

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 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 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.

Table of Contents

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:

Section 1: Experiencing a variety of emotions	5
Section 2: Telling people.....	9
Section 3: Learning about the disease	14
Section 4: Changes you may experience.....	19
Section 5: Continuing to care for myself	26
Section 6: Planning for the future	31

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:

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

section 1 Experiencing a variety of emotions

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.

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?

section 2 Telling people

Add some other questions you would like to ask:

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.

- *Alzheimer's disease: First steps for families*
- *Alzheimer's disease: Ways to help*
- *Just for Kids: Helping children understand Alzheimer's disease and other dementias*
- *Focus: Helping teens understand Alzheimer's disease*

Learning about the disease

Learning what you can about Alzheimer's disease and how it progresses may help you adjust to the changes that you are experiencing. The changes are due to the disease; they are not your fault. Some of what you learn may be overwhelming. Learn only as much as you feel you can. Encourage your family members and friends to also learn about Alzheimer's disease. Your family doctor and the local Alzheimer Society are good sources of information.

Some questions you may have about Alzheimer's disease

What is Alzheimer's disease?

Alzheimer's disease is the most common of a large group of disorders known as "dementias." It is a disease of the brain, characterized by deterioration of thinking ability and of memory, caused by the progressive degeneration of brain cells. The disease also affects mood and emotions, behaviour and one's ability to perform activities of daily living. There is no cure for Alzheimer's disease at present nor can its progression be reversed. However, current treatment options and lifestyle choices can often significantly slow the progression of the disease. Other dementias include Vascular dementia, Frontotemporal dementia, Creutzfeldt-Jakob disease and Lewy body dementia. For more information on other dementias, contact the Alzheimer Society or visit our website (www.alzheimer.ca).

What causes Alzheimer's disease?

We do not yet know what causes Alzheimer's disease but researchers have identified risk factors associated with it.

Age: Alzheimer's disease usually affects people over the age of 65, although people may be diagnosed at an earlier age. The older you are, the greater the risk.

Family history: People with a parent, brother or sister with Alzheimer's disease may have a slightly greater chance of developing the disease than those with no family history.

Other factors: Research is being done on other factors such as existing diseases or conditions that the person may have, infections, toxins in the environment, education level, alcohol and tobacco use, diet and exercise.

Are there treatments for Alzheimer's disease symptoms?

Several medications are now available to treat some of the symptoms of Alzheimer's disease. These medications seem to slow down the decline in memory, language and thinking abilities. The treatments work for some people. These drugs are not a cure for the disease. They do not stop its progression. Ask your doctor what is available, and if there is a treatment suitable for you.

Why did I get Alzheimer's disease?

There is no easy answer to this question. Researchers do not know the cause of Alzheimer's disease. They do not know if it is caused by a single factor or a combination of factors.

Will my children get Alzheimer's disease?

The majority of people with the disease have a common form called sporadic Alzheimer's disease. Researchers are trying to determine what role heredity plays in this form.

A very small percentage of people have an inherited form of the disease. This rare form is called familial autosomal dominant Alzheimer's disease. In certain families, it passes directly from one generation to another. Having more than one family member with Alzheimer's disease does not necessarily mean that your family has the inherited form.

Is there genetic testing for Alzheimer's disease?

Genetic testing for the disease is not widely available in Canada. It is usually limited to people with a strong family history of the disease who are enrolled in specific research studies. Some testing is also done on referral from a family physician. You cannot request genetic testing on behalf of another family member.

How does Alzheimer's disease progress?

While the progression of the disease varies from person to person, it usually follows some predictable stages. The average length of the disease is between seven to 10 years, but some people may have it for a longer or shorter time.

To learn about how Alzheimer's disease progresses, please refer to our Progression series (Overview, Early stage, Middle stage, Late stage, End of life). It is available from the Alzheimer Society or on-line at www.alzheimer.ca/stages.

How do I live with Alzheimer's disease?

Keeping stimulated, maintaining a healthy lifestyle, living one day at a time, and doing the things that you enjoy are just some of the ways to live well with Alzheimer's disease.

While abilities will change as the disease progresses, learning to adapt to changes can help to maintain your quality of life for as long as possible. Many people are ready and willing to offer you support – family members, friends and your local Alzheimer Society.

Practical tips for daily living with Alzheimer's disease

We asked people living with Alzheimer's disease for some practical tips for daily living. Here are some of their suggestions:

“Do one thing at a time.”

“Write things down.”

“Follow routines.”

“Stay away from large crowds.”

“Avoid overstimulation.”

“If you forget something, don't dwell on it.”

“If you are having problems with one activity, try something else.”

“Ask someone to help.”

“Use a dispenser for pills.”

“Set the timer when using the stove or oven.”

section 3 Learning about the disease

Add tips that work for you: _____

Additional resources

To learn more about Alzheimer's disease, please refer to the following print materials. These are available from the Alzheimer Society or visit our website at www.alzheimer.ca.

- *What is Alzheimer's disease?*
- *Risk factors*
- *Understanding genetics and Alzheimer's disease*
- *Progression series*

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."

section 4 Changes you may experience

“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

Continuing to care for myself

Alzheimer's disease research

Several medications are now available to treat some symptoms of Alzheimer's disease. These medications can slow down the decline in memory, language and thinking abilities. The treatments work for some people. These drugs are not a cure for the disease. They do not stop its progression. Ask your doctor what is available and if there is a treatment suitable for you.

Experimental drugs and therapies

Other drugs and therapies are also being tested for the treatment of the symptoms of Alzheimer's disease. Your local Alzheimer Society should have information on clinical drug trials and other research taking place in your area. Clinical trials study the safety and effectiveness of new drugs or treatments by testing them on people who volunteer to participate in the studies.

What is happening in Alzheimer's disease research?

Scientists in Canada and around the world are working hard to figure out the causes of Alzheimer's disease so they can develop effective treatments and, ultimately, a cure. Among other things, they are investigating ways to:

- Replace lost nerve cells with cells from bone marrow
- Develop a vaccine to prevent the build up of toxic plaques in the brain
- See if non-steroidal anti-inflammatory drugs can prevent or delay Alzheimer's disease by decreasing inflammation in the brain

Researchers are also trying to understand the psychological and social effects of the disease on individuals and families.

We do not know what the next major research breakthrough will be or how soon it will happen. But there is optimism for major successes in Alzheimer's disease research, if not for the people who have already been diagnosed, then for their children and the next generation.

Participation in research

If you are interested in participating in research, your local Alzheimer Society can give you information on some things to consider. Research participation is also something to discuss with the family members who will be closely involved in your care, since they are the ones who may have to weigh the risks and benefits of your continued participation in research as you progress through the disease.

Healthy living

There is no way to stop the progression of Alzheimer's disease. There are, however, many things you can do to maintain a healthy lifestyle. Eating a well-balanced, nutritious diet is extremely beneficial and provides the fuel and nutrients that our bodies need to function efficiently, maintain general health and provide energy.

Physical activity can help you feel better, reduce stress and maintain health. Choose physical activities that you enjoy and make them part of your daily routine. Ask your doctor what types of activities you can do to keep active.

Stay connected

It is easy to become isolated and lonely when living with Alzheimer's disease. Stay connected with family and friends. Finding opportunities to interact with the people around you will help you stay engaged. Talking to someone you trust about your feelings, your hopes and worries or simply sharing a good laugh can provide the support and encouragement you need.

Meaningful activities

Things that were important and meaningful for you throughout your life will still continue to be. If you enjoyed cooking, gardening, fishing or sports, continue making them a part of your everyday routine. You can also take pleasure in living in the moment, appreciating the small joys of life, such as seeing flowers coming into bloom, watching birds at a feeder and pushing a child in a swing. Capture these moments and enjoy them.

Visit your physician

See your doctor regularly for check-ups and to address specific health concerns. Take your medications as prescribed.

Safety

The gradual loss of memory and the difficulties with decision-making and communication often raise concerns over safety. The following are a few suggestions to keep you safe, especially if you live alone.

- Contact your local Alzheimer Society for resources available in your community.
- Talk to your doctor about getting assistance in the home with things like housekeeping, meal preparation, transportation, etc.

- Some banks have “bank at home” services that may be helpful. If yours does not, let the bank manager know you have Alzheimer’s disease and that you have difficulty keeping track of your banking. He or she can help you.
- Arrange for direct deposit of cheques such as Old Age Pension or Canada or Quebec Pension to your account.
- Meals on Wheels can ensure a good meal is delivered to your home once a day. Fresh fruit and vegetable baskets and frozen meals are also often available.
- Have a family member sort out your closet and dresser drawers to make it easier for you to choose what to wear.
- Leave a set of house keys with a neighbour you trust.
- Use a toaster oven or microwave, if you are familiar with using one, rather than the stove.
- Leave written reminders to yourself like “turn off the stove” or “unplug the iron.” Make sure they are placed where you will see them often.
- Have family or friends arrange for a daily call-in or visit. Some communities have a service that will do this.
- Talk with someone about sorting and securing items that could be mistaken for something else (e.g. cleaning fluids could be mistaken for something to drink, or nail polish can be mistaken for eye drops).

Staying alone

The person you live with may worry about leaving you alone for a long period of time. While you may feel you will be fine alone, having a companion may help the time pass more pleasantly and decrease the worry for everyone.

Electrical appliances

If there are certain appliances you use frequently, you may want to ensure they all have automatic shut-offs.

Smoke detectors

Every home should have a smoke detector on each level. Ensure that your home does. A smoke detector could save your life in case of fire.

Dealing with people you do not recognize

If someone comes to your door that you do not recognize, ask for their name and telephone number instead of letting them in. You or your family member can call them back later.

Additional resources

For more information on treatment options, maintaining health and wellness, and safety, please refer to the following print materials. These are available from the Alzheimer Society or visit on-line at www.alzheimer.ca.

- *How drugs are approved in Canada*
- *Treatment options*
- *Long-term care*
- *Living alone*
- *Driving*
- *Heads up for healthier brains*
- *Safety*
- *By Us For Us (BUFU) Guides* - created by people with dementia and/or caregivers - *Enhancing Wellness* and *Memory Workout*

Planning for the future

Planning for the future is one of the positive steps you can take to help you and your family prepare for the challenges that having Alzheimer's disease will bring.

You may still be independent, but as the disease progresses, your ability to make your own decisions will decline. Talk to family members, close friends and health-care professionals now about your needs and wishes for the future.

Topics to discuss

- Work, retirement and volunteer activities
- Money and legal matters
- Living arrangements
- Health-care and personal care planning

Speaking about these matters now gives everyone an opportunity to bring their concerns out into the open and develop some solutions. This can help to reduce potential conflicts in the future. Planning for the future may bring you comfort in knowing that you will have some control over your life and quality of life as the disease progresses, and that your wishes are known by the people who will be making decisions on your behalf when you are no longer able to. It may also reassure all those involved that decisions made respect your wishes and needs and honour your personal values and beliefs.

Work, retirement and volunteer activities

If you are still working, consider talking to your employer about Alzheimer's disease and your symptoms. Before doing so, be aware of your employment rights and options. Do not quit work until you have been fully assessed and can make choices and access employee benefits where available based on a correct diagnosis. Cutting down on your hours and responsibilities may be an option, or you may have to stop working. If you own your own business, you will want to plan for its future.

Volunteering may give you an opportunity to continue using your skills and participate in activities that you have always enjoyed.

Money and legal matters

Talk to your family. Make sure your money matters will be in the hands of someone you trust —a family member or close friend.

You may wish to arrange for a trusted relative or friend to be authorized to legally make financial decisions on your behalf once you are no longer able to. This person may be called a power of attorney or representative. Terms and legal requirements vary by province. Talk to a lawyer about naming someone to look after your financial interests.

Pull together all of your legal and financial documents such as bank accounts, mortgages, insurance policies, pension plans, RRSPs, investments, ownership of home, car, real estate, and business. Putting someone you trust in charge of these documents now helps protect your assets later. Make a will, if you have not done so already.

Living arrangements

For now, you may be living on your own, with a family member or with a close friend, and may need little or no assistance with daily living. As Alzheimer's disease progresses, you will find that you need help with activities such as cooking, housekeeping, shopping and transportation. Talk to family members and friends to see who would be able to help you with these tasks.

section 6 Planning for the future

Your local Alzheimer Society can provide information and referrals to community and social services that are available in your area.

As your abilities change, there may also have to be changes in your living arrangements. Perhaps a family member could come to live with you. Or, you could move to live with someone else.

There may come a time when you need to be in a safer environment or require more assistance with daily living. There may be options in your community such as live-in companions, assisted-living homes, supportive housing, retirement and long-term care homes. Find out what is available. Arrange a visit. Go with a family member or friend and ask questions.

Some questions to ask

Is the residence Alzheimer-friendly?

- Are staff members trained to care for people with Alzheimer's disease?
- Can you walk safely indoors and outside?
- Does it have a home-like environment?
- Are the rooms private or shared?

What is the care philosophy of the residence?

- Does it focus on the person's needs?
- Can it accommodate your personal preferences for food, routines and activities?

What kind of medical care does the residence provide?

- Can you continue to see your own doctor?
- Is there a doctor on call?
- How often does the doctor visit?
- Can you meet the doctor?
- How are medical emergencies handled?

What kind of personalized care is available?

- Can you choose menus?
- Can you bring your pet?
- Can you bring your own furniture?
- Is there a hairdresser that comes into the home?

Changes to the living environment can be stressful for everyone concerned. Looking into the options now and discussing the choices ahead of time can help relieve some of the stresses of decision-making.

Health-care and personal care planning

Just as you can name someone to look after your financial interests, you can also name someone to make health-care decisions for you when you are no longer able to do so. This person may be called a substitute decision-maker or power of attorney and may or may not be the same person helping you with your finances. Terms and local requirements vary by province. Contact your local Alzheimer Society for more information.

Let the person know that you have chosen him or her to act on your behalf on matters relating to your health and personal care. Topics to be discussed may include medical treatments, caregiving options, housing options, and end-of-life care.

Why is this important to discuss now?

As the disease progresses, your substitute decision-maker will have to make decisions about your care. For most people, making decisions on behalf of someone else is difficult. By talking to your decision-maker now about what level of care you do and do not want in the future, you may reduce the person's anxiety when it is time to make those choices. You will also have the comfort of knowing that your future care will be in good hands and that your wishes will be respected.

If you think it would be helpful, write down your wishes. Some provinces have legally-recognized documents in which you can set out the type of care you wish to receive. The name and wording of the document varies from province to province. Your local Alzheimer Society can help you find out if your province has legal documents regarding planning for future health-care.

Even if you choose not to write things down or draw up a legal document, talk about these matters. Your verbal wishes can be just as valid. Let those closest to you know what you want and what you do not want for your future health and personal care.

When planning for the future and discussing health-care options with your family and substitute decision-maker, you may want to discuss your options with your physician care team.

There are three main categories of treatment: extraordinary medical care, conservative medical care, and comfort or palliative care.

Extraordinary medical care

In extraordinary medical care, the goal is to prolong life using all available types of treatment. This could include using kidney dialysis for kidney failure, tube feeding when swallowing is no longer possible, or cardiopulmonary resuscitation (CPR) to restart the heart.

Conservative medical care

With conservative medical care, the goal is to maintain or improve the current state of health. This could include using blood pressure medication to treat high blood pressure, insulin for diabetes, or setting a fractured hip.

Comfort or palliative care

The goal of comfort or palliative care is to give comfort when there is no treatment for an illness and death is near. Pain control is a priority, as is emotional and spiritual support for the person and his or her family.

More than anything else, planning for the future is about communication. Talk to the people who are going to be involved in your care – whether it be your husband, wife, son, daughter, another family member, close friend, doctor or the members of your health-care team.

Additional resources

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

- *Decision-making: Respecting individual choice*
- *Ways to help: Assisting families living with Alzheimer's disease*
- *Dementia and end-of-life care available at www.alzheimer.ca/endoflife*

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



Alzheimer *Society*

Alzheimer Society of Canada
20 Eglinton Avenue West, 16th Floor, Toronto, Ontario M4R 1K8
Tel: (416) 488-8772 1-800-616-8816 Fax: (416) 322-6656
Email: info@alzheimer.ca Website: www.alzheimer.ca

Facebook : www.facebook.com/AlzheimerCanada
Twitter : www.twitter.com/AlzCanada

Charitable registration number: 11878 4925 RR0001