



ALS WAYS TO HELP

Fact Sheet

Assisting families living with ALS

If you know someone with ALS, you may want to help but don't know where to begin. Here are some ideas.

ALS will affect the roles and responsibilities of family members. Spouses, parents, and children can find themselves providing care and support to someone with ALS. Caregiving can make recreation, chores, and even employment difficult or impossible to maintain for the primary caregiver.

Many caregivers report high levels of stress and stress-related illness. Caring for someone with ALS is challenging. As time passes, the need for commitment increases. Eventually, ALS requires round-the-clock care.

Friends and neighbours are important sources of support for the family. Whether you live close by or far away, there is still plenty you can do.

KEEP IN TOUCH

Maintain contact with family caregivers. A card, a call, or a visit means a great deal. Caregivers as well as the person with ALS will benefit from your visits or calls. Continue to send cards or letters even if you don't receive a reply. It's a simple yet important way to show you care.

DO SMALL THINGS

Little things mean a lot. When cooking, make extra portions and drop off a meal (in a freezable container). If you're on your way out to do an errand, check with the caregiver to see if there is anything needed. Surprise the caregiver with a special treat such as a rented movie, a library book, or a gift certificate for a massage or dinner out.

GIVE THE CAREGIVER A BREAK

Everyone needs a little time on their own. Offer to visit with the person with ALS so the caregiver can run errands, attend a support group meeting, do a favourite activity, or attend a religious service. Even if the caregiver does not leave the house, this will provide some personal time. Chances are the person with ALS will also enjoy your company.

HELP WITH A SPECIFIC TASK

Many caregivers find it hard to ask for something specific. Ask the family to make a "to do" list of hard-to-get-done chores such as laundry, yard work, or shopping. Decide what you can do, then spend some time on a regular basis to help out.

BECOME INFORMED

Learn about ALS and how it impacts the person and their family. Information is available at www.als.ca or from your local ALS Society.

PROVIDE A CHANGE OF SCENERY

Plan an activity that gets family members out of the house. Invite the family to your house or to a nearby park for a picnic or a walk.

LEARN TO LISTEN

Sometimes caregivers just need to talk with someone. Ask family members how they are doing and encourage them to share. Be available when the caregiver is free to talk without interruptions. Try not to question or judge, but rather support and accept. You do not need to provide all the answers – just be a compassionate listener.

TAKE CARE OF THE CAREGIVER

Caregivers need to eat well, exercise, and get enough rest so that they can remain healthy. Encourage caregivers to take care of themselves. Pass along useful information. Offer to attend a support group meeting with them. Information is available from your local ALS Society.

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REMEMBER ALL FAMILY MEMBERS

The person with ALS will appreciate your visits, even if they are unable to show it. Hold a hand, give a hug, talk with the person the way you would want to be talked to. Spouses, adult children, and even young children are all affected in different ways by ALS. Be attentive to their needs too.

GET INVOLVED

There are many things you can do to help fight ALS. Consider making a contribution to the ALS Society to support research. Volunteer at your local Society to raise funds for local services for those affected by ALS. Get involved with the WALK for ALS or Hike 4 ALS in your area. By choosing to do any of these, you are providing help for today and hope for tomorrow.

The ALS Society has information and support programs. Find the society nearest you and give them a call. We are here to help.

You are not alone.

YOU MAY NOT KNOW THAT

ALS CAREGIVERS

- often feel alone and isolated from friends
- may need assistance, but are reluctant to ask
- are often unable to do errands or complete household tasks
- experience stresses that sometimes affect their health
- need regular breaks from caregiving
- may need someone to listen

PEOPLE WITH ALS

- need to feel valued
- face an uncertain future
- may worry about being a burden to their families
- need companionship
- strive to maintain independence and quality of life