

## Alzheimer's disease and other dementias First steps



### Step 9 Consider getting involved in advocacy and/or research

The Alzheimer Society Advisory Group of People with Lived Experience helps direct our national strategies and policies. Visit [alzheimer.ca/AdvisoryGroup](https://alzheimer.ca/AdvisoryGroup) for more details. Dementia Alliance International and Dementia Advocacy Canada are run by people living with dementia. These organizations (and more) offer contacts, learnings, connections and meaningful activity.

Research studies can help you access scientists, new drugs, therapies and peer connections. Participating can also help advance dementia research. Find a list of current studies seeking participants at [alzheimer.ca/Find-Studies](https://alzheimer.ca/Find-Studies).

### Step 10 Take care of yourself

Maintain your mental and physical health, stay active, make healthy food choices and spend time with your family and friends. Enjoy life to the fullest. Take your prescribed medications and attend all medical follow-up appointments. Try to maintain or improve your sleep, and talk with your health workers about that too.



### Step 8 Plan for the future

Start planning now for the future:

- If you are working, it may be important to prepare for your future retirement. Also, if you are employed, you may want to discuss disability accommodation with your employer.
- If you own a business, you will need to make plans for when you can no longer do things on your own.
- If you have been putting off decisions about your personal life, make them now.
- Make sure your paperwork and important documents are in order, including legal and estate planning.
- Ensure that you have chosen someone to make financial and healthcare decisions for you when you are unable to do so. Talk to the person about your wishes and write them down. This will ensure that your requests are followed when you are unable to communicate them yourself.
- Talk to staff at your local Alzheimer Society for any relevant workshops or supports they might have on advance care planning, finances, work or other related topics.

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, 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.

For more information, contact your local Alzheimer Society or visit our website at [alzheimer.ca](https://alzheimer.ca).

Help for Today. Hope for Tomorrow...®

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## Alzheimer Society

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)

✉ [info@alzheimer.ca](mailto:info@alzheimer.ca) 🌐 [alzheimer.ca](https://alzheimer.ca)  
f @AlzheimerCanada 🐦 @AlzCanada  
📷 @AlzheimerCanada

Charitable registration number: 11878 4925 RR0001



## First steps

You have likely been worried and anxious about the changes you are seeing in yourself. Now that you have been diagnosed with dementia, you may be concerned about the future. However, you have already taken an important first step in caring for yourself: getting a diagnosis.

## Changes to expect

The changes you are experiencing are because of dementia. You may have trouble finding words, completing thoughts, following directions or remembering information. Later, you may feel confused and have difficulty with familiar tasks. These changes are related to dementia as it affects memory, thinking and behaviour. Other people may notice changes in your behaviour or personality. The effects of dementia will change how you live day to day.

The information in this brochure can help you cope with the changes you are experiencing, and plan for future changes so you can continue living your life to its fullest every day.

### Step 1 Call or email the Alzheimer Society's First Link® service for free dementia help

The Alzheimer Society is here to help anyone in Canada who is facing the challenges of dementia. The Society can help by:

- Giving you information you need to learn more about dementia and coping strategies.

- Providing support by telephone or email, or through a support group.
- Locating services for you in your community.

Reach us at **1-855-705-4636** or [info@alzheimer.ca](mailto:info@alzheimer.ca) for free support and referrals. Or learn more at [alzheimer.ca/FirstLink](http://alzheimer.ca/FirstLink).

### Step 2 Recognize that you are going through a variety of emotions

You may respond to the news of the diagnosis and the changes caused by dementia with a variety of emotions. You might feel angry, embarrassed, frustrated, afraid or sad. These emotions and more are normal and may come and go.

Let those close to you know how you are feeling. Your family and friends may also be experiencing the same types of emotions. Sometimes, people with dementia feel sad or depressed. If your feelings are overwhelming and won't go away, talk to your doctor.

### Step 3 Learn about dementia

Find out what you can about dementia and how it will progress. Learn about tips and strategies that might help you day to day. The Alzheimer Society has many useful resources to help people with dementia, such as our **"Shared Experiences"** booklet, our website ([alzheimer.ca](http://alzheimer.ca)) and support groups.

### Step 4 Tell people

If possible, let the people closest to you know that you are living with dementia. Explain what dementia is and how it is affecting you. Sharing this information will help them understand that the difficulties you are experiencing are a result of dementia. Sharing this information will also allow you to tell them how they might be able to support you.

Refer friends and family to your local Alzheimer Society for useful information and resources.

### Step 5 Explore treatment options

While there is no cure for dementia, medications may help with managing some of the symptoms. Read about the treatments that are available. Discuss their risks and benefits with your doctor. You may wish to participate in a research study. Your local Alzheimer Society will have information on treatment options and research studies in your area.

### Step 6 Focus on what you can do – and on what you enjoy doing

- Adapt your interests and abilities.
- Pursue a hobby you enjoy or listen to your favourite songs.
- Find ways that help you cope with the changes. For example, write down important things in a memory book, smartphone or tablet.



- Whenever possible, simplify your life.
- Following a routine may also be helpful.

### Suggestions from people with dementia

People who have dementia say you should:

- Learn to be patient
- Try not to be hard on yourself
- Always carry an appointment book and write notes of discussions with your health-care provider

### Step 7 Develop a support group

Find people you are comfortable with to share your feelings and emotions. It may be a member of your family, a good friend, another person with dementia, a therapist or an Alzheimer Society support group.

No matter who it is, the important thing is to share your experiences and how you are feeling. Some people also find it helpful to write their thoughts, feelings and experiences in a journal.