Adapting to Life as a Multiple Sclerosis (MS) Support Partner

As a support partner, you naturally want to do all you can to help your loved one manage life with MS. But MS doesn’t just impact people who have the condition—it impacts the whole family. So don’t forget that you, too, need guidance and support.

About MS

MS is a disease in which an abnormal response of the body’s immune system is directed against the central nervous system. It produces a wide range of symptoms and varied levels of disability.

Approximately 400,000 people living in the United States have MS, and they’re usually diagnosed between the ages of 20 and 40. Currently, there is no cure for MS, which is why it is considered a chronic disease. But its symptoms can be managed.

MS can be unpredictable

Most people have a relapsing form of MS, with short periods of new or worsening symptoms. These are usually followed by long stretches of relative relief, with partial or full recovery. Other people have a type of MS that gets progressively worse over time. Such differences mean that the course of MS can be unpredictable. This can be challenging when you’re trying to anticipate care needs. You’re certainly not alone in this struggle, as support partners provide 80% of the care to patients with MS.
The importance of staying on therapy

If you’re helping someone who is still physically independent, they’re likely treating symptoms of MS with medications and physical therapy. But medications only work if they are taken as prescribed by the healthcare provider.

*Some people fear needles or have difficulty injecting themselves.*

You can help by learning the injection procedure from the instructions included with the medication. Some medications must be infused at a clinic, so make sure the person you are supporting keeps these appointments.

Work with the whole healthcare team

Today’s MS care environment is often collaborative. With the permission of the person with MS, speak with all members of their healthcare team for tips on managing health and symptoms. This can include guidance for coping with bowel and bladder issues or sleep problems. If you’re supporting a person with a more advanced level of disability, you may need guidance for help with common daily activities, such as going to the bathroom, dressing, and feeding.

Adjust to shifting levels of physical ability

If MS progresses, your loved one may become increasingly dependent. This is challenging, yet manageable. Even people with a considerable level of disability can be supported at home with specific physical accommodations, such as a lift to help transfer them from a wheelchair to a bed or bath. Wide doorways and grab bars can also help. [Learn more about adapting your environment on the National Multiple Sclerosis Society website.]*

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Consider home help or facility care

You can’t be an effective support partner if you’re anxious or burned out. If work is a conflict, consider an adult day program. Your healthcare team can refer you to a professional nurse or therapist. Home care aides may also be an affordable option. Your loved one with MS needs to feel secure at home, so he or she should always be included in the interviewing process. Learn about reliable agencies that screen and refer potential caregivers on the National Multiple Sclerosis Society website.*

There may come a time when providing care at home no longer makes sense. Explore all your options, including live-in facilities, such as assisted living, supportive housing, continuing care communities, and nursing homes.

Get support from the community

Self-help groups can provide you with crucial emotional support and practical information. Even if you don’t have time to attend meetings, you can access supportive caregiver groups and blogs online. Learn more about finding support in the community.*

Although self-help groups can offer emotional support and advice, it is not medical advice and should not be taken as a substitute for guidance from your healthcare team.

Leverage financial resources

MS care can be very expensive, especially if the person with MS does not have long-term care insurance. Some services are covered by the patient’s private medical insurance, Medicare, or Medicaid, but others are not. It’s important to understand what financial resources and support are available. You can get more information about financial support on the National Multiple Sclerosis Society website.*

• Learn more about the Equal Employment Opportunity Commission*

• Get more information on the Americans with Disability Act on the National Multiple Sclerosis Society website* and on the United States Department of Labor website*

• Learn about veteran benefits on the US Department of Veterans Affairs website*

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Know it all, but don’t do it all.

The more you and your loved one learn about living with MS, the more equipped you’ll both be to meet the challenges and leverage the opportunities ahead. Remember, you’re part of a collaborative healthcare team, not a solo act.

Candid communication and proactive research are key. So reach out to the medical team, your social worker, and/or advocacy organizations like the National Multiple Sclerosis Society* when you have questions or need help. The course of MS may be unpredictable, but resources for support may help provide more confidence and reassurance.

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