

8. Seek out help

There are community agencies and services to help you now and in the future. These services can help you 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. Figure out who might be able to help and then ask.

Learn about the system of resources in your community. Learn how the services work, what you can expect from them and how you can access them. Your local Alzheimer Society can help direct you to the services in your community.

9. 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 local Alzheimer Society. The important thing is to find an outlet where you can express your feelings. Caregivers often become isolated and lonely, so it is important to stay connected to the people around you.

10. Know that the Alzheimer Society is here to help

The Society can help by:

- Giving you information you need to learn more about the disease, caregiving and coping strategies.
- Providing support whether with a telephone counsellor or a support group.
- Registering the person with the disease with the Safely Home™ - Alzheimer Wandering Registry program to ensure that if the person gets lost, there is help at hand.
- Locating services in your community.

The Alzheimer Society is a national not-for-profit health organization dedicated to helping people affected by Alzheimer Disease. The Society has numerous resources and support programs for people with the disease and their caregivers. The Society also funds research into finding the cause and cure of the disease, and into improved methods of caregiving.

For more information, contact your local Alzheimer Society or visit our Web site at www.alzheimer.ca.

Help for today. Hope for tomorrow...

Pictured on our cover is Dale, 64, and her granddaughter Elyse. Dale was diagnosed with Alzheimer Disease in 1998. The Alzheimer Society would like to thank both Cynthia and Dale and their families for agreeing to be part of this brochure and for helping raise awareness of Alzheimer Disease.

Alzheimer Society

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First Steps

For Families of Those Recently Diagnosed With Alzheimer Disease

Alzheimer Society

First Steps for Families

When someone has just been diagnosed with Alzheimer Disease, the news may be upsetting for both the individual and those who care about him or her. Most likely you have been worried about the changes you have been seeing in the person and you may also be 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. The information in this brochure can help.

1. Learn as much as you feel you can

Learn as much about the disease and providing care as you can. Find out how the disease can affect a person, 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 those closest to the person, such as family members, friends and co-workers; it will help them understand. The Alzheimer Society has many useful resources that can help such as *The Alzheimer Journey* video series, *Guidelines for Care* and the Web site (www.alzheimer.ca).

2. Recognize that the disease affects the person's abilities

Alzheimer Disease progresses over time. It will affect how the person functions on a day-to-day basis. Learn about the changes the disease will cause so that you have realistic expectations of the person's abilities. Ask the person how you can help him or her stay independent and maintain a sense of control. One tip often heard from caregivers is that you must learn to be patient.

3. Don't lose sight of the person

No matter how the disease affects the individual, it is important to treat him or her with dignity and respect. Although certain abilities will be lost, the person's emotions and feelings will remain, as will the 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 help the person maintain a sense of self.

4. Explore treatment options

Currently there is no cure for Alzheimer Disease. But medications are available that can help some people with some of the symptoms. Discuss their risks and benefits with the person's doctor. As well, your local Alzheimer Society will have up-to-date information about new treatments that might be available through drug trials. If the individual chooses to participate in such research, you may be asked to help.

5. Recognize that you are going through a variety of emotions

The news of the diagnosis and the changes it will bring can cause you to have a variety 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 won't go away, talk to your doctor.

It is important to be aware that the person with the disease and other family members may also be experiencing the same types of emotions.

6. Plan for the future

Support the person in planning for the future.

Decisions about work and personal issues need to be made while the person is able to be involved 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 health-care decisions when the person is unable to do so.

Make certain the individual has talked about health-care decisions or written his or her wishes in an advance directive. Legal and estate planning should also be discussed. Create a backup plan should you be unable to provide care.

7. Recognize that caregiving can take its toll

Providing care to a person with Alzheimer Disease can take its toll on the caregiver. Caregivers are often at risk for physical and emotional problems. Those who provide care should be aware of this and take steps to care for themselves. Maintain your physical health, exercise and eat a healthy diet. Find time for activities you enjoy. See the brochure *Caring for Someone With Alzheimer Disease? Take care of yourself too!* available from the Alzheimer Society.



"Before I participated in the early stage support group, I was upset with everyone that told me I was forgetting. I was upset because I could not understand what was happening to me."

— Cynthia, 58, has Vascular Dementia, a dementia related to Alzheimer Disease. Cynthia is pictured here with her daughter.