

Life with MS: Mastering Your Career



MASTERING



Multiple Sclerosis

Essential Information About MS

Multiple sclerosis (MS) is a disease that attacks the central nervous system (CNS). MS usually progresses over time, but early diagnosis and treatment may help slow disease progression. It is important that people recognize the symptoms of MS as early as possible. Research has found that starting treatment after the first clinical attack suggestive of MS could slow disease progression and delay disabilities. People with MS who begin treatment after their diagnosis can also benefit from long-term, consistent treatment.

For more information about MS, visit:

<http://www.ms-gateway.ie>

Mastering MS

Mastering MS is a global awareness campaign designed to illustrate how MS can affect a person's personal relationships and work life, whether as a spouse, parent, child, friend or coworker. The campaign shows that with the right tools, people with MS can continue to lead physically and emotionally fulfilling lives. The campaign offers resources to help people with MS manage their condition, as well as to better cope with changes that may occur in their personal and professional relationships.

Dear Friends,

For many of us, working gives our lives a sense of meaning and purpose.

Now that you have multiple sclerosis (MS), you may be asking yourself, “Can I keep working? Should I keep working? Will I lose my job or not get hired? Will working affect my health?”

You are not alone. Many people diagnosed with MS worry about their ability to continue performing well at work or what their coworkers will think of them. That was my fear when my doctor first told me I had cancer—I did not want to be defined by this label.

But this is the time to focus on what you can do, not on what you can’t do!

In this brochure, you will find stories from people just like you—people with MS who faced tough choices in their work life and how they overcame those issues. I hope you find helpful insights and inspiration from these stories as you navigate through this difficult time. Always remember, you are not alone.

Michele Wahlster

To Work or Not to Work

It's common for people to leave the workforce after being diagnosed with a chronic illness, like MS. Often, that decision is made in haste, before they've had a chance to really comprehend what their diagnosis means.

Family members, friends, even your doctor may urge you to quit your job. But having MS doesn't mean you can't work. In fact, more than one in three people with MS are still employed after having the condition for 20 years.¹

When making your decision, consider the following:

- MS is a lifelong condition—symptoms vary and fluctuate unpredictably, so first learn what life is like with MS, how to manage symptoms and how much they affect you.
- Symptoms may take years to appear—it may be quite some time before symptoms or disabilities actually impact your daily life. Having MS doesn't mean you will need a wheelchair tomorrow, or even at any point in your life.
- Treatment may help you stay in control—interferon-beta drugs, or disease-modifying drugs, may slow disease progression and even delay disability progression if started early.
- You have options—your employer can make reasonable accommodations to make your work life more manageable.

To Disclose or Not to Disclose

Sooner or later, you'll be faced with the questions:

"Should I tell my employer that I have MS? If so, when is the right time?"

To keep her diagnosis hidden from her boss at the bank, Anke and her cousin, Katja, of Germany would make up different illnesses so that the sick notes didn't always come from the neurologist. *"Sometimes we tried salmonella poisoning, sometimes something else. I would describe the appropriate symptoms to Anke so she could pull it off. Everyone who knew that Anke had MS advised her to keep it a secret as long as she felt okay. We started thinking, what kind of society is this where you have to put on an act to be accepted?"*

If you're feeling fine and your MS symptoms haven't created any limitations for you, then you may choose not to disclose your condition. But as your disease progresses, you may want to tell your supervisors and coworkers, especially if you require certain accommodations at work.

Know Yourself Before You Disclose

Only you can determine when you feel it's the right time to talk about your MS. How comfortable you feel at work and with your coworkers should guide whether or not you tell.

Before you disclose your diagnosis, however, you need to first be able to handle your disease both psychologically and emotionally.

- 1. Understand how you feel:** Are you feeling depressed now that you have MS? Angry? Confused? Take time to talk to your family, your doctor, or even a counselor, and work through your emotions. It's better to talk to your employer and coworkers after you feel more comfortable with your diagnosis.
- 2. Listen to your body:** Other people may jump to conclusions about what you can and can't do. That is why it's important that you first understand what you are capable of doing.
- 3. Know what you need:** Identify what modifications, if any, you might need to your working environment in order to stay productive and healthy. When discussing these changes, present them in a way that shows your employer you will still be a valuable asset at work.

“After suffering a severe attack, I realised it was time to tell my employer. She reacted well—her mother is a doctor so she was able to get information about MS. We came to an agreement: my boss treats me just as before, but if anything was wrong, I only needed to tell her. She told me, ‘If you have headaches for two or three days, then just phone in and you don’t need to get a sick note.’ I was so relieved.” – **Anke, Germany**



Tips on Disclosing

"I am still afraid to tell employers about my MS because my experiences are not so encouraging. Nearly everyone I told thought that I was handicapped and could not work."

- Gerald, Austria

Telling people at work that you have MS can be a very stressful experience, especially if you are like Gerald and find many people are not receptive.

These are some things you should consider when telling employers and coworkers about MS:

- *Be honest, brief and unapologetic.* Explain what MS is and how it affects you now. You might say, *"If you notice that I'm moody one day and don't want to talk, or need to take an additional break, it's just because of my condition."* Provide them with literature from your local MS organization to help dispel any misconceptions.
- Open communication is important in helping people understand your symptoms.

- Emphasize your abilities and skills. Focus on your ability and commitment, and what you can do.
- Suggest any changes or modifications to your work environment. Show your employer that any changes will only enhance your ability to meet your work responsibilities.

Full or Partial Disclosure

Open communication is important to help people understand what you are going through. But you don't need to give your full diagnosis. It is okay to explain that your problems are due to a "medical condition" or illness.

Should You Tell a Prospective Employer?

“I returned to University to learn a new profession. When I begin interviewing for jobs, I want to make sure I make a good impression, so I won’t tell them immediately that I have MS. I don’t want to be dishonest, but I don’t want my skills and experience to be clouded by their misperceptions about what a person with MS is capable of doing.” – Gerald, Austria

First impressions during a job interview are important. For prospective employers, this is the time they decide whether or not you’re the right person for the job and the company. But for you, this also is a time to discover whether or not the job, the people, and the working environment are right for you.

This is your time to see if the job meets your needs and to focus on your abilities. Disclosing might be okay during the second or third interview—by this point, you can be sure the prospects are interested in hiring you for your skills. Telling them you have a “medical condition” is okay especially if MS might affect your work at some time later.

If you need more information and advice, you can contact your local MS patient group.

Making Reasonable Accommodations at Work

If MS symptoms are starting to affect you at work, consider talking to your employer about modifying your working environment or hours. Many companies can make reasonable accommodations that allow you to stay at work—and be productive—while also addressing your needs.

These changes include:

- Increasing the font size on your computer (something you can do yourself)
- Moving your desk closer to the lavatory or the elevator
- Parking in a space closer to the building
- Combining shorter breaks into a longer rest period
- Switching to flexible hours, such as a day or two working from home

- Obtaining equipment or software that can enhance your work productivity
 - Some companies are open to implementing ergonomic workplace designs or furniture (e.g., desks, chairs, etc.). This is something that not only benefits people with MS, but also all of the people you work with. Ergonomic furniture is designed to improve health and productivity. It can also help you better manage symptoms of fatigue and impaired fine motor skills and keep you working at your best.
 - There are also products including voice recognition software that will type whatever you dictate or even allow you to have complete voice control over the computer without using the keyboard. Talk with your boss to see if these are possibilities.



Changes that Work

“I am a children’s nurse, which involves being on my feet and being very busy for much of each 12-hour shift. I was worried when I was diagnosed with MS that my work might become too exhausting. I actually found it easier to work the night shifts, which tend to be a bit quieter.”

– Louise, UK

To address her increasing fatigue, Louise talked to her manager at work about switching to the night shifts rather than working the more strenuous day shifts. It was a simple scheduling change that helped her conserve energy while maintaining the same work hours.



Finding a New Role at Work

When Hans-Dieter of Germany was diagnosed with MS 10 years ago, he first thought that he would have to quit his job as a mechanic. Even his wife and children urged him to stop working, thinking that the stress would be too much.

“But the thought of not going to work every day or being able to pay my bills was even more stressful to me.”

Hans-Dieter evaluated his situation. Instead of quitting, he talked with his supervisor and they trained him for a new position. *“The change has been great and I’m grateful my company gave me the opportunity to keep working.”*

Right now, your symptoms may be manageable and not preventing you from working. But if you’re like Hans-Dieter and need to make adjustments at work, try asking what accommodations are available to help you stay productive while taking care of your health.

Regaining Your Dreams

Life turned upside down for Fred of Canada after being diagnosed with MS. He had to stop working and became depressed and withdrawn. All of that changed when he started on interferon beta treatment, which helped control his symptoms and outbreaks.

“Since this time, my life has changed dramatically. I managed to get my life back on track. I went back to school to get a degree in social work and a master’s degree in education. I now work full-time in child and adolescent mental health and I love the work I do. I have made great strides in getting my life back together. The dreams that I thought were lost are becoming a reality.”

– Fred, Canada



Maintaining Work Relationships

What kind of relationship do you have with coworkers now? Before telling them you have MS, did coworkers see you as a private person? A team player? A leader? Have you noticed any changes in how they treat you now that they know?

When we learn someone has a chronic disease, it's easy to feel sorry for them. The last thing you need is someone's pity.

Maintaining good relationships means keeping honest, direct communication with your colleagues. Michele Wahlder, career coach, worked with a woman whose coworkers constantly asked how she was feeling. Although she appreciated the sentiment, the repeated questions only reinforced their image of her as a sick person.

Once in a while, Michele's coworker said, *"Thanks for asking but today, I'm just not in an MS mood."* That approach was perfect in helping her establish boundaries—it was okay for coworkers to ask about her condition, but not all the time. That way, they could once again discuss work issues and other related interests.

Managing Your Performance at Work

Fatigue, blurry vision, difficulty maintaining your balance. You may experience a variety of symptoms during the course of your disease. There are steps you can take to continue performing at your personal best. Talk to your doctor or MS nurse about specific symptoms and how you can manage them.

“I have built a business and I now only work when I want to. I started thinking life is too short to waste. So in a twisted way, MS even helped me improve my life. Now my lifestyle is better than it was before I was diagnosed with MS. I even started playing rugby again when I realized MS didn’t pose any extra danger and I plan to ride a push bike from London to Paris.” – Philip, Switzerland



Listen to Your Body

Don't ignore the pain or fatigue you may experience as your MS progresses. Know when you can push ahead and when you've had enough.

- Set priorities each day—save your energy for your most important tasks
- If you need help, ask for it. Maybe a coworker has time to take one of your assignments
- Energize your body by taking breaks, getting a good night's sleep, and by eating a healthy, nutrient-rich, low-fat diet
- Track your symptoms and progress in an MS journal so you know what your productivity level is on a given day
- Exercise, but know your limitations
- Learn relaxation techniques to reduce stress and promote healing

Getting Advice: Speaking With a Career Coach

We all find ourselves at certain points in our lives and careers needing additional encouragement, direction and guidance to get from where we are to where we want to be!

Each person's concerns are unique, so you may benefit from talking to a local career expert about these issues prior to addressing them in your workplace.

A professional can also offer encouragement and support as they have dealt with many other people facing the same challenges. When searching for a coach, try looking for someone who has worked with people with chronic diseases.

What can a career coach help you do?

- Devise a plan to address work-related issues, such as disclosing your condition
- Help you clarify your career goals, especially if you are deciding to change jobs
- Assess your abilities, interests and skills to help identify different career options
- Teach you how to find a job; assist you with developing a resume and cover letter

- Provide support if you experience job stress or if you lose your job

Know That You Are Protected

After learning that she had MS, Julie's boss told her that she was *"a valuable member; you've been with us for 20 years. We will support you."* But after her second relapse, six weeks later, her employer dismissed her.

"I don't have the stress of work, and that's probably a good thing. Now I have other things to do. But at that time it was worse losing my job than being told I had MS."

– Julie, UK

Are you in a similar situation as Julie? Then you should know your rights. Depending on the country you live in, the local regulations are different. Your local MS patient group will be able to provide you with more information on your rights.

It's Okay to Stop Working

Julie of the UK, worked for the same company for 20 years. But shortly after telling her employer about her diagnosis, she lost her job. Shocked at first, Julie later saw it as an opportunity to enjoy her life and spend time with the people she loves.

“My Dad is 85 years old and my mom is 82, and I’m not working, so it means I can spend more time with them. I never saw them because I went away on a Monday and came back on Friday for work. I spend more time with my husband Patrick. I think we are closer now than we were before, even with everything we have been through. I think we just realise what is important in life.” – Julie, UK





Staying Active and Involved

As MS progresses, you may find the physical demands of work difficult to manage. If you are unable to work—or choose not to be in a full-time job—then still do things that provide meaning and purpose in your life, similar to what a job once provided.

Start a new hobby, volunteer in the community, or join a support group. Even having a pet can help you focus your attention away from sitting around and thinking about MS.

Gérard of France lived with MS for 10 years when walking became increasingly difficult. He became housebound and depressed. Gérard's wife, Laurence, decided to buy him a dog, and that, she says, has been "a real boon" to his emotional health.

"Gérard goes out every day with his dog. It's a positive element in his everyday reality." – Laurence, France

Caregivers Need Special Attention Too

We tend to think that only the person with MS faces the difficult choices at work.

Your spouse, parents, children or anyone who helps care for you also may need to think about their own working situation, and possible alternative arrangements.

Consider Gérard's wife, Laurence.

"I know I cannot get a promotion at work because they fear I won't be able to meet my responsibilities while caring for my husband. But I have a good working environment. There are weeks when I have to arrive early for certain tasks. But I never know if I'll get there on time, because there are some mornings when Gérard copes very well and others when he's completely confined to bed and I'm forced to help out. So my colleagues tell me not to worry, that they'll cover for me. I've always been someone who's helped others. Both of us were like that. Now we are the ones who are being helped." – Laurence, France

Endnotes

1. National MS Society Web site www.nationalmssociety.org

Contributors



Michele Wahlder, a certified life and career coach for more than 15 years, counsels clients on how to deal with life, health, and career issues. As a two-time cancer survivor, she has had first hand experience in dealing with the challenges of a chronic illness and how it affects a person's career.

Resources

- www.ms-gateway.ie

All the people with MS mentioned in the “Mastering MS” brochures have been diagnosed with multiple sclerosis (MS), and are currently receiving treatment for their disease.

The testimonials represent each person's own experience, both with the disease and any treatment history. Statements regarding MS treatment represent the individual's own experience and perspective. Not all people receiving treatment will have the same results.

Mastering MS has financially been made possible by Bayer HealthCare Pharmaceuticals—Bayer Schering Pharma.



Bayer Schering Pharma, The Atrium, Dublin 18. Telephone: 01 2999313

Date of preparation: September 2008.