

SHARED EXPERIENCES

Suggestions for living well with Alzheimer's disease



The Alzheimer Society would like to thank all the people with Alzheimer's disease whose photos and comments appear in this booklet. We are grateful to everyone who gave us suggestions on the content.

This booklet incorporates and replaces information from the Alzheimer Society's *Just for You* book.

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.

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

Living with Alzheimer's disease

While the information in this booklet is specific to people with Alzheimer's disease, it can also be helpful to people with other dementias.

The Alzheimer Society met with groups of Canadians across the country who are in the early stages of Alzheimer's disease. They agreed to talk to us about what it is like to live with the disease. They shared their experiences, thoughts and feelings and offered practical tips and suggestions for others with the disease. They also told us how family members, friends, the Alzheimer Society and others can help.

They reviewed copies of the Society's brochure, *First steps: For those recently diagnosed with Alzheimer's disease*, and told us what type of information they would like to receive next.

We are indebted to these individuals who willingly offered their insights and experiences to help create this booklet for people living with Alzheimer's disease. We have drawn on their comments to provide real-life examples for the text.

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The information in this booklet is intended to help answer some of your questions and address some of your concerns about living with Alzheimer's disease. The topics included are:

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Some topics in this booklet deal with sensitive issues that you may not be comfortable dealing with right now. You can save them for later.

Additional resources — books, information sheets, videos, and on-line resources — are available through the Alzheimer Society. Some of these materials have been written by people with Alzheimer's disease. The Society's website — www.alzheimer.ca — has information and resources about living with dementia and how we can help. There are also conferences and workshops that may be of interest. For more information, contact your local Alzheimer Society or visit www.alzheimer.ca.

Experiencing a variety of emotions

For some people, the diagnosis of Alzheimer's disease is a shock. For others, there may be an initial sense of relief at finally being able to put a name to their symptoms. You may be overwhelmed by the many changes that are taking place in your life – receiving a diagnosis, telling others, experiencing changes in your abilities, anticipating further losses, changes in your relationships and more. Whatever your immediate response to the diagnosis, over time, you will find yourself experiencing a variety of emotions.

Some common reactions and feelings

We asked people about their reactions and feelings about living with Alzheimer's disease. They are only a sample and it does not mean that you will experience any or all of them. Here are some of their comments:

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| Denial | "Sometimes I think they made a mistake. I don't have Alzheimer's disease. I'm still functioning." |
| Anger | "It angers me that I can't pull myself up." |
| Anxiety | "I'm scared about losing my abilities." |
| Guilt | "I feel guilty, like a dead weight around my husband's neck." |
| Frustration | "I start talking to people, then I forget what I'm talking about; it blocks me." |
| Hurt | "If I make a mistake, don't correct me. That hurts." |

section 1 Experiencing a variety of emotions

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| Humour | "I have to laugh. That's therapy. If I didn't laugh, I would cry." |
| Sadness | "I feel the end of something." |
| Depression | "It's all black." |
| Loneliness | "You are not in the circle but on the outside." |
| Acceptance | "I take it as it comes at this stage of the game." |
| Hope | "You have to fight. Hang on. One of these days they will find a cure." |

Experiencing this range of emotions is a normal reaction to having a disease whose symptoms affect the way you see yourself. As one person with Alzheimer's disease says, "Your inner world is changing." Each person responds to these changes in his or her own way.

Talking to someone about how you feel is one way to get these feelings out into the open. Talk to a close friend, a family member or someone with whom you feel comfortable.

It can be especially helpful to meet with other people who have the disease. Together, you can share your feelings and experiences and offer each other social and emotional support.

Contact your local Alzheimer Society to see if there is an early stage Alzheimer's disease support group in your area. If not, you may be interested in helping the Society start one. Another option may be to have the Society get you in touch with someone who can provide one-on-one support.

Some suggestions for coping with your emotions

Each of us has our own way of dealing with our feelings. The important thing is to find a way or ways of coping with these emotions that makes you feel better.

When we asked people how they coped with their emotions, here is what they said:

“Acknowledge it.”

“Take one day at a time.”

“Join a support group. The more you speak, you get a load off your chest.”

“Be with people you can laugh with.”

“Go for a walk with someone or on your own – sometimes a walk to ‘smell the roses’ is just as therapeutic.”

“Don’t be shy. Ask for help.”

“Tell people if they hurt your feelings.”

“Animals are good for people. Animals are calming.”

“Don’t stay enclosed, isolated. Get out.”

“Never give up hope. Living is worth it.”

Add suggestions that work for you:

Dealing with depression

Considering the many changes associated with Alzheimer's disease, it is understandable that you may feel sad or unhappy at times. Don't carry the burden alone. Talk to people who can help you deal with your feelings. Remember that tomorrow may be a better day. Try to do things that will lift your spirits.

Spend time in the company of people you care about and who will support you during the difficult days.

Try some activities that can help take your mind off your worries, such as playing your favourite music, gardening, taking a walk or caring for pets. These activities can have a beneficial effect.

If the feelings of sadness and hopelessness become overwhelming, make an appointment to see your doctor. Professional counselling may be recommended or medication may be considered.