

# SHARED EXPERIENCES

Suggestions for living well with Alzheimer's disease



## Telling people

Each person reacts differently to the idea of telling people about living with Alzheimer's disease. Some people may want everyone to know. Some may want to tell only a few people. Knowing whom to tell, what to tell, how and when can be very challenging. You may not want to upset others or worry about how they will react. There is also a lot of stigma around Alzheimer's disease and you may have concerns about being treated or thought of differently by friends, family, neighbours and employers.

Receiving one-on-one support from staff at your local Alzheimer Society or talking to others who have been affected by the disease may help you to begin difficult conversations with the people in your life.

By speaking out, people with Alzheimer's disease can help others understand what it is like to live with the disease. In turn, this may encourage people to learn more about Alzheimer's disease and what they can do to help.

### Whom to tell

The people who are closest to you are the people to tell first. Husbands, wives, sons, daughters, grandchildren, other family members and close friends are the people who know you best. You would likely want them to be aware of this change in your life, just as you would with any major illness. Tell the people with whom you are most comfortable. Tell the people who need to know.

### What to tell

Tell people as much as you are comfortable with. Let people know what you need and how you want to be treated. If you need assistance, ask for it. If you need family members to leave you alone or to give you some space, let them know. Speak up. Encourage people to learn more about the disease. It may help to have information about Alzheimer's disease and what to expect to be able to answer any questions others might have.

### Talking to family members

Just as you are coping with the physical, emotional and behavioural changes brought on by your Alzheimer's disease symptoms, your family members also have to adjust. Relationships with family members may change. Family roles may change. A husband may have to take on some of the tasks and responsibilities that used to be performed by his wife or vice versa. A son or daughter may become more involved in a parent's day-to-day activities. You may fear losing your independence and worry about becoming a burden to your family. These kinds of changes, fears and worries can challenge the best of family relationships.

Talk to family members. Tell them how the disease affects you. Let them know how their positive or negative reactions and comments make you feel. Help them see that there are things you can do for yourself and that you can still make many of your own decisions. Discuss what you can do to help and support each other.

Your conversations with family members should also include putting your legal and financial affairs in order and looking ahead to a time when family members may have to become more involved in your day-to-day care.

## Talking to your doctor or health-care professional

You may have questions about Alzheimer's disease, such as symptoms, treatments, how to participate in drug trials and other research, and what to expect. Make a list of the questions you want to ask your doctor on your next visit. Take a family member or friend with you to take notes, help clarify information and provide emotional support. Ask that the information be explained to you slowly and with diagrams, if necessary.

In addition to your family doctor, you may be referred to a specialist, such as a neurologist or a geriatrician, or to other health-care professionals, such as a nurse or social worker. Together, they make up a care team to monitor all aspects of your health. Communicating your health concerns and wishes to everyone is important.

Doctors are not the only support you have available to learn about Alzheimer's disease and other dementias. Get in touch with your local Alzheimer Society. Staff can connect you to information, education and support.

### Some questions to ask your care team:

Where can I go in the community to get help?

What kinds of activities can I do to keep active?

What kinds of changes should I expect over the next six months or 12 months?

Would any of the current treatments for Alzheimer's disease symptoms be suitable for me?

What can I do to lessen the side effects of my medication for Alzheimer's disease?

When should I come back for my next appointment?

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Add some other questions you would like to ask:

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### Talking to friends and neighbours

Friends need to know how you are doing. Talk to them. Stay in touch, even if you are having problems communicating. Friends and neighbours often want to help in any way they can. They often do not mind that you may be forgetful or experience mood swings. Trust them to accept you as you are.

### Talking to other people with Alzheimer's disease

Talking to other people with Alzheimer's disease will put you in touch with the only people who know first-hand what you are experiencing.

Contact your local Alzheimer Society to see if there is an Alzheimer's disease support group in your area. If not, you may be interested in helping the Society start one. People have said that attending a support group is a unique opportunity to talk with others who are sympathetic and understanding. You are also able to talk about your feelings and maybe even share a laugh about some of your experiences. That's an important part of any support group. And everything stays within the group.

Another option may be to have the Society put you in touch with someone who can provide one-on-one support.

### Additional resources

For more information on telling people, please refer to the following print materials. These are available from the Alzheimer Society or on-line at [www.alzheimer.ca](http://www.alzheimer.ca).

- *Alzheimer's disease: First steps for families*
- *Alzheimer's disease: Ways to help*
- *Focus: Helping children understand Alzheimer's disease*
- *Focus: Helping teens understand Alzheimer's disease*