

Tips for Women with MS

Often, women who are diagnosed with multiple sclerosis (MS) are immersed in work, relationships, and planning for a family or taking care of one. An MS diagnosis can stop women in their tracks and make them reconsider their plans and dreams.

Fortunately, there are many life-enhancing tips, strategies and resources available to help women fit MS into their lifestyle and support the areas of their life that are most important to them. Compiled below are some suggestions for women diagnosed with MS to help them navigate life to the fullest. It's important to speak with your healthcare team before making any lifestyle changes.

- Because MS is an unpredictable disease, many women are concerned about their ability to continue working if their disease progresses. A good strategy is to initiate an in-depth conversation with your doctor as early after your diagnosis as possible about how MS might affect your ability to work, and how to best address and prepare for any of your concerns.
- Become familiar with the provisions of the Family Medical Leave Act (FMLA) and Americans with Disabilities Act (ADA) so that you understand you may have rights in the workplace. You are not required to disclose your disability at work. If your symptoms are invisible and you have no needs for accommodations in the workplace, you may choose not to disclose your diagnosis. If your symptoms become visible or interfere with your performance, you may want to seek the counsel of an employment attorney to determine the best next steps for you.
- MS may at times increase your stress level at work, so learning to practice and incorporate simple breathing or meditative techniques while at work may help you function better throughout the day. It can also help to plan your most strenuous work obligations around your fatigue. If your fatigue kicks in towards the end of the work day, plan to do tasks that require more focus in the mornings. If your employer offers flexible work hours, consider taking advantage of that.
- Disrupted sleep patterns are linked to poor daytime cognitive ability and can affect a person's ability to function at an optimal level during the day. Find a relaxing activity that you enjoy and practice that activity before bed to help calm your mind and set yourself up for a more restful and restorative sleep. Work with your doctor to manage any MS symptoms that disrupt your sleep.
- Find a support group or place to connect with other women with MS, and schedule time to regularly discuss your questions and concerns with one another. Knowing that you have dedicated time in the evening or on the weekends to talk through what's on your mind with like-minded people can help "free up your mind" during the week so you can focus on your work.
- Keep a journal of how you're feeling at work and your current symptoms. Any challenge you are experiencing, whether it be physical, cognitive or emotional should be tracked and shared with your doctor. This can help you determine where you might be struggling, and serve as a helpful diary for your doctor to use in directing your management plan. In particular, be sure to let your doctor know if you are experiencing changes in your mood, thinking or memory that are interfering with your work performance.
- If you feel that you need accommodations in the workplace to optimize your work performance, you can work with your healthcare providers to request the kinds of accommodations from your employer that will work best for you.
- It is important to understand your health and short/long term disability benefits. If you are unsure, call your providers and find out more details.





- A sometimes tricky and sensitive topic, relationship concerns affect many women with MS those in a relationship may worry about the pressure their partners might feel, and those not in a relationship may worry that they might never have one. Regardless of your relationship status, it may be helpful to receive professional guidance and support when it comes to navigating this important part of your life. You can take an important step towards enhancing your relationship and intimacy by talking openly and candidly with your neurologist/MS specialist, general practitioner, OBGYN, therapists/counselors or nurses about any concerns or questions.
- Relationship concerns may extend to children, other family members or friends, including whether or how to tell them about your diagnosis, and how the news will affect them or their perception of you. Don't be afraid to seek professional guidance on how to manage some of these issues.
- If you're in a relationship, it's also good to involve your partner in the discussion with your healthcare team. Both partners deserve to have their questions and concerns heard, supported and addressed. Being open and honest together can help you both find out what works best for you as a couple.
- Don't let MS define your relationships. Be candid with your healthcare providers about your relationship and intimacy concerns. Address each issue as it arises in order to better manage any issues and understand how to overcome them without them taking over your relationship.
- Your body may be experiencing many changes, some of which can affect your sexual feelings and responses. However, not all sexual difficulties are MS-related. Having a conversation with your doctor early on can help you differentiate what may be due to your MS and which solutions will work best for you and your partner.
- There is no right or wrong way to disclose your health condition. However, immediate family and closest friends will want to know about your MS and how it affects you. Talk to a therapist or counselor about disclosing this information to your inner circle if you aren't sure you are emotionally ready to share, but want to begin thinking about the best way to do so.
- You may not know how your closest friends or family will respond to the news of your diagnosis. Some may respond with silence. Others may have an abundance of questions or suggestions – either way be prepared for the various responses and how you can best help someone understand. You may consider watching a video together or providing them with a pamphlet to help answer their questions.
- Whether you are ready to start a family now or sometime in the future, it's important to share your plans with your doctor as soon as possible so s/he can work with you to manage this part of your future.
- When speaking with your doctor about planning for a family, make sure to consider every stage from trying to conceive through pregnancy, the post-partum period and breast-feeding. The more knowledge you have in advance, the better prepared you'll be to navigate this exciting time in your life.
- It really does take a village to raise a child, and that's even truer when you're parenting while living with MS. If you don't have one already, take the time to build a solid support network of reliable friends and family whom you are comfortable calling on for support. While pregnancy and child-rearing are wonderful stages in life, they can also be very physically and emotionally demanding.
- Track your feelings and mood changes and be sure to report any significant changes to your healthcare provider. Depression and anxiety are common in MS and need to be carefully diagnosed and managed.
- Continue to be open and honest with your doctor about any concerns you may have. While a trusting relationship with your physician is always important, it becomes significantly more critical when you're pregnant and/or already caring for your existing children.



Remember, you are not alone in this. Seeking the support of a therapist, social worker or other counselor can help you relieve worry and stress and provide you with the tools to live your life with MS to the fullest. For additional resources, see the recommended reading list here:

Work

- National Multiple Sclerosis Society (NMSS): Employment Information
- The Win-Win Approach to Reasonable Accommodations

Relationships

- National Multiple Sclerosis Society (NMSS): Dating & MS Video
- Foley FW, Werner M. How MS affects sexuality and intimacy. In (R. Kalb, ed.) Multiple Sclerosis: The Questions You Have; The Answers You Need (5th ed.). NY: Demos, 2012.
- Kalb R, Giesser B, Costello K. Multiple Sclerosis for Dummies (2nd ed.). Hoboken, NJ: Wiley, 2012. [This book has a chapter on Managing Lifestyle Issues that includes information about relationships and intimacy.]
- Kalb R. (ed.) Multiple Sclerosis: A Guide for Families (3rd ed.). NY: Demos, 2006.

Family Planning

- Giesser B, Benedetto-Anzai M, Werner MA. Fertility, pregnancy, childbirth and gynecologic care. In R Kalb (ed.) Multiple Sclerosis: The Questions You Have; The Answers You Need (5th ed.). New York: Demos, 2012.
- National Multiple Sclerosis Society Video: Pregnancy and MS: Kara's Story part 1
- National Multiple Sclerosis Society Video: Pregnancy and MS: Kara's Story part 2

