

Workplace Accommodations for Workers with Multiple Sclerosis: A Case Study Example

INTRODUCTION:

Although 98% of people with MS have employment histories and 82% were still working at the time of diagnosis, the vast majority of workers with MS disengage from the workforce before retirement age. The current rate of unemployment for people with MS in the United States has been estimated to be between 55% and 70%. The result is a disproportionately high level of unemployment among a group of both qualified and experienced workers. By their own reports, people with multiple sclerosis (MS) are gravely concerned about their long-term employment prospects. Surveys of people with MS in a number of countries repeatedly document concerns related to workplace discrimination, interest in learning more about legal protections and employment-related resources, the need for more widespread availability of assistive technology in the workplace, and the desire for more effective self-advocacy strategies to aid in continuing one's career. This fact sheet provides one case study example of an individual with MS who has maintained employment with the support of his employer and workplace accommodations.



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MEET ARNOLD:

Arnold is a 44 year-old man who works as an academic advisor at a community college. He was diagnosed with relapsing-remitting MS at the age of 32. MS is a chronic, unpredictable, and sometimes progressive auto-immune disease that affects the myelin or insulation covering white matter tracts in the brain and along the spinal cord. MS-related lesions cause a wide range of symptoms depending upon their size and location within the central nervous system.

Arnold works with students in person, over the telephone, and online to help them in selecting major courses of study, choosing classes pursuant to those majors, and preparing for their careers after graduation. He works full-time, 40 hours per week, on a 12-month basis. His job requires periodic automobile travel to meetings and conferences in the community and airplane travel to conferences once or twice per year.

Arnold has two or three exacerbations of MS symptoms each year, lasting between two and three weeks each. These exacerbations are characterized by periods of extreme fatigue, numbness and tingling in his left hand, gait problems, and problems with short and long-term memory. Arnold takes accrued sick leave during his exacerbations, usually two or three days at a time. One year, he exhausted his accrued sick leave and had to take five days of unpaid leave under the Family and



Medical Leave Act (FMLA). Under the FMLA eligible employees can take up to 12 weeks of unpaid, job-protected leave per year. One reason that an employee can take unpaid leave is if he or she is unable to work because of a serious health condition such as MS.

DISCLOSURE:

Arnold disclosed his MS status to his employer shortly after learning of his diagnosis. He disclosed his MS both in writing and during an in-person meeting with his immediate supervisor. Before disclosing, Arnold consulted a brochure published by the National Multiple Sclerosis society entitled ***Enhancing Productivity on Your Job: The Win-Win Approach to Reasonable Accommodations***. This brochure describes strategies for disclosing MS to employers in a way that protects the person's right to privacy while providing the employer with sufficient information about the person's on-the-job needs.

Arnold's supervisor was not familiar with MS, and she asked a number of questions about his symptoms and prognosis for the future. The supervisor told him that she valued his work and that she would do whatever she could to accommodate any issues that might arise due to his illness. Arnold loaned his supervisor a book entitled ***Multiple Sclerosis: The Questions You Have, the Answers You Need***, which provides a comprehensive overview of the etiology, symptoms, and treatment of MS. At that time, Arnold did not know what accommodations he might need to combat the effects of his MS at work. His supervisor told him to let her know whenever he identified a need for accommodations.

A friend that Arnold made at a support group for newly diagnosed people with MS recommended that Arnold contact the Job Accommodation Network (JAN) for assistance in identifying needed supports. Based upon Arnold's symptoms and his job requirements, JAN recommended several accommodation strategies. Arnold soon began to implement the recommendations with his employer's cooperation.

WORKPLACE ACCOMMODATIONS:

When Arnold's MS is in remission, usually 40-42 weeks per year, he usually does not require any workplace accommodations. During exacerbations, Arnold uses accrued sick leave when he is unable to work or unpaid Family and Medical Leave when he exhausts his paid time off. He also uses a quad-cane for mobility and a tablet with organizational and memory enhancement applications or 'apps' to combat MS-related cognitive impairments. In fact, Arnold is now using the tablet and apps to assist him in remembering appointments and managing tasks in his personal life, even during periods of remission when he is not experiencing MS symptoms. Arnold also asks his employer to make minor scheduling modifications on days when he is working and experiencing fatigue. One such scheduling modification involves an extended lunch break during which he goes home to take a one-hour nap. After the nap, Arnold returns to work and stays after hours to make up the time. Sometimes during remissions, Arnold will request a part-time work schedule for one or two weeks at a time. So far, his employer has been willing and able to accommodate his requests for modified schedules during exacerbations.

THE RIGHT TO PRIVACY:

Arnold has chosen not to disclose his MS to his co-workers, although they express concern for his well-being when he takes sick time during an exacerbation. One colleague asked him if everything was okay when he

came to work with his quad-cane. Arnold casually replied, "It's a nerve thing, the cane helps me walk straight." Arnold decided not to disclose his MS to his co-workers on the advice of the JAN, who informed him that he has no legal obligation under the Americans with Disabilities Act (ADA) to share health-related information with co-workers and colleagues. In fact, many disability advocates recommend that workers with disabilities disclose to their employers only what they are legally required to in order to be eligible for on-the-job accommodations, keeping all other information about their health and disability status to themselves. About his decision not to disclose to co-workers, Arnold, who considers himself a private person, remarked, "If the law says they don't have the right to know, I guess I consider it none of their business. I'm more comfortable keeping my MS to myself if I'm not required to tell them. I don't think anyone would respond badly if I did disclose. I just prefer to maintain my privacy about this private matter."

Although Arnold is certainly within his rights not to disclose his MS to co-workers, he sometimes wonders what they are thinking when he takes sick leave, goes home mid-day, or exhibits gait problems without any explanation from him. One of his friends in the MS support group chose to disclose her MS to co-workers. She reported that her disclosure enabled her friends and colleagues at work to better understand her symptoms and her cycles of relapses and remissions. One of her co-workers remarked, "I'm glad you told me. Sometimes when you were having balance and mobility problems in the middle of the day, I thought you might have been intoxicated. I was afraid you might have a drinking or drug problem." Arnold's friend believes that disclosing her MS status to her co-workers brought an increased empathy and understanding on the part of her colleagues. Still, as of this writing, Arnold prefers to keep his MS status to himself, and his supervisor remains the only person at work he has told about his diagnosis. The decision to disclose is a personal one and needs to be made by each person seeking accommodations on the job.

SUMMARY:

Like the vast majority of people with MS across the globe, Arnold is an experienced and well-trained worker who has much to contribute to the labor force. He hopes to work to retirement age, and he consults his neurologist regularly and adheres strictly to his medication regimen. Thanks to advances in medicine, technology, and Federal laws protecting workers with disabilities and entitling them to reasonable accommodations at work, Arnold's long-term career prospects are good.

Many people with MS share Arnold's successful employment history. Many have worked at some time in their lives. However, as time and the illness progress, there emerges a precipitous decline in labor force participation. Only about 40% of Americans with MS are currently employed for pay, and estimates indicate that only 20% to 25% will continue working until age 65. One of the reasons that have been cited for this seeming "mass exodus" from employment includes a need for on-the-job accommodations that could enhance productivity and reduce turnover. This brief fact sheet on accommodations provides one success story to demonstrate that individuals with MS can continue to be employed.

REFERENCES:

National Multiple Sclerosis Society (2015). MS prevalence. New York: National Multiple Sclerosis Society. Retrieved from: <http://www.nationalmssociety.org/About-the-Society/MS-Prevalence>.

Roessler, R. T., Rumrill, P. D., Li, J., & Leslie, M. J. (2015). Predictors of differential employment statuses of adults with multiple sclerosis. *Journal of Vocational Rehabilitation, 42*(2), 141-152. doi:10.3233/JVR-150731

Rumrill, P., Roessler, R., Li, J., Daly, K., & Leslie, M. (in press). Surveying the employment concerns of Americans with multiple sclerosis using a participatory action research approach: Results from a national stratified random sample. *Work: A Journal of Prevention, Assessment, and Rehabilitation*.

RECOMMENDED WEB LINKS:

Employment Outcomes for People with Multiple Sclerosis: Vocational Rehabilitation RSA 911 Closure Data FY 2011, 2012, and 2013 -- <http://www.vcurrtc.org/resources/content.cfm/1167>

Family and Medical Leave Act Leave Benefits -- <http://www.dol.gov/dol/topic/benefits-leave/fmla.htm>

JAN: For Individuals -- <https://askjan.org/individ/>

JAN provides free consulting services for individuals with physical or intellectual limitations that affect employment. Services include one-on-one consultation about job accommodation ideas, requesting and negotiating accommodations, and rights under the Americans with Disabilities Act (ADA) and related laws. Although JAN does not help individuals find employment, JAN does provide information for job seekers.

Multiple Sclerosis: The Questions You Have-The Answers You Need 5th Edition osalind Kalb MD
<http://www.amazon.com/Multiple-Sclerosis-Questions-Have-The-Answers/dp/1936303167>

National Multiple Sclerosis Society -- *Enhancing Productivity on Your Job: The Win-Win Approach to Reasonable Accommodations*
<http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Win-Win-Approach-to-Reasonable-Accommodations-Enhancing-Productivity-on-Your-Job.pdf>

United States Department of Labor Fact Sheet #28: The Family and Medical Leave Act
<http://www.dol.gov/whd/regs/compliance/whdfs28.htm>

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For more information on the VCU-RRTC, please visit:
<http://www.vcurrtc.org>

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QUESTION:

What other resources are available to learn more about SSDI?

ANSWER

A good resource to learn more about work incentives can be found at:
www.SSA.gov/redbook.

A local WIPA provider can also offer a lot more specific and individualized information on work incentives that are applicable to a beneficiary's situation.

A good resource to learn more about a PASS can be found at:
<http://www.ssa.gov/pubs/EN-05-11017.pdf>

Another good resource that is located on line at:
www.chooseworkTTW.net.

When visiting the web site a person can click on the button that says "find help" and enter his city, state, or zip code. This will bring up a list of providers that serve the local area like the State's vocational rehabilitation (VR) agency, the entities that make up the employment networks (ENs), the WIPA provider, and the protection and advocacy provider.

A person can also call the Ticket to Work Help Line at 1-866-968-7842. This is a good place to get general information about the Ticket to Work program, some of the work incentives and the best way to connect with VR, ENs, the WIPA provider, and protection and advocacy agencies.

REFERENCES

Coffey, Laura (2014). Employment and Social Security Disability Benefits – Important Considerations: Webcast Transcript.

Social Security Administration (2015). Benefits for People with Disabilities. Retrieved from <http://www.ssa.gov/disability/>