

Alzheimer *Society*

Alzheimer's disease

First steps for families



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A diagnosis of Alzheimer's disease may be upsetting for both the individual and those who care about him. Most likely you have been worried about the changes you have been seeing and you may also be anxious about the future.

Knowing the following tips may help make life easier and more enjoyable for you and the person with dementia as well as to prepare for the future.

Note: This brochure is a companion piece to "First Steps" for people recently diagnosed with Alzheimer's disease.

Step

1

Recognize that you are going through a variety of emotions

The news of the diagnosis and the changes it will bring may cause you to feel anger, denial, embarrassment, frustration, fear, sadness and guilt. These emotions are normal and common among caregivers. Sometimes people get depressed. If your feelings are overwhelming and won't go away, talk to your doctor.

Be aware that the person with the disease and other family members may also be experiencing the same types of emotions.

Step 2 Learn about Alzheimer's disease

Learn as much as you can about the disease and providing care. Find out how the disease can affect a person, what changes you can expect, and how you can help to maintain her independence and quality of life. Share this information with those closest to her, such as family members, friends and co-workers to help them understand.

Contact your local Alzheimer Society for useful information and resources or visit our website (www.alzheimer.ca).

Step 3 Recognize that the disease affects a person's abilities

Alzheimer's disease progresses over time. It will affect how the person functions daily. Learn about the changes the disease will cause so that you have realistic expectations of his abilities. Ask him how you can help him stay independent and maintain a sense of control. One tip often heard from caregivers is that you must learn to be patient, though it isn't always easy.



Step 4 Don't lose sight of the person

No matter how the disease affects the individual, it is important to treat her with dignity and respect. Although certain abilities will be lost, her 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.

Step 5 Explore treatment options

Currently there is no cure for Alzheimer's 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.

Step 6 Recognize that caregiving can take its toll

While caring for a person with Alzheimer's disease can be rewarding, caregivers are often at risk of physical and emotional problems. If you are the caregiver, make sure you maintain your physical health, stay active and make healthy food choices. Find time for activities you enjoy. See the brochure "Reducing caregiver stress" available from the Alzheimer Society.

Step 7 Seek help

Call your local Alzheimer Society to find out what help is available in your area. Community agencies may offer practical services like helping with household or caregiving tasks. You may also have a network of family and friends who are willing to lend support.

Think about your strengths and weaknesses, what you need and what would help you in your caregiving role. Family and friends may want to help but often don't know what to do. Figure out who might be able to help and then ask.

Learn how the support services work in your community, 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.

Step 8 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. Caregivers often become isolated and lonely, so it is important to stay connected to people and share your feelings.

Step 9 Plan for the future

Support the person in planning for the future:

- Make decisions about work and personal issues while the person can be involved in making those decisions.
- Make sure the person has discussed and documented her wishes for future health-care.
- Identify someone to make financial and health-care decisions when the person is unable to do so.
- Make an alternate plan if you are no longer able to provide care.

Make certain the individual has talked about future health-care decisions or has documented his wishes. Legal and estate

planning should also be discussed. Create an alternate plan should you be unable to provide care.

Step 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 by telephone or through a support group.
- Registering the person with the disease with our MedicAlert® Safely Home® program to assist first responders identify the person who is lost and bring the family back together.
- Locating services in your community.



The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities right across Canada, the Society:

- Offers information, support and education programs for people with dementia, their families and caregivers
- Funds research to find a cure and improve the care of people with dementia
- Promotes public education and awareness of Alzheimer's disease and other dementias to ensure people know where to turn for help
- Influences policy and decision-making to address the needs of people with dementia and their caregivers.

Help for Today. Hope for Tomorrow...[®]

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