

Accelerated Cure Project for MS

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Accelerating research towards a cure for multiple sclerosis

Work and Family – Covering All the Bases

Multiple sclerosis is at least two to three times more common in women than men. Most are diagnosed between the ages of 20 and 50, right at the time when they are juggling increasing demands of both career and family. In 2014, the [Working Mother Research Institute](#) (WMRI) conducted a nationwide [study](#) to better understand how MS affects women. The results were published in the [Women and MS report](#). Data was collected for the study via an online questionnaire. With the help of the National Multiple Sclerosis Society (NMSS), 1,248 women with MS were enrolled in the study, the vast majority of whom (95%) were employed. The average age of participants was 40, and the average age of MS diagnosis was 32. The results shed light on many of the challenges that women with MS face in their personal and professional lives.



Data collected for the study revealed that most women deal with the impact of MS on a daily basis. The most common MS symptoms were fatigue, numbness and tingling, followed by difficulty with thinking and memory. More women found it easier to manage these symptoms in their personal life than in their professional life. In general, women with mobility issues worried more and had more difficulty managing symptoms. The majority of respondents were pro-active about treatment, 85% felt they were well versed on treatment options and 79% reported taking a disease modifying treatment (DMT).

Study results suggested the vast majority of women with MS are likely to consult their doctors (95%) or do online research (99%) when they have questions about their disease. Most participants were satisfied with the information they gathered. However, younger women (particularly those under age 30) expressed dissatisfaction with available information about the impact of MS on women's health (fertility, pregnancy, childbirth and breastfeeding). Women of this age also preferred a more "conversational" approach to learning about MS. They were more likely than older women to seek information from blogs, social media, friends or family.

According to the WMRI study, having MS doesn't appear to affect a woman's decision to marry or have a relationship, but it does have a mixed impact on raising children. On the plus side, the vast majority of women in the study (95%) felt a strong relationship with their children was possible despite having MS.

The majority of those surveyed also felt having MS showed their children how to face challenges and succeed (71%), as well as how to deal with the unexpected (66%). On the other hand, there was a consensus that MS symptoms prevented moms from participating in activities with their children (64%) and decreased spontaneity in family activities (51%).

About a third of respondents were concerned their children would feel embarrassed or nervous about bringing friends home because of their MS. Of note, those with mobility issues were more likely to have difficulties with regards to these last three points. Of interest, less than half of study participants reported their kids took on more responsibility around the house as a result of mom's disabilities.



The WMRI study provides revealing data on how women with MS cope in the work environment. Approximately half of those who were not currently employed (but were within two years of completing the survey) cited MS as the reason. Bladder and/or bowel problems were a common source of anxiety and discomfort on the job. Over half of those surveyed said they struggled with thinking or memory. Many also had difficulties with mobility at their workplace (for example, walking long distances and navigating uneven surfaces) or attending work events late in the day. In addition, environmental factors (such as certain kinds of lighting) were challenging for a number of subjects. Over half (55%) of study participants felt they were not performing their best at work. More subjects (71%) worried about their ability to continue working (a legitimate concern as 60% of them missed work due to MS in the 12 months prior to completing the survey). The data indicated that many (60%)



try to hide their MS symptoms on the job. Only half of women felt their supervisor was sensitive to their needs, and fewer (39%) felt their supervisor was interested in helping them manage their MS symptoms in the workplace. Sadly, a third of women dreaded going to work because of their MS.



These data clearly indicate that women with MS need more help while at work. Flexibility was the number one priority among study participants. Unfortunately, surprisingly few reported being offered the flexibility they need. For example, the vast majority (95%) indicated flexibility to take time off for doctors' appointments was necessary, but less than half (43%) were able to do so. Most (91%) needed the ability to change their work schedule, however only 41% had this option. In addition, three quarters of those surveyed needed flexibility regarding the ability to work from home or to work part-time and only 26% could do either.

The Women and MS report includes several avenues by which employers can help those with disabilities reach their career goals and improve their job satisfaction. To name a few, employers can discuss career planning, including opting for a less intense career path, reducing the number of hours worked, or taking time off. It's important for employers to encourage openness in the workplace so teams understand what an individual living with MS is dealing with and what changes might be helpful for them (for example, scheduling critical meetings in the morning when energy levels are higher, evaluating accessibility, or adjusting the temperature/lighting of an individual's office). Employers can also consider offering additional benefits, such as counseling or support groups. Roughly half the women surveyed in the WMRI study said they often felt overwhelmed and more than a third said they felt isolated, indicating a need for these services. Health savings accounts can be used for gym memberships, or incentives offered for employees that reach personal fitness goals. These benefits can encourage employees to stay physically active (the [benefits](#) of which have been clearly demonstrated in people with MS, and in the general population).

The WMRI study illuminates how difficult it is to juggle a career, family and MS. Study results stress the importance of staying proactive about treatment options, as well as making accommodations in home and work routines to compensate for disabilities and to preserve energy levels. It's critical for all people with MS to have a support system to help meet the demands at home and in the workplace. As described in our Partner Spotlight this month, the

[Multiple Sclerosis Association of America \(MSAA\)](#) offers many valuable resources for the MS community.

