www.nationalmssociety.org