

SHARED EXPERIENCES

Suggestions for living well with Alzheimer's disease



Changes you may experience

Alzheimer's disease affects thinking ability and memory. It also affects mood and emotions, behaviour and ability to perform activities of daily living. Alzheimer's disease typically follows certain stages that bring about changes in the person's and family's lives. It affects each individual differently – the symptoms, the order in which they appear and duration of each stage vary from person to person. In most cases, the disease progresses slowly; the duration of the disease is usually seven to 10 years, but may be longer in some people.

Memory loss

You may find that you do not remember a person's name at the time, but the name comes to you later. Or, you start talking to someone and in mid-sentence you forget what you were talking about.

Communication problems

You may find yourself reaching for a word but it is not there. Or, you intend to say one word but a different word comes out. Finding the words to express your thoughts and feelings may become harder.

Reading may become more difficult. It may seem as though the words all run together. You may have trouble writing things down.

In groups, you may find it difficult to follow conversation, but you may be fine talking to one person face to face.

To learn about communication tips and strategies, please refer to our Information sheet on the topic. It is available from the Alzheimer Society or on-line at www.alzheimer.ca.

Difficulty performing tasks

You may find yourself getting frustrated trying to do things you used to be able to do, like following a recipe, using woodworking or craft tools, turning on the correct burner on the stove or balancing a chequebook.

Disorientation or confusion about time and place

You may find yourself becoming confused about time and place. For example, you may show up to church an hour early. Or, you may be walking in a familiar neighbourhood or taking your normal route home and suddenly forget where you are.

Visual perception problems

With visual perception problems, you may be looking straight at an object, but you cannot identify it. For example, with money, you may have difficulty telling one coin from another.

Spatial perception problems

With spatial perception problems, you may have difficulty walking up and down stairs because you are misjudging the height of the stairs or the distance between them.

Poor or decreased judgment

When judgment is affected in Alzheimer's disease, you may choose clothing that is not appropriate for the weather, or not understand why it may not be safe for you to continue driving.

Changes in mood and behaviour

It is natural to feel anxious, irritable and moody at times as you cope with the changes in your skills and abilities. These mood swings can be unsettling for you and those around you. Some people may also find that their personality is changing. As one person describes it, “You don’t smile like you used to.”

Changes in physical abilities

In addition to the changes in mental abilities, Alzheimer’s disease can affect your physical co-ordination. For instance, you may not be able to get your arm into a shirt sleeve. As the disease progresses, there will be more physical decline.

Some suggestions for adjusting to changing abilities

One way to cope with the changes is to focus on what you are still able to do, and to continue to participate in activities that are meaningful to you. There may come a time when you will have to accept help from family members and friends. If you let them know what is needed, they can help you maintain your independence.

Talking to others:

- Take your time.
- Tell people you have a problem with thinking, communicating and remembering.
- If you did not understand a statement, ask them to repeat it.
- It is okay to ask over and over again.
- If too many people or too much noise bothers you, find a quiet place.
- If you lose a thought, let it go – it is okay if you forget it – it may come back.

Memory loss:

- Keep a memory book of important things and keep it with you at all times. This book can be kept in a pocket or purse. It may contain:
 - Important phone numbers, including your own and ones that may be needed in an emergency
 - People's names
 - A list of things to do
 - Appointments
 - A map showing where your home is
 - Any thoughts or ideas you want to hold on to

You may also want to consider the use of an electronic device such as a mobile phone to help with the above.

- Label cupboards and drawers with words or pictures that describe the contents, for example, dishes, knives and forks.
- An answering machine is useful to keep track of telephone messages.
- Get a remote control for the TV that has large and easy to read numbers.
- Telephone numbers written in large print and posted by the telephone can be helpful. Include emergency numbers, as well as a description of where you live.
- You may find it helpful and comforting to have a friend, relative or volunteer call to remind you of meal times, appointments or when to take your medication.
- Keep a collection of snapshots of those people you see regularly. Label the photos with their names and what they do.
- Marking off days on a calendar is a way of keeping track of time. You may find it easier to get help from someone with crossing off the days.

- You can find pill boxes in pharmacies that will help you organize your medications. They will also remind you when to take your pills.
- Keep in mind there will be days that are better than others. Do what you can in a given day.

Finding your way:

- Don't be afraid to ask for help.
- Explain to people that you have a memory problem and need assistance.
- Carry a business card that says you have Alzheimer's disease.
- Take someone with you when you go out.
- When you think you are lost, go to the nearest house or store for help.
- Don't keep trying to find your way.
- Consider registering the person with the disease with the MedicAlert® Safely Home® program to assist emergency responders to identify the person who is lost and bring the family back together. For more information on the program, contact your local Alzheimer Society, visit www.medicalertsafelyhome.ca or call MedicAlert® Safely Home® at 1-855-581-3794.

We asked people living with Alzheimer's disease for their advice on how to adjust to changing abilities. Some of the following suggestions may work for you and some may not. Here are some of their suggestions:

"Write things down in a notebook when you are in a conversation."

"Use Post-it notes."

"Do one thing at a time."

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“Use loud, noisy timers to remind you that you have something on the stove.”

“Take your time and tell others to give you time.”

“Don’t be shy to ask for help.”

“Keep busy. Find things to do that you enjoy.”

“If you no longer enjoy reading, try talking books, CDs and DVDs.”

“If church services are too crowded, find out which services have less people.”

“Join a support group. You can talk about your experience with others. It reduces the isolation.”

Add tips that work for you:

Driving and Alzheimer’s disease

Alzheimer’s disease gradually affects the skills and abilities needed for driving:

- Memory
- Judgment
- Visual perception
- Spatial perception
- The ability to read signs
- The ability to understand directions
- Orientation (a sense of place/time)
- Physical co-ordination

Depending on your symptoms and how far they have progressed, you may still be able to drive safely - for now. Perhaps you have adjusted your driving habits to travelling shorter distances or only during the day. As your mental and physical abilities decline, your driving ability will also decline.

Signs that driving abilities are declining:

- Traffic violations
- Accidents
- Getting lost
- Taking too long to reach a destination
- Misjudging distances
- Forgetting the rules of the road
- Slow response times

At some point, it will no longer be safe for you to drive. By that time, the disease may have affected your ability to understand why you have to give up driving. If you are still driving, ask someone you know if he or she has noticed changes in your driving. Arrange for a driver's test if you are not sure if you should continue to drive. As the disease progresses, you may need to be re-tested. Start thinking now about alternatives, such as asking family members and friends to drive you where you need to go, or using public transit and taking taxis.

Giving up driving may be one of the most stressful events you experience, but, in the end, the privilege of driving has to be measured against your safety and the safety of others.

Additional resources

For more information on adjusting to changing abilities, please refer to the following print materials. These are available from the Alzheimer Society or visit on-line at www.alzheimer.ca.

- Quality of life
- Communication
- Driving
- Progression series