Disclosing a Multiple Sclerosis Diagnosis at Work May Have Pros and Cons

More than 400,000 Americans and about 2.5 million people worldwide have multiple sclerosis (MS), according to the Multiple Sclerosis Foundation. MS is a chronic condition affecting the central nervous system, which usually starts between the ages of 20 and 50. It can cause symptoms such as fatigue, trouble walking, vision problems, or problems with thinking and memory. These symptoms may not be obvious to other people. People who are employed when they develop MS may face difficult decisions regarding whether, and how, to tell their supervisors and coworkers about their MS. Disclosing MS may help employees receive accommodations that improve their job performance and satisfaction. However, employees with MS may fear a negative reaction or discrimination at work if they disclose their diagnosis. In a recent NIDILRR-funded study, researchers asked people with MS about their experiences in the workplace after their diagnosis. The researchers wanted to find out the reasons why people with MS chose to disclose or not to disclose their diagnosis at work. They also wanted to find out what happened afterward if these individuals disclosed their MS diagnosis to their supervisors and coworkers.

Researchers at the Rehabilitation Research and Training Center on Employment of Individuals with Physical Disabilities held focus groups with 72 people with MS living in South Carolina, Georgia, and Ohio. The participants were 20-81 years old, and they had had their MS diagnosis ranging from less than a year to 44 years, with an average of 11.6 years. All of the participants had worked at some point after their diagnosis, and about 60% of them were employed at the time of the focus groups.

During the focus group discussions, the researchers asked the participants whether or not they told supervisors and coworkers that they had MS, and their reasons for disclosing or not disclosing their diagnosis. For those participants who did disclose their diagnosis, the researchers asked them how the decision to disclose impacted their experience at work.

The researchers found that there were a few disclosure patterns emerging from these focus groups: general disclosure; delayed or limited disclosure; and no disclosure. For the general disclosure pattern, the participants chose to disclose their diagnosis to supervisors and coworkers in general and had few concerns about sharing their diagnosis. Some of these participants intentionally disclosed their diagnosis early in order to prepare their employers for possible changes in their work performance that were related to MS symptoms, to request accommodations so they could continue to work, or to educate their employers and coworkers about their condition. Others simply disclosed because they had no concerns about how their supervisors would react. For the delayed or limited disclosure pattern, the participants expressed a desire to be in
more control of who knew about their diagnosis and what or when information was shared. These participants either opted to disclose their diagnosis to a limited group of supervisors or co-workers, or delayed their disclosure until after they were hired, their symptoms worsened, or they needed to request accommodations. Lastly, some of the participants chose not to disclose their diagnosis at all or were unsure if they would disclose their diagnoses in future jobs for fear of negative consequences such as termination or being denied a promotion.

The participants who disclosed their MS diagnosis experienced a variety of reactions from supervisors and coworkers. Some participants reported positive reactions, such that supervisors were understanding and provided accommodations while still valuing their performance at work. These participants felt that disclosure was positive for their professional lives. Other participants said that their supervisors and coworkers had no reaction either way or mixed reactions to their disclosure. For example, one participant’s supervisor was understanding at first and offered accommodations, but then took away some of her duties such as sending her to business meetings out of state. Participants also encountered discomfort from coworkers after disclosing: They felt their coworkers either became overly cautious around them or seemed not to believe that the diagnosis was real. A few participants reported that they were laid off, or denied a promotion, after disclosing.

According to the authors, past research has found benefits for people with MS who choose to disclose their diagnosis. These individuals may receive needed accommodations, and may have improved working relationships with their supervisors and coworkers. However, some of the participants in this study encountered unfavorable reactions when they disclosed, and others were afraid that disclosing could have a negative impact on their employment. The participants in this study also expressed a desire to have control over when, how, and with whom their diagnosis was shared. Vocational rehabilitation professionals may want to discuss the pros and cons of disclosure with clients who have MS so that they can gain control over the process and understand their legal rights in the workplace. Future research may be useful in identifying factors that determine who is most likely to have a positive disclosure experience.

To Learn More
The RRTC on Employment of Individuals with Physical Disabilities offers many resources on employment and workplace accommodations including

- Question & Answers on Employment of Individuals with MS
  https://pd.vcurrtc.org/resources/content.cfm/1127
- Workplace Accommodations for Workers with MS
  https://pd.vcurrtc.org/resources/content.cfm/1175
The ADA National Network regional centers offer information and resources to help employees with disabilities and employers to understand their rights and responsibilities under the Americans with Disabilities Act. Visit http://www.adata.org to learn more.

To Learn More About this Study

Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study and the work of the greater NIDILRR grantee community, visit NARIC at www.naric.com or call 800/346-2742 to speak to an information specialist.

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