

Multiple sclerosis: A guide for caregivers

We've developed this guide to support you on your care journey and share practical ways you can live your life to the fullest.



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Caring for someone with MS

Whether your loved one has been recently diagnosed with multiple sclerosis (MS) or has been living with MS for some time, the stress and worry for you as a caregiver may be ongoing.

Care-related tasks may include helping with dressing, bathing, eating, toileting, exercising, transportation, doctor visits and taking medication. This is in addition to regular household tasks such as general cleaning, shopping, cooking, laundry, childcare and transportation, as well as regular daily activities such as managing family commitments, work, recreation, entertainment, exercise, hobbies, private time and religious activities.

MS care creates unique challenges. Because MS develops in young adulthood, the initial impact can begin during the years of college education, marriage, career development and family life.

Over time, the emphasis in MS treatment and management needs to shift from addressing only the patient to an approach that combines the patient and you.

The bond between a person with MS and you can be very strong and positive. At the same time, caregiving can also be physically and emotionally demanding and exhausting.

Caregivers are the “hidden patients.” Your well-being is of the utmost importance for the well-being of the person with MS.



Burnout arising from caregiving

As MS progresses, caregiving may become more physically and emotionally demanding and time-consuming. This combination sometimes leads caregivers to neglect their own needs and self-care.

Caregivers sometimes develop feelings of inadequacy, guilt and self-blame despite their commitment to their loved one. They might struggle to stay organized and perform care tasks effectively.

As a caregiver, remember that you're allowed to ask for support before you get to a place of feeling overwhelmed.

The following are signs of caregiver burnout. If you recognize them in yourself, you should talk to your doctor, and be sure to remind them that you are a caregiver to a person with MS.

- 1 Feeling unusually tense, irritable or agitated with others
- 2 Being irritable and angry toward the person for whom you are providing care
- 3 Feeling sad, tearful or dissatisfied with life in general
- 4 Feeling exhausted and overwhelmed
- 5 Withdrawal from friends and enjoyable activities due to loss of desire and/or energy
- 6 Lowered immunity: getting sick more often and taking an unusually long time to recover
- 7 Increased need for medications and/or use of drugs or alcohol
- 8 Feeling out of control in attempts to manage your usual daily routine, with no sense of how to regain that control any time soon
- 9 Trouble sleeping and/or disturbing dreams
- 10 Change in appetite



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Stay involved in activities that have meaning for you, including maintaining social ties.



Take care of yourself

The person with MS needs you to be a healthy care partner. An effective partnership depends on the physical and emotional well-being of the both of you.

- Make time for your own health needs such as physical exercise, a healthy diet and regular medical examinations.
- Find downtime and get enough rest.
- Stay involved in activities that have meaning for you, including maintaining social ties.

Seek emotional support

Caregivers often think that they can—and should—handle everything alone. The best way to avoid burnout is to have the practical and emotional support of other people.

Beyond seeking support from your family and friends, consider participating in a caregiver self-help group. If you don't have time to go to group meetings, explore online caregiver support resources.

If you're experiencing disturbing emotions or thoughts, consider seeking out the guidance of a counsellor or therapist.

Communicate effectively

Take time to sort out your feelings, then schedule some time to clearly and calmly discuss them. Not expressing your feelings can lead to a range of emotions, including guilt, numbness, anger and resentment.

Understand that the emotional and cognitive symptoms of MS are often more distressing than the physical changes. If memory loss, problems with problem-solving, mood swings or depression in the person in your care are interfering with open communication or disrupting daily activities, consult a healthcare professional.

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can be vital members
of your circle of care.



Manage the unpredictability of MS

People with MS experience attacks and remissions, loss and recovery, or partial recovery of abilities. One day a person with MS can dress alone, the next day the person can't. You may be unable to predict the onset of a relapse, the progression of the disease or even the functional ability of your loved one over the course of a day.

Caregivers have to cope with this unpredictable trajectory of MS, including the possibility of the patient becoming severely disabled.



Although the unpredictability of MS can be very stressful, there are steps you can take to manage it:

- Give yourself permission to allow your role to flex and change as the care needs change.
- You may have to regularly take, then give back, responsibility for tasks— remind yourself that you're allowed to have care boundaries.
- Re-evaluate schedules and tasks as your needs and circumstances change.



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Adapt your home

You may need to adapt your home to increase its safety, accessibility and comfort for the person in your care and to ease your caregiving. Ramps, widened doorways, and renovations in the kitchen and bathroom can often solve accessibility problems.

Seek the help of an occupational therapist (OT) and physical therapist (PT) for suggestions on ways to keep the person with MS as independent as possible, ensure safety and reduce the physical strain on you.



Learn as much as you can

Management of MS and its symptoms will be easier if you, the person in your care, and extended family and friends learn as much about the disease as possible.

For example, invisible symptoms such as profound fatigue, sensory symptoms and vision loss are common among people with MS.

The most difficult invisible symptom for the caregiver to understand is fatigue and its intensity. MS-related fatigue is very different from regular fatigue because it generally occurs during the day; it can even occur in the morning after a good night's sleep. It can worsen during the day and is likely to interfere with normal activities.



Make the most of medical visits

As a caregiver, you're a vital member of the care team.

You may be responsible for keeping track of medications, administering injectable drugs or performing intermittent urinary catheterization.

You will need to make appointments with healthcare professionals to get information, advice and training. Treatment plans can fail if the caregiver does not know the medical staff, does not understand why and how a procedure is done, or is given instructions that seem impossible to carry out.

Keep in mind that your pharmacist is a valuable resource who can help optimize the care of your loved one with MS. They can:

- Review all of the medication and determine what is working and what is not working
- Assess possible reasons for non-adherence
- Identify potential drug interactions or contraindications to certain MS treatments

Tips

- ✓ Keep a log of new or changing symptoms, and outcomes of medical visits.
- ✓ Be prepared to advocate for your care partner to access needed assessments, services and therapies. You are allowed to have a voice.
- ✓ Be sure that you understand and are involved in treatment plans.
- ✓ Record and report any changes in behaviour or mental state.
- ✓ Be clear about your boundaries—let others know what you can and cannot do.



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Ask for help

You may be a spouse, partner, parent, child, family member or friend providing care on a regular basis to someone with MS. Your role as a caregiver is an important one.

Family and friends can be vital members of your circle of care. Tell your friends and family that you need their help. Friends often worry that offering help might seem intrusive, so let them know their help is welcome. Don't hesitate to be specific with your support needs.

Keep a list of projects, errands and services that others can do. Then, the next time someone offers to help in some way, you can guide them on how to best support you.

People with MS often need significant help with daily care. In many cases, family and friends may not be able to do it alone, and additional help may be needed. Talk with your medical team or your local MS Society to determine what additional professional care is available. This additional help may be covered by the government or private insurance.



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Additional resources

Please see our website, sharedsolutions.ca for more MS-related information, services and support.

Huddol

Visit the largest online caregiver support network in Canada, where you can learn, share and connect with experts and other caregivers:

— huddol.com

MS Society of Canada

To access caregiver information and support from the MS Society of Canada, visit:

— mssociety.ca/support-services/caregivers

— mssociety.ca/support-services/ms-peer-support-program

To access a series of MS Society programs and external community resources to help you find the support you need while caring for someone with MS, visit:

— mssociety.ca/support-services/programs-and-services

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