

What do working women with MS want?



A new report points to the challenges that working women with MS face at their jobs, and factors that can help them manage their disease and perform at their best.

by Marcella Durand

The ability to keep working—and parenting—is a major concern for the more than 1,200 women living with multiple sclerosis who participated in a survey conducted last spring by the Working Mother Research Institute (WMRI) with help from the National MS Society and support from Novartis Pharmaceuticals Corp.



A total of 18 percent of women in the survey have mobility issues, and the vast majority of them—82 percent—are worried about being able to continue working.

When she was a child, Janelle Camacho witnessed the financial havoc that MS can inflict on a

family when her own mother had to leave her job after she was diagnosed with the disease. Camacho received her own MS diagnosis in 2004. “There isn’t a day that I don’t think about the what-ifs or whether I will be able to continue to work and take care of my children,” says the Ephrata, Pennsylvania, mother of four children. Camacho says her bosses at her part-time waitressing and bartending jobs are “willing to work with me,” to accommodate symptoms, but not everyone in the WMRI survey had such positive experiences.

While the survey results painted a picture of often-stressful challenges, they also indicate that women are proactive in managing their MS, taking steps such as communicating frequently with their healthcare providers and pursuing disease-modifying treatments.

Perhaps not surprisingly, parenting with MS was a particular area of stress for many respondents. More than 75 percent of those under age 31 said they were afraid that MS would prevent them from being good moms. However, while symptoms such as fatigue—reported by 85 percent of the women—can affect activities with children, 95 percent of the women with children stated that MS hadn’t prevented them from developing a strong bond with them. “My daughters understand that sometimes Mommy needs a time-out,” says Camacho.

Work is also an ongoing challenge, with 71 percent of respondents saying that they worry about becoming unable to work—with reason: Sixty percent reported they missed work in the last 12 months due to MS symptoms, and that they try to hide their symptoms, although they don’t believe they can do so indefinitely. Women with mobility issues (18 percent) are particularly concerned, with 82 percent of them worried about being able to keep working.

Respondents were clear about what they needed most to keep working at their best: flexibility.

Based on the survey results, WMRI created a list of recommendations for employers, which include work flexibility, career planning options, counseling, an atmosphere of openness and dialogue, accommodations and adaptive workspaces, and wellness benefits such as gym memberships.

To read the full report, visit workingmother.com/womenandMS.

The National MS Society offers many resources on how to manage MS at work and at home. Call 1-800-344-4867 to speak with an MS Navigator, or visit nationalMSSociety.org/employment to find peer support groups, downloadable brochures, videos and more.