

ALS FIRST STEPS

FACT SHEET | AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA | SOCIÉTÉ CANADIENNE DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE

FOR FAMILIES OF THOSE RECENTLY DIAGNOSED WITH ALS

When someone has just been diagnosed with ALS, the news is upsetting or both the individual and those who care about him/her. Most likely, you have been worried about the changes you have been seeing in the person and are probably anxious about the future. However, an important first step has already been taken: getting a diagnosis. If you will be the primary caregiver or an involved family member, there are things you can do right now that might make life a little easier.

LEARN AS MUCH AS YOU CAN

Learn as much as you can about the disease and providing care. Find out how the disease can affect an individual, what changes you can expect, and how you can provide help and support to maintain the person's independence and quality of life. Share this information with the person with ALS as well as other family members, friends, and co-workers; it will help them understand. The ALS Society has many useful resources that can help, including the web site www.als.ca and the **Manual for People Living with ALS**.

PREPARE FOR THE FUTURE

Support the individual in planning for the future. Decisions about work and personal issues need to be made while the person is able to have maximum involvement in the decision making process. Help to get all paperwork in order if it is not already. Ensure that someone has been chosen to make financial and health-care decisions as the disease progresses. Make certain the individual has talked about health-care decisions or has written his/her wishes in an advance directive. Create a backup plan in case you are unable to provide care.

RECOGNIZE THAT YOU ARE GOING THROUGH EMOTIONAL TURMOIL

The news of the ALS diagnosis and the changes it will bring can cause you to have all kinds of feelings: anger, denial, embarrassment, frustration, fear, sadness, and guilt. These emotions are normal and common among caregivers and may come and go. Sometimes people get depressed. If your feelings are overwhelming and will not go away, talk to your doctor or seek the help of a professional counsellor. It is important to be aware that the individual with ALS and other family members will also be experiencing the same type of emotional turmoil.

DEVELOP A SUPPORT NETWORK

Find people with whom you are comfortable to share your feelings and emotions. It may be a member of your family, a good friend, members of a support group, or someone at the local ALS Society. The important thing is to find an outlet where you can express and learn to manage your feelings. Caregivers often become isolated and lonely, so it is important to stay connected to the people around you.

SEEK OUT HELP

There are community agencies and services to help you now and in the future. These services can assist with everyday household or caregiving tasks. You may also have a network of family and friends who are willing to lend support.

To determine what help you need, think about your strengths and weaknesses, what you need, and what would help you in your caregiving role.

Determine who might be able to help and then ask. Learn about the system of resources in your community. Try to understand how the services work, what you can expect from them, and how you can access them. Your local ALS Society can help with this process.

RECOGNIZE THE PROGRESSIVE NATURE OF THE DISEASE

ALS is a progressive disease. It will affect how the person functions on a day-to-day basis. Learn what the person can or can not do at each stage, so that you have realistic expectations of his/her abilities. Always focus on what the person can do, not on what abilities are gone. Ask the person how you can help him/her stay independent and maintain a sense of control. One tip often heard from caregivers is that you must learn to be patient.

RECOGNIZE THAT CAREGIVING CAN TAKE ITS TOLL

Providing care to an individual with ALS takes a toll on the caregiver. Caregivers are often at risk for physical and emotional problems. It is important to be aware of this and take steps to care for yourself. Maintaining your physical

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health, exercise, and eating a healthy diet are crucial. Find time for activities you enjoy. The ALS Society can help you find support.

EXPLORE TREATMENT OPTIONS

Currently there is no cure for ALS, but medications are available that can help some people with some of the symptoms. Discuss their risks and benefits with the person's doctor. Your local ALS Society will have up-to-date information about new treatments that might be available.

DON'T LOSE SIGHT OF THE PERSON

No matter how the disease affects the individual, it is important to treat him/her with dignity and respect. Provide activities and interactions that bring a sense of joy and celebration. Focus on the abilities that remain. This will go a long way in adding to the quality of life and help the person maintain a positive sense of self.

KNOW THAT THE ALS SOCIETY IS HERE TO HELP

With one call (1-800-267-4257) or one click (www.als.ca) you will be connected to the ALS Society nearest you. The ALS Society is in your community to help you and your family. We can :

- find the information you need to learn more about the disease, caregiving, and coping strategies
- find the support you need, whether with a telephone counsellor or a support group
- locate and access services in your community

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.

