### **Alzheimer** Society

#### Alzheimer's disease and other dementias First steps for families





#### First steps for families

Knowing the following tips may help make life easier and less stressful in the future for you and the family member living with dementia.

A diagnosis of dementia may be upsetting for you and your friends and family. Most likely you have been worried about the changes you have been seeing and you may also be anxious about the future. Having the validation of a diagnosis will lead to access for supports and services going forward.

Please note this brochure is a companion piece to "First Steps" for people recently diagnosed with dementia.

#### Step 1 Call or email the Alzheimer Society's First Link<sup>®</sup> service for free dementia help.

The Alzheimer Society is here to help anyone in Canada who is facing the challenges of dementia. Through our First Link<sup>®</sup> service, the Society is here to help you by:

- Giving information you need to learn more about dementia, caregiving and coping strategies.
- Providing support by telephone or through a support group.
- Locating services in your community that can give you additional help and support.

Reach us at **1-855-705-4636** or **info@alzheimer.ca** for free support and referrals. Our trained staff will refer you to the appropriate local, provincial or federal services available. There's more to learn at **alzheimer.ca/FirstLink**.

# Step 2 Recognize that you may experience 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/or guilt. These emotions are normal and common among families. Sometimes people get depressed. If your feelings are overwhelming and won't go away, talk to your doctor.

Be aware that the person living with dementia, as well as other family members and friends, may also be experiencing the same emotions. For more information, visit **alzheimer.ca/Grief**.

#### Step 3 Learn about dementia

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

Contact your local Alzheimer Society for useful information and resources – you can find your local Society at **alzheimer.ca/Find**. Or visit our webpage about dementia at **alzheimer.ca/ WhatIsDementia**.



### Step 4 Recognize that dementia affects a person's abilities

Dementia progresses over time and will affect a person's daily functions. Learn about the changes dementia can cause so that you have realistic expectations of the person's abilities. Ask the person how you can help them stay independent and maintain a sense of some control. One tip often heard from caregivers is that, though it isn't always easy, it helps to be patient. For more information, visit **alzheimer. ca/ChangesInAbilities**.

## Step 5 Treat the person with dignity and respect

No matter how dementia affects the individual, it is essential to treat them with dignity and respect. Although certain abilities may change, their emotions and feelings will remain, as will the need for companionship and a sense of belonging. Provide meaningful activities and interactions that bring a sense of joy. For more information, visit alzheimer.ca/ MeaningfulVisits.

#### Step 6 Explore treatment options

Currently, there is no cure for many types of dementia. But medications are available that may help with some of the symptoms. Discuss the risks and benefits with the person's doctor. Your local Alzheimer Society will also have up-to-date information about new treatments that might be available through drug trials or therapy. If the person chooses to participate in research, you may be asked to help. For more information, visit **alzheimer.ca**/ **Treatment**.

## Step 7 Recognize that caregiving can affect your health

While caring for a person living with dementia 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, maintain your social connections and make healthy food choices. Find time for activities you enjoy. See the brochure **"Reducing caregiver stress"** available from the Alzheimer Society or visit **alzheimer.ca**/ **ReducingCaregiverStress**.

# Step 8 Reach out to other organizations that can help you

More than 50 different diseases and conditions are associated with dementia. Connecting with the leading organizations related to the person with dementia's specific disease or condition can provide you with further information and support. Community agencies may offer practical services like helping with household or caregiving tasks or respite care.

If you need more information, your local Alzheimer Society will be happy to refer you to the people who can help you. Visit **alzheimer.ca/Find** to get connected to your local Society.

#### Step 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, a therapist, members of a support group or a person working at your local Alzheimer Society. If you belong to a faith community or cultural organization, workers or advisors there may also be able to help. Caregivers often become isolated and lonely, so it is important to stay connected and share your feelings. For more information, visit **alzheimer.ca/FindingHelp**.

#### Step 10 Plan for the future

Support the person living with dementia in planning for the future:

- Involve the person when making decisions about work and personal or financial issues.
- Make sure the person has discussed and documented their wishes for future healthcare.
- Identify someone who can make financial and medical decisions for the person, with the expectation that they will take on these roles when the person is unable to do so. Legal and estate planning should also be discussed.
- Create an alternate plan if you are unable to provide care.

For more information and resources on planning for the future, visit our website at **alzheimer.ca/Plan**.



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

- Offers information, support and education programs for people with dementia and their caregivers.
- Funds research to find a cure and improve the care and well being 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.

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

#### Help for Today. Hope for Tomorrow ...®

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### **Alzheimer** Society

This resource is informed by research and the experiences of a caregiver of a person living with dementia. We thank Catherine Hofstetter for her generous contribution to the development of this resource.

Alzheimer Society of Canada 20 Eglinton Avenue West, 16th Floor Toronto, Ontario M4R 1K8 National office: 1-800-616-8816 Information and Referrals: 1-855-705-4636 (INFO) Email: info@alzheimer.ca Website: alzheimer.ca Facebook: facebook.com/AlzheimerCanada Twitter: twitter.com/AlzCanada

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