

Tipping Point #3 – When MS Begins to Impact Employment

Many of us identify who we are by the job we do. It's often how we describe ourselves to others. —I'm a teacher. —I'm in construction. —I'm an office manager. But what if MS begins to affect how well you are able to do your work? Is the print on contracts becoming too difficult to read? Am I so tired by 2 p.m. that I worry about making it through the rest of the day? Am I having a harder time remembering or retrieving pertinent information related to my responsibilities?

MS may, indeed, affect productivity at work and that, of course, triggers other questions. What will happen if I can no longer work? How will I survive economically? How will it affect my health insurance and other benefits? How will it affect my family? If we believe that MS may affect productivity at work, we also believe that accommodations may effectively address some diminished abilities.

But that brings up another issue. If I disclose my MS to my employer to justify my requested accommodations, might I jeopardize retention of my job? Could I be fired because I have MS? We know it's illegal to do so but we also know it may not be easy to prove and, in reality, illegal things happen. So, once again, we need to be proactive to lessen the impact of this tipping point on our lives.

1. Start by reviewing an article from a previous MSQLP newsletter, **November 2007**. It is available on our website: www.msqplp.org. Go to the Newsletter link. It has an article on *Employment and MS* that starts on page 6. The article summarized what had been discussed at an MSQLP educational event on MS and Employment that had been sponsored by EMD Serono. It includes information about work and fatigue, to disclose or not to disclose and workplace accommodations that may work for you.

2. A major decision is when (if ever) to disclose information about your MS to your employer. There is no rule that applies across the board. Even though it is illegal to discriminate against persons with disabilities, we have clients who believe they lost their jobs once employers became aware of their disease. It may not have resulted in immediate dismissal (that would make discrimination much easier to prove) but they believe their disclosure played a role in their eventual dismissal.

Other clients have reported very successful adaptations made in their work environment that supported them as they pursued their careers. You need to carefully consider whether or not to disclose, and if so, to whom? The National Multiple Sclerosis Society's website has an excellent

overview of the issue of disclosure. It includes sections on Should I Tell? Whom Should I Tell? and How Much Should I Tell? It also has a downloadable worksheet you can use to help you analyze the pros and cons of your own situation.

It does not prescribe an answer—you are the one who has to make that decision—but it gives you the information you need to find the answer that is best for you. Go to www.nationalmssociety.org and click on *Living with MS* at the top of the screen. Scroll down and click on *Employment* (on the left). You can then click on *Disclaimer Decisions, Knowing Your Rights, and Workplace Options*.

The more information you have, the stronger your position will be at your place of work. Each of these sections of the website has important information you should know. Read about the Americans With Disabilities Act so you know your rights.

3. There are adaptations that may help you maintain your productivity. The Office of Disability Employment Policy sponsors the Job Accommodation Network (JAN) that has much helpful information on accommodations and compliance. One paper focuses on accommodations that may be useful for workers with MS. (Go to www.jan.wvu.edu. Click on *Accommodation Search* at the top of the home page.

On the next screen, click on the large question mark. Then scroll down and click on *Multiple Sclerosis*). It identifies possible accommodations that address the following issues: Activities of Daily Living, Cognitive Impairment, Fatigue, Fine Motor Impairment, Gross Motor Impairment, Heat Sensitivity, Speech Impairment, and Vision Impairment. Many would be easy to implement and would make your workstation, workstation, schedule, parking situations or transportation system better adapted for your needs.

4. Just as an Occupational Therapist (OT) can help persons with MS assess the safety of their home environment and recommend appropriate adaptations, the same OT can help you identify possible accommodations that would better meet your needs at your place of work. Ask your primary care provider for an OT referral.

5. If you believe you will not be able to continue the work that you presently do because of developments with your MS, it may be time to explore other types of work. Review your resume. What skills do you have that may be transferable to other jobs? Focus on your strengths, not your disabilities. You may want to consult with a vocational rehabilitation counselor at a local community college or university. They are trained to help people move into job placements in which they can be independent.

They have knowledge of college programs that can help you transition to different types of employment. Also, let your network of professional colleagues know you are exploring other options. They may have ideas.

6. How will you economically survive when you stop working? If you work until retirement, have social security and a pension or IRAs put aside, you may have few concerns. But if you have to leave work earlier than expected because of your MS, you may not have as many options. It is important to make plans now so that you are prepared if employment conditions change for you.

- Do you have disability insurance? If so, read your policy carefully. Call your insurance company to discuss any sections you do not understand.

- Investigate whether you qualify for Social Security Disability Insurance (SSDI), a national program, or State Supplemental Income (SSI/MediCal), a state-funded health insurance for which you may be eligible based on financial need. It may take years to actually qualify (as there are strict guidelines about past earnings and assets) but, if you understand the requirements, you will know when you are eligible to enroll.

- Work with a financial planner—he or she may have ideas for using your income in more productive ways and how you can best plan for an uncertain future. Obviously, the sooner you make plans, the better it will be for you.

7. Attend an MS support group. If you have not yet attended an MS support group, consider it now. Group members will have advice and stories to share about their experiences with employment. Use their knowledge to improve your own life. See the end of this newsletter for the list of meeting times and locations of support groups in the Tri-Counties.

8. Continue to share your thoughts, beliefs and experiences with the members of your personal support group—those people with whom you can share what you are going through. If any member wishes to attend a caregiver support group meeting, encourage them. It will give them a change to talk with others who support persons with MS. Share your written and online resources with them; information will empower them as well as you.

9. Agencies that may help explore issues related to this tipping point:

National MS Society: www.nationalmssociety.org

The Office of Disability Employment Policy: www.dol.gov/odep Job Accommodation Network: www.jan.wvu.edu/

Social Security Disability Insurance (SSDI): www.ssa.gov/disability

State Supplemental Income (SSI/MediCal): www.ssa.gov/ssi/
California Department of Rehabilitation: www.dor.ca.gov

The Best Thing I Did When MS Affected my Employment ...

By Amy Lamb Heckel, RDH

My paramount symptom is heat intolerance. The operatories (treatment rooms) in the dental office where I work all have large, unshaded skylights. As an accommodation I now work in the mornings only, thereby avoiding the afternoon sun streaming directly onto me. This required that my boss give up one of his operatories on Monday mornings so that I could use it instead—which he did. Preventing contamination by blood-borne pathogens dictates that I wear long sleeves, gloves, and a mask. To keep cool I place a dampened paper towel inside my mock turtleneck, open the window, and have a fan that I can direct at myself without it blowing on my patients. This works—and so do I!

By Tracy Tucker, MSQLP support group leader and technology advisor

The best thing I did was to disclose to an HR occupational nurse where I worked that MS was affecting my productivity. This was 8 years after I was diagnosed with MS. I was then working as a technical professional in a field where learning speed and information recall were key to job performance. Many years earlier, I had asked my manager if I could move to a cooler office because my office was very warm in the afternoon, which triggered my MS heat sensitivity and affected my ability to work. My manager had arranged this office move, but in later conversation with subsequent managers, I was surprised to learn that my disclosure had not become part of my permanent employee record, probably due to corporate privacy guidelines. When I later began to experience cognitive problems that affected my productivity, I decided to investigate a career that might be a better fit for me given my MS. I found a program in Boston that taught piano technology. I had studied piano performance for many years, and I liked the idea of tuning and maintaining pianos for performing artists. I discussed my plans with my manager at the time, along with my reasons for these plans. She was very supportive and arranged an unpaid one-year sabbatical for me for this training. She also arranged that I contact an Occupational Health Nurse in Human Resources to discuss my health issues. At the request of this nurse, my doctor sent in a Medical Treatment Report that documented my medical condition and its impact on my career. This report became part of my permanent employee record in HR.

As much as I enjoyed the program in Boston and the summer I worked at Tanglewood, I soon recognized that lower body weakness and poor stamina would make such work unsustainable for me. I returned to my life as a software engineer with my original employer.

I continued to work another 10 years, but I knew that my productivity was continuing to decline. My yearly performance evaluation indicated this. Although I asked for accommodation under the ADA (work at home, for example) this was not granted. Eventually, I was given a 3-month notice to look for work elsewhere. I, once again, contacted the HR occupational nurse that I had been in contact with off and on since my return. My doctor sent in another Medical Treatment Report and I quickly qualified for short-term and eventually, long-term disability. So for me, the decision to disclose my MS changed my life positively in terms of financial security after I was no longer able to work as a software engineer.

So what has helped me now that I am no longer working? First, I have found ways to stay busy and socially connected by volunteering my time to help others. Second, I strive to set realistic goals for myself every day. Too often, I plan to complete too many things in one day, and then end up feeling frustrated by my lack of success. I need to remind myself to set realistic goals and to more fully enjoy fewer activities.

By Tammy Jennings, MSQLP Volunteer

The best thing I did was quit. I started using a wheelchair 11 years into my job. It certainly helped with mobility but it did not solve all my problems. I used the chair for 2 additional years but, looking back, I realize I was struggling much of the time with hand tremors, memory/cognition problems, and urinary/bowl incontinence. Fatigue was still my biggest obstacle, however. The wheelchair saved some energy but not enough. I was still so fatigued after working eight hours that all I could manage was to go home and sleep. It was hard to get through each day. By noon, 90% of my energy had already been depleted.

I also hadn't realized how my attitude had changed. I was angry and frustrated most of the time and apparently wasn't very good at hiding my emotions, as my co-workers pointed out after my departure. They said that the "old Tammy" reemerged once I quit working.

I'd been afraid to quit because, with the loss of my one and only source of income, what would I do? How would I survive without being a burden on anyone? (I pride myself on being independent and self-sufficient.) Well, before I quit, I tried to get all my ducks in a row. I called the Social Security Administration and found out what my Social Security Disability Income would be after my State Disability Insurance ran out. Also, would I be eligible for Medicare when my employer-provided health insurance ran out as I was only 47-years-old at that time? Additionally, I inquired about other assistance available to me, i.e. Monterey-Salinas Transit RIDES, Meals on Wheels, etc.

After 2 years of my doctors telling me I should "retire", I did. Today, I live frugally but I am surviving. On the plus side, I have much more energy because I am able to sleep/rest when I feel the need. I have also been able to travel, volunteer, and take some classes to enrich my mind. Additionally, my attitude and outlook on life in general is very good. Basically, I live my days as I want to live them . . . I am finally taking care of ME. So, retiring from my job was actually the best thing I could have done.