

Practical Tips for Caregivers

Caring for someone with a chronic disease like MS can be deeply satisfying. But caregiving can also be physically and emotionally exhausting, especially for the person who is the primary caregiver. Caregivers can be faced with a variety of life circumstances. This resource provides an overview of some of the potential situations and questions that may arise.

Financial and life planning

Financial and life planning for continued financial stability is essential and should be undertaken early. The process of long-term planning will help everyone feel more secure about their well-being, regardless of what the future brings.

- Life planning includes an investigation of income tax issues, protecting existing assets, saving for future financial needs, and end-of-life planning.
- Learn about the coverage and policies of your medical insurance, including provincial healthcare coverage, provincial and national benefits offered through [Employment and Social Development Canada](#) (ESDC), and available private disability insurance.

What level of care is needed?

Evaluating care needs should also be a joint effort. It's important to be realistic about what the person with MS needs, and what the caregiver can provide in terms of time, caregiving duties, and financial responsibility.

- **At-home care:** People with higher levels of disability can live at home successfully. There are a number of solutions to practical barriers. Adaptations can increase safety, accessibility, independence, and comfort for everyone. Before deciding to make major home renovations, ask your healthcare team for a referral to an occupational therapist (OT) for a home visit. The Canada Mortgage and Housing Corporation may be a helpful resource, especially where more substantial adaptations are required. Please see <https://www.cmhc-schl.gc.ca/> or call 1-800-668-2642 for more information.
- **Live-in-facilities:** There are several types of live-in-facilities, including assisted living or long-term care. Deciding what kind of living arrangement is best will depend on individual needs and financial resources available.

Flexible roles

MS can be unpredictable. People can experience relapses and remissions, and loss and recovery or partial recovery of abilities. People living with progressive MS may lose independence and caregivers may need to take on more responsibilities. In shared living spaces, everyone will need to rethink who does each task necessary for the smooth running of the household.

When a child is a caregiver

Sometimes children assume major household and personal care responsibilities when a parent has a chronic condition, such as MS. Children are not equipped to handle the stress of being a primary caregiver. Children under 10 can certainly handle some household chores. Young teenagers can take on more responsibility. Older teenagers and young adults may be competent caregivers, but they should not be expected to undertake long-term primary care.

When a parent is a caregiver

The return of an adult child to the home can be stressful for both the parents and the adult child. As parents age, providing care will become more difficult. In time, one or both parents may become ill and require care themselves. Therefore, alternative care plans and living arrangements should be discussed with the adult child well before such a situation occurs.

Family and friends

Family and friends are critical members in your support network. Keep a list of projects, errands, and services that friends could do. The next time someone offers to help in some way, it will be easy to oblige them. Don't be afraid to ask for help or to accept help being offered.

Hiring help

There may be certain care needs that require professional health services. This kind of help is typically only covered up to a certain extent, if at all, by provincial insurance plans. Professional nurses and therapists are usually referred by a physician. However, home care aides and domestic assistants can be hired. Hiring capable, reliable, and trustworthy help will be easier if the needs and concerns of the person receiving care are discussed in advance. The person receiving the care should always be part of the interview process.

Safety and security

Leaving a loved one living with a higher level of disability at home alone may cause some anxiety. Advance planning and adaptation of the home can decrease these worries. For example, installing automatic door openers and emergency call systems may provide some security.

The healthcare team and symptom management

Many MS symptoms can be managed by medications, rehabilitative therapies, and other wellness techniques. Where required, caregivers should seek advice and training on assisting with symptom management routines from the healthcare team. Management of MS and its symptoms will be easier if everyone involved becomes educated about the disease.

It isn't always MS

Some caregivers neglect their own physical health, including exercise, diet, and regular medical examinations. Both the person living with MS and the caregiver need to remember that having MS doesn't protect anyone from the normal ills that can affect us. Regular visits to your healthcare team for routine, preventive health exams are important to maintain.

Two-way communication

MS doesn't change the fact that important relationships are always a two-way street. Many emotional stresses are the result of poor communication. The caregiver should be able to discuss concerns and fears openly; the person receiving care isn't the only one who needs emotional support. Although collaboration isn't always easy or possible, working out long-term plans and goals together will help both people feel more secure.

Managing unpredictability

The unpredictability of MS can be very stressful, but it can be managed by making backup plans and focusing on what can be done rather than what can't. Call ahead to check accessibility of buildings, don't make plans too complicated, have alternative plans, or create a list of back up people who can assist on short notice.

Dependency, isolation and anger

Some caregivers don't ask for the help they need because they don't want to feel dependent on others, which can also lead to isolation. Anxieties are greatly reduced for care-partners who can develop personal and social support.

Anger and frustration are common emotions and should always be addressed, and healthy outlets developed before angry encounters become physically or emotionally abusive. Family and social groups may provide support and counsel. Therapists and marriage counsellors can help partners work out problems.

Sex and intimacy

Caregivers who are also spouses or partners usually experience some changes in their sexual relationship. These changes can have physical or emotional causes. MS can interfere with both sex drive and function. For more information please see the MS Society resource about [intimacy and sexuality](#).

Self-Care for the Caregiver: Resources for Caregivers

Providing emotional support and physical care to someone with MS is often deeply satisfying, but it is sometimes distressing, and at times, overwhelming. Some caregivers feel they can handle everything alone. The best way to avoid burnout is to have the practical and emotional support of other people. Sharing problems with others not only relieves stress but can give new perspectives on problems. Although family and friends make great confidantes, sometimes it helps to speak with others who understand what you are going through; The MS Society offers a [1:1 Peer Support Program](#) for caregivers and some chapters have caregiver self-help groups available. Religious and spiritual communities can also provide support and guidance.

Caregivers are encouraged to continue participating in enjoyable activities or hobbies. Some local organizations have respite care programs, and it may be possible to arrange respite care on a regular basis. Keep a list of people to ask on an occasional basis as well.

Relaxation

Relaxation isn't something you just decide to do; it's something that is learned. You will need to discover what works for you. Some relaxation techniques include:

- **Deep breathing**: Deep breathing and focusing on your breath can help reduce tension and allow your mind and body to feel more comfortable.
- **Meditation**: Many people find that meditation greatly decreases the stress in their lives. There are many apps and online tools that can help you get started with meditation.
- **Visualization**: Visualize an appealing scene and move yourself –in your mind – into the picture.
- **Progressive muscle relaxation**: Progressive muscle relaxation involves going through your body's entire group of muscles – tensing, relaxing, and focusing on the changes occurring.
- **Yoga**: Yoga involves breathing exercises and a range of stretches that revolve around the spine. Yoga increases the body's flexibility and releases tension.
- **Tai chi**: Tai chi involves deep breathing, slow gentle movements, and relaxation. As a conditioning regime, it is considered gentler than yoga.
- **Traditional exercise programs**: Exercise or any physical activity, especially when done on a regular basis, has been found to reduce stress and improve physical and mental health. Walking, swimming, or gardening can all relieve stress. Speak with your healthcare team about developing a program to suit your needs and abilities.

For additional information related to any of the topics listed in this resource, please contact the MS Knowledge Network at 1-844-859-6789 or by email at msnavigators@mssociety.ca