

Should I Stay or Should I Go (Now)? MS: Working and Retirement

By Jeffrey N. Gingold

With my MRI images and cognitive assessment report in hand, my neurologist explained how MS had compromised my cognitive and physical functions, leaving me disabled and unable to work. He explained that “chronic” meant “permanent” disabilities. The employment rug was yanked out from under me and there would be no holding onto my career.

As far as facing my cognitive impediments is concerned, I already understood that important knowledge and details were escaping me. I experienced a daily mental fog and a noticeable loss of presence. Familiar locations, directions, and faces were often confounded and obscured. My ability to recall and process information was compromised, resting on fractured and missing pieces of reason. Medical opinions confirmed that MS was causing information recall to be challenging and unreliable. (Aren't you glad that I don't fly airplanes? I am.)

Fortunately, I knew enough to see that keeping it all to myself wouldn't help me preserve my career or strengthen the bonds with family and friends. Being open about my MS cognitive and physical challenges did.

To better cope with MS, I accepted this reality and re-prioritized my life. When MS damaged my mental and physical well-being, it was time to re-chart the future for our family. There were others to consider and choices to discover.

Perhaps you will land in the MS “contemplating retirement” continuum? If you are still working and MS is making it difficult to function in your job (cognitively, physically, or both), I encourage

you to speak to an informed person regarding your employment options. Whether it is a trusted friend, significant other, an attorney, or an HR person, understand your rights for employment accommodation(s), before making any irreversible moves.

While exploring your options to remain at work, don't ignore the MS challenges and risk unfavorable job reviews leading to termination or worse. Seek accurate information regarding job expectations and avoid being blindsided through denial. Choosing retirement is a very difficult decision, true. Isn't it better that you address it and protect your benefits, rather than being shown the door, perhaps without retirement and health insurance options?

Since you may not be able to undo MS-compelled life decisions, focus on making informed choices. Own your retirement choices. It is not the same for everyone, so be careful when considering what others may have done. Your work requirements and MS limitations are unique for you.

Retirement allows you to re-consider and identify your real priorities. Once you have retired, be cautious about filling the time. For example, don't feel obliged to leap into the first request to volunteer. Commit thoughtfully, leaving flexibility to develop more choices that will come your way. Be cautious not to flatter yourself by accepting the first, second, or even the third request for your time. Make the right connection for your interests, skills, and MS life, while saving time and energy for your medical and exercise regimen. With MS, meaningful volunteering also requires pacing.

Cutting loose from draining and otherwise toxic tasks may also be a great path to manage your MS symptoms, but don't swap it out for a different burden. Prioritize and learn to say "thank you for the opportunity, but I can't commit to that right now." It is a skill to save your energy and focus on what matters, like your health. Practice conserving your energies, while showing appreciation for being asked to be involved.

There is a bit of good news. Whether you learned from a technical school, high school, or institutions of higher learning, MS does not erase the education and degrees. (Unfortunately, it also doesn't erase any lingering student loan debt.) While the knowledge may be slower or more difficult to recall, it should not be erased because of MS. There are successful cognitive coping strategies that have allowed other MSers to use portions of their skill set for other purposes, even on a voluntary basis.

Never walk away from your experience, but maybe retool pieces to help others who will benefit from your knowledge. For example, while fundraising welcomes you to fight MS, so does writing and speaking - sharing your story with the MS community. You have probably learned some of life's pitfalls and successes. Chances are that an organization (whether it is religious, educational, physical, artistic, or intellectual) would welcome your insight. What have you always wanted to do with one of your skills? Now can be the time to connect it with one of your passions.

Throughout the retirement process, seek out individuals for your network, whether a trusted professional or friend, who can assist you in organizing a retirement transition. Unreliable cognitive functions can also be a bit financially dangerous. It calms my mind to have a "safety" person to rely upon when making significant life planning decisions, especially

if they affect others. Do not underestimate the effect of leaving a career behind, but relish the opportunity to do more, even with less. Instead of being perceived as retiring, leaving the work force can be seen as a new level of productivity, if you are prepared.

Takeaways:

1. Asking for help is strength, not a sign of weakness. If struggling to tread water, there is nothing wrong with requesting a tossed life-preserver. When you were diagnosed with MS, I'll bet that you weren't told to deal with it on your own, so don't. Stubbornness doesn't prove anything, especially in retirement.
2. Contact MS Focus: the Multiple Sclerosis Foundation, and other relevant organizations, who offer the resources and direction for retirement planning, including: tax planning, budgeting and various forms of counseling.
3. MS is not temporary. Since there isn't a cure, yet, be prepared to move forward with your life instead of hanging on to matters that drain your daily reserve of physical and cognitive energy.
4. Identify your skill set and volunteer to share your knowledge and experience. There may be many requests to fill your time through various service activities. Be selective with your time and energy, identify a passion and avoid rash decisions accelerating MS fatigue
5. If you face MS cognitive challenges (and the majority of us MSers do, at some point) then be sure to have a trusted person review your post-retirement budget and plans.

An extra point: Be thankful to those who are trying to help you and don't think of them as obstacles, but a bridge to a safe retirement harbor.