

ALS First Steps

To determine what help you need, think about your strengths and weaknesses, what you need and what would help you in your caregiving role. Figure out 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. The ALS Society of Alberta can help with this process. When someone has just been diagnosed with ALS, the news is upsetting for 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 you 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.

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 cannot 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.

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.

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. Although certain abilities will be lost, the person's emotions, intellect, self awareness and feelings will remain, as will their need for companionship and belonging. 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 will help the person maintain a positive sense of self.

EXPLORE TREATMENT OPTIONS

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

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

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continued

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 coworkers: it will help them understand. The ALS Society has many useful resources that can help, including the web site www.alsab.ca and the Manual for People Living with ALS.

PLAN 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 get all paperwork in order if it is not already. Ensure that someone has been chosen to make financial and healthcare decisions as the disease progresses. Make certain the individual has talked about healthcare decisions or written his/her wishes in an advance directive. Create a back up plan should you be unable to provide care.

DEVELOP A SUPPORT NETWORK

Find people you are comfortable with 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 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.

RECOGNIZE YOUR EMOTIONS

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 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. Seek the help of a professional counsellor.

It is important to be aware that the individual and other family members will also be experiencing the same type of emotional roller coaster.

KNOW THAT THE ALS SOCIETY IS HERE TO HELP

With one call **(1-888-309-1111)** or one click **(www.alsab.ca)**, you will be connected to the ALS Society of Alberta. The ALS Society is in your community to help you and support 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.