



**MS Learn Online  
Feature Presentation  
Rehabilitation Counseling  
Kurt L. Johnson, PhD**

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Tom

Hi I'm Tom Kimball

Tracey

And I'm Tracey Kimball. Welcome to MS Learn Online. In this program, we'll be exploring a topic that not many people are familiar with ... rehabilitation counseling.

Tom

...And that includes me.

So we're glad that our medical correspondent, Kate Milliken was able to speak with Dr. Kurt Johnson who's a professor in the department of rehabilitation medicine at the University of Washington in Seattle.

Tracey

So, you may ask, why would a person with MS want to know about rehabilitation counseling?

**>>Kurt Johnson:** We know that people with multiple sclerosis, that only about 30 to 35 percent of people with multiple sclerosis are employed. And of those that are unemployed, we know that about half of them would prefer to be employed. And we know that a lot of the barriers that they confront are related to their multiple sclerosis, and that includes -- the biggy is cognitive changes, but also fatigue and changes in mobility, and all the other kinds of things that go along with MS can get in the way of working.

We know that another barrier is, as related to systems. For example, long-term disability policies, social security disability insurance, where it makes it difficult for people sometimes to reduce the number of hours that they work and maintain their medical benefits and maintain the standard of living that they prefer.

And so it can be pretty challenging to know how to deal with the changes that come along with multiple sclerosis in terms of keeping your job or selecting another job and moving into that.

So, rehabilitation counselors are specially trained counselors who can help with how you feel about changes in your life because of multiple sclerosis, and work with you and your family and/or work with employers to help you negotiate those changes.

So, some of the outcomes people might want to take would be to modify the circumstances of their employment so they can do it with less effort or less pain, or where they can maximize their cognitive skills.

Perhaps people might want to move into a different job and need help in figuring out how do to that without losing benefits or with maximizing their salary. Perhaps they'd want to go and obtain additional training, or they might want to work part-time.

Or there are a group of people who have been working and just get to the point where they say, "This just isn't worth it anymore. It costs me too much from my outside life and I need to figure out a way to exit employment and move into another phase of my life." So, rehabilitation counselors can help with that.

**>>Kate Milliken:** So, what is the cost in terms of a patient coming to someone like you to help them with the process you just described?

**>>Kurt Johnson:** Well, at our MS Center at the University of Washington, we're unique in that we have a staff of rehabilitation counselors onboard for both inpatients and outpatients. But that's fairly unusual in medical settings.

So, probably the place that people have most access to rehabilitation counselors is through the state agency in each state that specializes in vocational

rehabilitation. And those are usually called Division of Vocational Rehabilitation, or Department of Vocational Rehabilitation.

And eligibility for those services is by having a significant disability that interferes with your ability to work. And it doesn't really matter what your financial status is, although people who have financial means may be asked to help pay for some portions of their services. And the goal of DVR, or Division of Vocational Rehabilitation, is to help people get back to work.

The problem is that often there's more people needing services than there is money to serve people in the DVR system, and so people may find themselves on waiting lists. And what we found is that a number of people with MS are actually not served by those state systems perhaps partly for that reason.

So, people seeking individual services can expect to, depending on who the service provider is, pay between \$80 and \$150 an hour, and that may or may not be paid for by their private health insurance.

**>>Kate Milliken:** How long would the process take given that it's an individual, case-by-case basis, but how long is the process when you are dealing with someone's vocation, from shifting from one to the other, ballpark, would it take to make that change?

**>>Kurt Johnson:** Well, let's start with somebody who's working but is encountering difficulties at work, and they're finding that they are just -- they feel like they're just barely holding on and that the demands of the work are starting to really push their limit. So, for them -- but they want to stay in that job and they work with the rehabilitation counselor.

And for them the process is putting together some accommodations that will help them change the job so that they can continue doing it. That might be a fairly short process, maybe a two- or three-session consultation, maybe a consultation with the employer.

Maybe, and I think we'll talk about this a little later, they use some technology and then some follow-up. Lots of times with people in that position, they get to a point where they need a little help and then they'll manage it themselves.

But then let's take somebody who has gotten out of the workplace and wants to get back in and needs to really think of a new occupation. Perhaps that person had worked in a professional capacity with a lot of demands and wants

to reenter but can't handle as many demands. Then that might entail a process of counseling over a few weeks and then doing some job search to find out what's out there. And then how long it takes to actually get the job. It depends in part on the economy and how much effort a person has to look for a job, how mobile they are.

>>**Kate Milliken:** Right. Let's talk about the role of technology in what you do.

>>**Kurt Johnson:** I was going to bring props.

>>**Kate Milliken:** Oh, really, yeah. Well, there is some amazing stuff.

>>**Kurt Johnson:** Yes. Most of the technology that we see people with MS using is pretty low-tech. We all use technology in our jobs every day, so we use computers, most people do. And it turns out that using just off-the-shelf software that's part of most computers, we can help people compensate, for example, for cognitive changes.

For example, you can set up reminder systems, you can set up calendars that will alert you to things that are coming up, reminders to help you. You can set up task lists to help you sequence things so you don't try to do them all at once. So, that kind of technology is pretty straightforward. We can also use cell phones to provide some reminders and to automate text pages to people to help them remember.

Other technology is, I'm thinking of one woman we know who uses a power chair only at work, because she has to cover big distances at work. So, she has a power chair that she leaves at work. She drives in, they have a little place for the power chair in the garage. She gets in her chair and just by using the power chair she is able to preserve enough energy that she can still work.

>>**Kate Milliken:** I have to believe from your experience that because of your knowledge and because of what all of you guys do in these rehab roles is that by making little tweaks to somebody's life that you can make a big difference.

>>**Kurt Johnson:** I think that's often true, not always. But often it is true that if you think about what confronts people is an economy of energy and a lot of things detract from that economy, cognitive changes, fatigue, effort in walking. And so anything you can do in the workplace or perhaps outside of the

workplace that helps people improve that economy, that automates some elements of thinking, that reduces the demands for physical exercise. All of those things add up and help people preserve enough energy or enough cognitive resources or physical resources perhaps to be able to continue their preferred activities.

By and large, employers want to do the right thing. What we find is just because of the demographics of who people with MS are, they tend to be better educated than the general population. They're often working in positions of responsibility. They often have long careers and are really valued members of the work team. And so while this isn't always true, we often find that employers are willing to make a good faith effort.

But it may be true that neither they nor the person with MS knows what to do, how to preserve employment, and sometimes things have gone along far enough that the employers and the person with MS are confronted with some difficult decisions.

So, our idea is if you can get in earlier, do earlier intervention either with or without professional help, making those decisions about accommodation and conserving resources earlier puts everybody in a better position.

>>**Kate Milliken:** Awesome. Dr. Johnson, thank you so much.

>>**Kurt Johnson:** Thank you.

Tom

It's really unfortunate that half of the people with MS who are unemployed would really like to be working.

Tracey

If you're one of them, Dr. Johnson wanted us to mention that your local chapter of the National MS Society is a great place to start to find out about rehabilitation counseling and other employment resources in your area.

Tom

Thanks for joining us, and thanks to Dr. Kurt Johnson for talking to us about rehabilitation counseling on MS Learn Online.