

Alzheimer's disease:
A Handbook
for Care



Alzheimer *Society*

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Introduction

This handbook is for you - a person who is taking care of someone with Alzheimer's disease. Finding out that someone close to you has Alzheimer's disease can be overwhelming, for this is a devastating disease with no known cure. It is really important for you to know that there are things that can be done to make life easier. There is information to help you to understand the disease and to give care. There are people and services in your community to provide you with help and support.

You may be caring for your husband or wife, mother or father, sister or brother, your neighbour, or a friend. In this handbook, we refer to you as the "caregiver." We also refer to the person with Alzheimer's disease and professionals as "he" or "him." This does not mean that men get Alzheimer's disease more than women, or that all professionals are men. Using one term throughout makes for easier reading.

This handbook provides a person-centred approach to care. Person-centred care is a philosophy that recognizes that individuals are unique with personal values, unique history and personality and that each person has an equal right to dignity, respect, and to participate fully in their environment. Person-centred care focuses on individuals as whole persons rather than tasks. This holistic approach to care takes into account the specific needs and preferences of each person; it is grounded in mutually beneficial partnerships established between people living with dementia and their caregivers. Person-centred care is founded on an interactive process, in which people with dementia are active participants in their own care throughout the various stages of the disease and family members play a vital role in ensuring the health and well-being of their relative.

This handbook does not replace the services of a doctor or other trained health professional. You need to get the advice and support they can provide.

We hope you will find the information in this book helpful. We also hope that the ideas and suggestions will help you start thinking of your own ways of giving care and taking care of yourself. You know the person you care for and yourself best.

Chapter 1: 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 an irreversible disease of the brain in which the progressive degeneration of brain cells causes thinking ability and memory to deteriorate. Alzheimer's disease also affects behaviour, mood and emotions, and the ability to perform daily living activities.

There is currently no cure for Alzheimer's disease, but there are treatment options and lifestyle choices that can slow its progression. Also, the pursuit of new research strategies should one day help restore some lost function and memory.

Alzheimer's disease progresses through early, middle and late stages before reaching the final end of life stage. However, identifying the transition from one stage to another is often difficult. Not only does the disease usually progress slowly, but the symptoms related to each stage tend to overlap and the order in which they appear and how long they last varies from person to person.

The duration following diagnosis is usually seven to 10 years. However, when the diagnosis is delayed, as it may be if the affected person does not see a doctor early on, the disease duration may seem shorter than this. Conversely, as the ability to diagnose Alzheimer's disease improves and people become more willing to be assessed, survival times following diagnosis are lengthening.

"Other dementias" resemble Alzheimer's disease in that they also involve a progressive degeneration of brain cells that is currently irreversible. They include the dementia associated with Vascular dementia (the second most common dementia after Alzheimer's disease), Frontotemporal dementia or Pick's disease, Creutzfeldt-Jakob disease, Lewy body dementia, Parkinson's disease, Huntington disease, and others.

Brain function

The brain is the control centre for your whole body.

It has two very important roles:

- To make sense of information from the outside world, and
- To send messages to your body to make it behave in certain ways

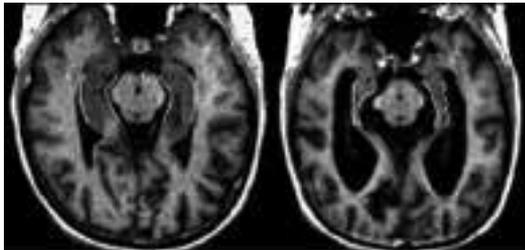
For example, if you are near a fire, the sensors in your eyes, ears, nose, and skin will send signals to your brain. Your brain will interpret these signals, and you will realize that a fire is nearby. Then, you will use your brain to think and to decide what is best to do. You may use your memories about how dangerous fire is, or how to put out fires, or how to call the fire department. You will also think about the different options available, and determine which is the safest. Then, by using your brain to send messages to your legs, arms, voice box, or whatever, you will take some kind of action.

Effects of Alzheimer's disease

In Alzheimer's disease, forgetfulness gradually increases, and in the later stages even close family members may not be recognized. The ability to carry out normal activities such as reading, driving, and cooking gradually decreases, as does the ability to make judgments and appropriate responses to everyday issues. There can also be behavioural changes such as agitation, aggression, depression, disturbances of balance and movement, and an inability for people to find their way even in familiar surroundings. In time the affected persons become unable to look after themselves and caregivers become essential for all aspects of daily living. Alzheimer's disease is ultimately fatal, and death usually occurs within seven to 10 years after diagnosis. Inactivity and muscle wasting weaken the body, and a lowering of the body's immune functions makes bacterial and viral infections very common. This leads to the usual cause of death, pneumonia, hastened by the decreasing ability to cough and generally to move about normally.

Brain changes

The disease was first identified by Dr. Alois Alzheimer in 1906. He described the two hallmarks of the disease: “plaques” - numerous tiny dense deposits scattered throughout the brain which become toxic to brain cells at excessive levels and “tangles” which interfere with vital processes eventually “choking” off the living cells. As well, when brain cells degenerate and die, the brain markedly shrinks in some regions.



The image above shows a person with Alzheimer’s disease has less brain tissue (right) than the person who does not have the disease (left).

As Alzheimer’s disease progresses and affects different areas of the brain, various abilities become impaired. The result is changes in abilities and/or behaviour. At present, once an ability is lost, it is not known to return. However, research is now suggesting that some relearning may be possible.

WHAT ARE THE RISK FACTORS FOR ALZHEIMER’S DISEASE?

While the specific cause or the cure for Alzheimer’s disease is not known, the disease appears to develop when the combined effects of certain risk factors reach a threshold level. Many of these risk factors are known but there are likely others that are yet to be identified. When the threshold level is reached, the brain’s ability to repair and maintain itself is overwhelmed, and the disease process begins.

Risk factors increase the chances of getting Alzheimer's disease. Age and genetics are two risk factors that can not be changed. However, it may be possible to reduce many of the other known risks for the disease through lifestyle choices.

Age - Advancing age is the most significant risk factor for Alzheimer's disease. Most people who develop Alzheimer's disease are over the age of 65. However the disease process is thought to begin years before cognitive and memory impairments are apparent. It is important to remember that most people do not get Alzheimer's disease as they age. It is not a normal part of aging. Whatever other risk factors are present, Alzheimer's disease never sets in until some minimum adult age is reached.

Genes - The familial form of the disease (FAD), passed on directly from generation to generation, accounts for only about seven per cent of the total incidence of Alzheimer's disease. While the common form of the disease (sporadic Alzheimer's disease) also has some genetic links much is still unknown. The majority of cases have no single identifiable cause. The role of genetics continues to be studied.

Other risk factors include:

- Unhealthy eating habits
- Diabetes
- High blood pressure
- High cholesterol levels
- Strokes
- Obesity
- Stress
- Chronic inflammatory conditions
- History of clinical depression
- MCI (mild cognitive impairment)
- Low levels of physical activity
- Low socio-economic status
- Inadequate exercising of the brain
- Low levels of formal education
- Brain injury
- Smoking

WHAT ARE THE WARNING SIGNS OF ALZHEIMER'S DISEASE?

Usually, the first signs of Alzheimer's disease are subtle changes. To help you know what warning signs to look for, the Alzheimer Society has developed the following list:

1. **Memory loss that affects day-to-day function.** It's normal to occasionally forget appointments, colleagues' names or a friend's phone number and remember them later. A person with Alzheimer's disease may forget things more often and not remember them later, especially things that have happened more recently.
2. **Difficulty performing familiar tasks.** Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them at the end of a meal. A person with Alzheimer's disease may have trouble with tasks that have been familiar to them all their lives, such as preparing a meal.
3. **Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute words, making his sentences difficult to understand.
4. **Disorientation of time and place.** It's normal to forget the day of the week or your destination - for a moment. But a person with Alzheimer's disease can become lost on their own street, not knowing how they got there or how to get home.
5. **Lapses in judgment.** People may sometimes put off going to a doctor if they have an infection, but eventually seek medical attention. A person with Alzheimer's disease may have decreased judgment, for example not recognizing a medical problem that needs attention or wearing heavy clothing on a hot day.
6. **Problems with abstract thinking.** From time to time, people may have difficulty with tasks that require abstract thinking, such as balancing a cheque book. Someone with Alzheimer's disease may have significant difficulties with such tasks, for example not recognizing what the numbers in the cheque book mean.

7. **Misplacing things.** Anyone can temporarily misplace a wallet or keys. A person with Alzheimer's disease may put things in inappropriate places: an iron in the freezer or a wristwatch in the sugar bowl.
8. **Changes in mood and behaviour.** Everyone becomes sad or moody from time to time. Someone with Alzheimer's disease can exhibit varied mood swings -- from calm to tears to anger -- for no apparent reason.
9. **Changes in personality.** People's personalities can change somewhat with age. But a person with Alzheimer's disease can become confused, suspicious or withdrawn. Changes may also include apathy, fearfulness or acting out of character.
10. **Loss of initiative.** It's normal to tire of housework, business activities or social obligations, but most people regain their initiative. A person with Alzheimer's disease may become very passive, and require cues and prompting to become involved.

These changes do not happen overnight. Changes in behaviour are usually quite gradual and may go on for a while before they are noticed.

HOW DO DOCTORS KNOW IF SOMEONE HAS ALZHEIMER'S DISEASE?

Ruling out other causes

There is currently no single test that can tell if a person has Alzheimer's disease. The diagnosis is made through a systematic assessment which eliminates other possible causes such as:

- Depression
- Conditions like thyroid disease, heart disease, or a stroke
- Infections
- A reaction to medication, both prescription and over-the-counter drugs
- Alcohol abuse

Finding out the cause of the symptoms can help people understand the source of the symptoms, get the proper care, treatment and support and plan for the future.

The earlier a treatment can be given, the better the result - and new treatments are on the way.

Until the time when there is a conclusive test, doctors may continue to use the words "probable Alzheimer's disease;" however, you should be aware that doctors making this diagnosis are accurate 80 to 90 per cent of the time.

Getting a history: Asking questions

You, the caregiver, are very important in helping the doctor make the diagnosis. The doctor needs to get as much information as possible about the person's behaviour now and in the past. Jot down the things you wish to remember to tell the doctor. A description of the changes you have noticed is often the key to a good diagnosis.

Be prepared for many questions. You will be asked for details about the person's life. The medical history of both the individual and the family is important information. The doctor will also want to know when the problems began, and whether things are getting better or worse. You may be asked for examples of some of the changes you have noticed. Even if these questions seem very personal to you, it is very important that the doctor gets the full picture. If the changes have not been going on for very long, your doctor may ask you to come back in a few months. By then you may have a better understanding of how the person's behaviour is changing.

Testing and consultation

The doctor will examine the person, and send him for many tests. These will include X-rays and blood tests. The doctor will ask him to remember and recall words, to read and write, or to do simple arithmetic. If the doctor is not certain after all of these tests, he may send the person to one or more specialists. The specialist might be a psychiatrist, a neurologist, a geriatrician, or a psychologist.

After reviewing all of this information, your doctor will decide if it is likely that the person you are concerned about has Alzheimer's disease.

WHAT ARE THE EFFECTS OF ALZHEIMER'S DISEASE?

Alzheimer's disease is a fatal disease which eventually affects all aspects of a person's life: how he thinks, feels, and acts. Each individual is affected differently. It is difficult to predict which symptoms he will have, the order they will appear, or the speed of their progression. The following are some of the changes you may expect as the disease progresses.

A person with Alzheimer's disease will still be able to hear, respond to emotions, and be aware of touch.

Changes in cognitive and functional abilities

Alzheimer's disease affects a person's ability to understand, think, remember, and communicate. At first you may not be aware of the small subtle changes. You will notice that the person gradually becomes unable to learn new things and make decisions. He will forget how to do the simple tasks he has done for years. He will have trouble remembering people's names, where he is, or what he was about to do. He will have difficulty understanding what is being said and making himself understood. He may continue to remember past events clearly. Eventually all the difficulties increase, and the past is forgotten.

Changes in emotions and mood

A person with Alzheimer's disease has less expression, is less lively and more withdrawn. At the same time, he loses the ability to control his moods and emotions. These may vary, change rapidly and become harder to predict. Sometimes he may become sad, angry, laugh inappropriately, or worry a great deal over small things. At other times he may be suspicious of people close to him. It may seem that his whole personality has changed. Eventually, he will appear to have little or no reaction at all to people or his surroundings.

Changes in behaviour

The changes in mental abilities and moods will result in changes in behaviour. The kinds of behaviour affected change and the length of time they are present are different for each person. Any

behaviour will be greatly influenced by the individual's physical abilities. Behaviours may include: pacing, repetitive actions, hiding things, constant searching, undressing, disturbed sleep, physical outbursts, restlessness, swearing, arguing, and inappropriate sexual advances. It is important to know that these changes in behaviour are not intentional. They are caused by the disease.

Changes in physical abilities

Changes in the brain of a person with Alzheimer's disease also result in decreased physical ability. You may see a difference in the way he moves and in co-ordination. Over time, he will have difficulties eating, dressing, or bathing himself. Bladder and bowel control will be lost. Eventually, he will be dependent on others for his care.

The type of change and the speed at which the disease progresses is different for each person. There is no way to know how long a person will be able to dress himself, or when, if ever, he will need to be in a nursing home. The disease may progress quickly in some people, while others have many years during which they can live relatively normal lives.

THERE IS HELP

There is a growing body of knowledge that can help you care for the person with Alzheimer's disease. Learning continues everyday, as both families and professional caregivers increase their understanding of the disease and its effects.

Chapter 2 gives some advice about how to care for a person with Alzheimer's disease. In Chapter 3, you will find suggestions about how to take care of yourself.

There is no doubt that caring for a person with Alzheimer's disease can be frustrating and difficult. Your experience can be made easier if you have information and support. Your local Alzheimer Society is available to help.

There is help available. Please call your local Alzheimer Society (see back cover for list of Alzheimer Societies across Canada). You are not alone.

Chapter 2: Caring for someone with Alzheimer's disease

Taking care of someone with Alzheimer's disease is not an easy task. It is important to try to understand the disease and its effects on a person's behaviour. Then, even if his actions may seem out of place to you, you may realize that they make sense to him. For example, if he throws his dishes in the garbage, it may be because he is trying to get rid of something dirty. He is trying to help and no longer understands that this is not appropriate. Although taking care of someone with Alzheimer's disease can be difficult, it can also be rewarding. Solving problems and becoming confident in knowing how to give care can provide you with a great sense of satisfaction.

MORE THAN PHYSICAL CARE

Most people think first about the physical care which the person with Alzheimer's disease will need. Though that is extremely important, the emotional and spiritual sides of a person's nature also need care and nourishment.

The person

"...people do not consist of memory alone. People have feelings, imagination, drive, will and moral being." O.Sacks

A person with Alzheimer's disease does not stop needing what made him feel happy and contented in the past. He needs to stay in contact with family and friends. He needs to feel secure and comfortable at home. If poetry, music, or walking in the woods were enjoyable and satisfying, then they should still remain part of his life.

Dignity

Everyone deserves to be treated with dignity and respect. Often respect is measured in little things, such as the way you help a person get dressed, how you take him to the toilet, or whether or not you talk about him to others when he is still in the room. We all need to remember how important these things are.

Spirituality

For many people, spirituality is an important component of their identity. Spirituality is not confined to religious beliefs and observance, although religion may be an important part of the person's spiritual life. Tapping into the spiritual traditions which have been a significant part of the person's life can provide solace, continuity and a sense of self.

There are many different ways to express spirituality (meditating, listening to music, praying, gardening, etc.) and you should encourage him to express himself in his own unique way.

The use of icons or symbols can be an important part of his life and brings reminders of his faith or beliefs and these should be accommodated if possible. Attending religious ceremonies or contacting his previous spiritual community should be available and organised if required.

Expressing spirituality through art, music, dance or poetry is encouraged. Reading excerpts from favourite books can trigger memories and connect with a person at a deeply emotional level when cognitive abilities have been severely impaired.

Also, for many people, connecting to nature, petting dogs or cats, or spending time in the garden can be comforting moments and pleasurable ways to help fill the person's spiritual needs.

How relationships change

Alzheimer's disease does not change the need for companionship, friendship, love and affection, but it does change many aspects of all relationships. You will lose the companionship of someone who has been close and important to you. It will be necessary to find different ways to express your feelings.

Alzheimer's disease can also affect the sexual relationship of partners. It can change a person's interest in sex: either increasing or decreasing it. This may create a problem. For example, the person may put demands on his partner for more sex than is wanted.

The physical ability to have sex is often also affected. Both men and women can have trouble if the disease has made them uncoordinated. For a man, the inability to have an erection can be a problem. In both cases, this can be quite distressing. Both partners need comfort and reassurance.

A person with Alzheimer's disease may be overly affectionate at the wrong time or place or to the wrong or inappropriate person. This can be embarrassing. If this happens, explain the disease and its effects to the people involved so that they will understand.

As the disease progresses, people with Alzheimer's disease may no longer be able to recognize their partners. The partners will need a lot of support and understanding. If the person with Alzheimer's disease chooses a new partner, it is important to ensure that those involved agree to the relationship, whatever form it takes.

Some partners of people with Alzheimer's disease may want to meet their companionship and physical intimacy needs with someone else, especially if the partner is no longer recognized. If so, they will need support and understanding to work through their feelings and to find ways of meeting their needs that make them comfortable.

At a later stage of the disease, you might make the decision to move the person you have been caring for to a care home. This may be one of the most difficult decisions you will have to make. However, it may also be one that is necessary, both for your well-being and that of the person you are caring for. It will take time for both of you to adjust to this new situation. Remember you have not lost your role as caregiver; you are now sharing the responsibility of care with others.

If any problems with your relationship become difficult to handle, discuss them with someone. You could talk with a family member, a friend, the people in a support group, or with a professional. Problems with relationships are common. Support and understanding from others can make a difference.

COMMUNICATING IS THE KEY

Communicating with the person with Alzheimer's disease is a challenge. In order to keep him in touch with the people around him, you will have to try to focus on his remaining abilities.

Knowing how to communicate is important. You need to use different ways of getting your message across, because the person gradually becomes less able to express his ideas in words and less able to understand what is said to him. Gentle touch, body movements, expressions on your face, and tone of your voice can all convey messages to which a person with Alzheimer's disease may respond. At the same time, the person can "speak" to you by actions and expressions when he is no longer able to use words.

Communication requires patience and imagination.

The following guidelines may help you.

1. Set the stage. Communication is always easier if other things are not happening at the same time. Keep your home quiet and calm. For example, if a TV or radio is distracting the person with Alzheimer's disease - turn it off.
2. Get his attention. Approach the person slowly and from the front. Gently touch the person's hand or arm to help get his attention. Don't start talking until you know he is ready to listen.
3. Make eye contact. If possible, sit facing him or stand in front of him and keep eye contact. This makes it easier for him to understand what you are saying.
4. Speak slowly and clearly. Use simple words and short sentences. If the person has hearing problems, face him and lower the pitch of your voice.
5. Give one message at a time. Keep conversations simple. Do not include too many thoughts or ideas at one time. Do not give many choices. Questions which can be answered with "yes" or "no" are easier than open-ended questions. "Would you like soup for lunch?" is easier than, "What would you like for lunch?"

6. Pay attention. His reactions to what you say can give you some idea of how much he is understanding. Pay attention to the expression on his face. Respond to his moods and feelings.
7. Repeat important information. If the person has not understood the message the first time, repeat it, using the same words.
8. Show and talk. Show him what you mean as well as tell him. For example, if it is time to wash his hair, have the shampoo and towel at hand to help you explain.

DAY-TO-DAY LIVING

Each one of us likes to be independent. For the person with Alzheimer's disease, this becomes increasingly difficult. As the disease progresses, he will need help to do day-to-day tasks. As a caregiver, you will have to try to adjust to some of the losses. At the same time, you should try to let him function as much as possible by himself.

Make sure your house is safe and gives a feeling of security. Doing things as simply as possible will make life easier for both of you. A daily routine will also help him to know what to expect and when.

No one can tell you exactly how to care for the person with Alzheimer's disease.

Try the basic guidelines outlined in this handbook, then use your imagination and try your own ideas.

You know him best.

ON THE SAFE SIDE

At home

Safety is an important part of caring for an individual with Alzheimer's disease.

It may be necessary to make some changes in your home to ensure that it is safe and secure.

Look over your house carefully in order to determine what is dangerous for the person with Alzheimer's disease. As the disease progresses, you will have to be aware of new hazards and take precautions as needed.

Here are some questions to consider in making your home safe:

- Do I need to store the scatter rugs and secure the carpet to prevent falls?
- Are the stairways safe for the person with Alzheimer's disease to use?
- Is the person with Alzheimer's disease able to use the electrical appliances in the kitchen and bathroom safely? Do I need to call an electrician or the gas company to help make the stove safe? Should I put away the curling iron or the blender?
- Should the hot water heater temperature be lowered?
- Are there any items in the house that should be stored in locked cupboards?
- Are there any medications, cleaning substances, or gardening chemicals which should be locked away?
- Do I need to be there when the person with Alzheimer's disease has a cigarette? Should I hide the lighter and matches?
- Should I lock some of the doors? Do I need to change the placing of the locks on the doors?
- Should I consider getting some safety equipment in the bathroom? Would grab-bars, an elevated toilet seat, or a non-slip mat make it safer for both of us?
- Is the lighting good enough to get rid of shadows that may cause confusion?
- Are there items such as pictures and mirrors that confuse the person with Alzheimer's disease?
- Should I get advice on what safety measures to take?
- Should I consult an occupational therapist for advice on routines, activities, and adapting the home to make it as safe and accommodating as possible?

Health

Keeping the person with Alzheimer's disease in good health is important. Providing him with nutritious meals, enough to drink, and opportunities to exercise will help to do this. Regular check-ups with the doctor and dentist should be continued.

Like all of us, the person with Alzheimer's disease can also develop problems like colds or toothaches. He can also suffer from serious diseases such as cancer or diabetes. As Alzheimer's disease progresses, the person may not understand what is wrong or even be able to tell you if he has any pain. You need to be aware of any sudden changes in behaviour which might be a sign of physical problems. Changes in eating patterns, sudden loss or gain of weight, or increased restlessness and anxiety should be reported to your doctor.

You should talk to your doctor or pharmacist before giving the person with Alzheimer's disease any prescription medication, over-the-counter product or natural remedy. All medicines and herbal products can produce side effects. Some can interact with medication that may be prescribed for Alzheimer's disease. Common side effects include: rashes, upset stomach, and drowsiness. The person with Alzheimer's disease may experience some of these but the medicine may also affect his behaviour by increasing confusion. It is important for you, as the caregiver, to be aware of all possible side effects. If you do give medication to someone with Alzheimer's disease, report any unexpected changes to your doctor.

You can ask your doctor and pharmacist for advice and avoid herbal remedies that can change the way prescription drugs work or have interactions with other drugs.

Driving

The lives of people with Alzheimer's disease should be as free and fulfilling as possible, but a totally risk-free life is not possible. Throughout the course of the disease, driving skills and abilities must be monitored. However, risks should never be assumed without an individual assessment and should not be exaggerated in order to remove driving privileges earlier than necessary. With

Alzheimer's disease there will come a time when the person is no longer safe to drive. It must be recognized, that people with Alzheimer's disease who drive when not competent to do so create an unacceptable risk for themselves and others in the community.

Restricting driving may threaten a person's independence and sense of freedom. Therefore, how and when to insist that a person stop driving is a difficult issue for people with Alzheimer's disease, family members, doctors and other members of the health-care team. Public discussion of this issue will become crucial as more and more people are diagnosed with Alzheimer's disease in Canada. Contact your local Alzheimer Society for information about provincial regulations for reporting potentially unfit drivers and the availability of driving assessment programs in your province.

"Driving with my husband was scary. At red lights, he'd go into the middle of the intersection before stopping. I knew he needed to stop driving."

Keep it simple

In order to make living easier for both of you, it is important to keep things simple. A person with Alzheimer's disease has increasing difficulty when he is faced with too much at one time. Even our most routine tasks are made up of many steps. For example: dressing includes choosing the right clothes, deciding the correct order, and putting them on. It may be necessary for you, the caregiver, to break down these tasks into manageable steps. This will allow him to do what he can for himself, leaving you to help with the rest.

Although it is necessary to simplify tasks, it is also important to allow the person to have as much control as possible of his life. Give him the chance to make choices as long as he is able, although it will eventually become necessary to limit choices. As his ability decreases, you will have to make the decisions for him.

Some ways of keeping day-to-day living simple are to:

- Buy clothes that are easy to put on
- Keep only a few clothes in the closet

- Choose a simple hairstyle
- Use an electric razor
- Remove unnecessary cutlery and dishes from the table when eating; and
- Provide finger foods when forks and knives become difficult to manage

ROUTINES AND REMINDERS

Activities which make up day-to-day living such as dressing, grooming, bathing, and eating can be made to form a routine. Routines allow the person with Alzheimer's disease to know what to expect and to continue to do things on his own for as long as he is able. Doing so will make him feel better about himself.

It will be easier if you continue the routines that he has been used to, much of his life. For example, if he is used to bathing in the morning it is best to make morning bathing the pattern. Carrying out the activities in much the same order each day will also help the person with Alzheimer's disease to know what to expect.

Reminders will help, particularly during the earlier stages of the disease. These can be written notes on the fridge to remind him to eat, or signs on a cupboard to tell him what is inside. If he no longer understands words, perhaps colour cues or pictures could be used. Cues such as a toothbrush on the counter will remind the person to brush his teeth. Clothes laid out in the order they are to be put on will make it easier for him to get dressed. Regular reminders might be needed to get the person to go to the bathroom.

THINGS TO DO

It can be a challenge to engage the person with Alzheimer's disease in meaningful and enjoyable activities throughout the day.

Keep in mind the things he liked to do in the past, respect his wishes and ensure that the activities are meaningful and achievable based on his capabilities (and limitations).

Suggestions for activities include:

- Listening to music. This is often soothing, and all of us respond to favourite tunes.
- Remembering the past. Looking at photograph albums can bring back pleasant memories.
- Helping with cooking, housework, folding laundry, and gardening. This is possible when you give him a chore that he is able to do.
- Exercising. Walking, dancing, swimming, and simple exercise routines can be enjoyable.

Remember that doing the same thing again and again may not be boring for him.

"I try to keep to a routine. It is very important to do the same thing at the same time each day."

IT MAY NOT BE EASY

Alzheimer's disease changes a person's behaviour. This is not intentional as it sometimes seems, it is part of the disease.

As Alzheimer's disease gets worse, most caregivers find that certain behaviours are more difficult to cope with than others. The following section gives you some thoughts on how to deal with common challenges. Remember, these are only suggestions. You may find better ways to handle them yourself.

Changed sleep patterns

Sleeping through the night can be very difficult for the person with Alzheimer's disease. He may be confused and think that he sees or hears things which are not there. He may get up and wander in the night and then become confused when he doesn't know where he is.

Make sure that the person is active during the day, so he will be more tired at night.

Try to discourage long naps during the day. Remember that most adults only need six to eight hours of sleep a night. Avoid caffeine;

if he has trouble sleeping, don't give him as much coffee, tea, or chocolate, especially before bed time. These all contain caffeine, which can keep people awake.

Don't give him too much of any liquid before bed, so he won't have to get up to go to the bathroom.

The person with Alzheimer's disease may not know the difference between night and day. Prepare the room by turning down the bed, and pulling the blinds.

If he does get up in the night, give him a gentle reminder to return to bed. Night lights in the bedroom and bathroom will help him find his way. If you do have to get up with him, help him to understand what is happening. Use his name, tell him who you are, and what time it is. This is often all he needs to go back to sleep.

"I'm exhausted. I can't sleep because I have to watch out for my wife."

Wandering

A person with Alzheimer's disease often walks and paces and may wander away. No one knows exactly why, although sometimes it is clear that the person is going in search of something or somebody. Other times it is a sign of boredom or need for exercise. It may be that he is trying to run away from something that seems unpleasant. Wandering may also occur at night when darkness adds to a person's confusion. No matter what the reason, wandering can be a constant worry for caregivers.

It will help to put locks on the outside doors which the person cannot use. You can also install alarms which ring to let you know when the door is open. If locked doors cause the person to become frustrated and angry, you may need to disguise them with paint or wallpaper. Regular walks or exercise help to make him less likely to wander.

Let your neighbours and local storekeepers know that the person with Alzheimer's disease may wander. Ask them, if they see him, to invite him in and call you.

Be sure you have all the information you need to identify him if he does wander. You will need a description including height, weight, hair colour, etc. as well as an up-to-date photo. Some caregivers have the person wear an identification bracelet or a name tag with a phone number and address on it. Others sew name tags onto the person's clothes.

Consider registering the person with the disease with our 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 MedicAlert® Safely Home® program, contact your local Alzheimer Society, call 1-855-581-3794 or visit www.medicalertsafelyhome.ca.

Toileting

A person who has Alzheimer's disease may sometimes soil or wet himself.

These accidents may happen because the person:

- Is unable to find the bathroom
- Cannot get his clothes off
- No longer understands when he should go to the bathroom
- Has a urinary tract or bladder infection, or
- Cannot control his bladder or bowel

You can reduce accidents by regular reminders to go to the toilet. Identify the bathroom with a sign or picture. If accidents continue to happen, notify your doctor and ask him to check for an infection. A person in the early stages of Alzheimer's disease usually does not lose control of his bladder or bowel.

When the person becomes unable to control his bowel or bladder, special pads called incontinence briefs can be useful. These are worn inside the underpants to protect clothing. You can buy them in a drug store.

Many people with Alzheimer's disease are able to use the toilet if they have some help. When accidents happen, a calm and

reassuring response is best.

Repeated actions / restlessness

The disease may cause a person to repeat words and actions over and over again. This is not intentional, though it may appear to be. He may pace for long periods of time which can be very stressful for the caregiver. Try to distract the person with simple activities or change the subject. Sometimes ignoring the behaviour is the only answer.

Try to think of the ways to use the repeated action to help you do a job which needs to be done. He may be able to fold clean clothes, dust, prepare vegetables, sand, or polish something. This will help both of you.

The person with Alzheimer's disease may be restless and confused at certain times of the day. Finding a pattern may help you understand when and why it is happening. If he tends to pace and be more restless late in the afternoon, try to arrange your schedule to be with him at this time. Try to find a simple activity to do together. This will reassure him that he is not alone.

Suspicion

A person with Alzheimer's disease loses the ability to understand what is going on around him. He may think that you or others are trying to hurt him or take away his belongings if he has misplaced something. He may accuse you or others of stealing.

It is important for you to remember that it does not help to argue. Agree with him that he has a right to be upset. Assure him that he is safe and that no one is trying to hurt him or steal his belongings. Then distract him.

If he accuses visitors or housekeepers of stealing things, explain to them that it is not a personal accusation, it is the result of the disease.

Extreme reactions

A person with Alzheimer's disease can get upset in situations which he could have handled easily in the past. Some of these

are: a new place, new people, large groups, a loud noise, a fall, or not knowing how to do something. These may cause him to become annoyed and frightened. He may show these feelings by loud crying or laughing. He may become angry and aggressive. He may scream, push or strike out at you. These outbursts can be frightening both for you and for the person with Alzheimer's disease.

Remember, they are not wilful or intentional. They are the result of the disease.

The following may help you in dealing with these reactions:

- Be calm and reassuring. A person with Alzheimer's disease will often respond to your mood.
- Stop the activity. Give him space and a chance to calm down.
- Distract him or remove him from the situation.
- If your safety is threatened, leave. Call for help.

Try to prevent situations which cause these reactions by:

- Knowing the person's abilities
- Sticking to daily routines
- Simplifying everything
- Not arguing or contradicting
- Being patient, not rushing the person, and
- Being aware of situations which cause stress

"My mom cusses at me every day, usually in public, and usually loudly. I suppose I am beyond the point of being mortified. There's nothing to do but accept it with good humour. That did not come easily or quickly. People in the support group tell me that this period probably will not last."

PLANNING AHEAD

As the disease progresses, you will need to become more and more responsible for the person you are caring for. This is not easy for most people. Knowing what might lie ahead and being prepared for it will help. You will then be more in control of your life. You will be capable of making decisions for the person and providing the necessary care. The areas you need to think about are:

Legal

Alzheimer's disease raises many legal issues which you need to understand. People with Alzheimer's disease gradually become less and less able to make decisions. You must be sure that someone trustworthy has the power to make the decisions that will be necessary. Talking about this with the person, when he is able, as well as with family members, helps. Advice from a lawyer as soon as possible is very important.

There are ways to arrange for someone else to make decisions on behalf of the individual.

These include:

- **Personal Arrangement.** The person with Alzheimer's disease can sign a document which gives someone else the power to look after his affairs. This may be called a "Power of Attorney" in some provinces or "Mandate" in Québec.
- **The Court.** The Court can appoint someone to look after the affairs of the person with Alzheimer's disease.
- **A Government Officer.** A government officer can be appointed to look after the affairs of the person with Alzheimer's disease.

Finances

You need to be aware of the person's financial situation, as this affects future decisions. A banker, financial consultant, or lawyer can help.

Items you should review include:

- **Bank accounts**
- **All insurance policies (auto, life, disability and home)**

- Pension plans
- Registered Retirement Savings Plans (RRSPs)
- Annuities, stocks, and bonds
- Credit cards
- Company benefits
- Business ownership
- Mortgages

It is not unfeeling to consider finances at this time. It is in the best interest of the individual and his future.

Emergencies

It is not possible to plan for every emergency. But things can happen suddenly and you may need to have help immediately.

Have emergency numbers beside the telephone. Make arrangements so that someone -- a neighbour, friend, or family member -- will respond immediately if you call.

Planning ahead will make things easier for you. Having a plan will make you feel more secure and better able to cope.

THERE IS HELP

Every community has some agencies and services to help you. They might give medical care, arrange for you to have relief from caregiving, help with errands, or assist you with housework. There are people who can talk to you about caregiving or help give care. Others bring meals to your home or take the person for a walk. Services vary from province to province and region to region. They are not all available everywhere, but finding out what is in your area is important for you.

Begin by talking to someone at your local Alzheimer Society and to your doctor. Friends or people from your faith group may also make you aware of what is available.

Call them. Services in the community are provided to help you.

You are not alone.

Chapter 3: Caring for yourself

WHY IS IT IMPORTANT?

You are the most important person in the life of the individual with Alzheimer's disease. He is relying on you for his care. He is depending on you to interpret life for him.

Taking care of someone with Alzheimer's disease can be a demanding task. It requires time and energy. Even if you are looking after someone you love, giving care can be difficult. Even if you are young and in good health, it can be hard on you. If you wish to continue to give care, it is essential that you look after yourself.

Your body will let you know when you are working too hard or feeling too much stress. There will be signs.

For example, you may:

- Notice that you are more easily upset, feel on edge, get angry, or cry more easily and sometimes feel that you just cannot handle everything;
- Have tense or sore muscles, stomach aches, headaches, or problems sleeping, you may be much more tired or get more colds than usual;
- Realize that you are eating or sleeping more, you are less able to concentrate and simple tasks take longer to do.

It is important to be aware of these signs. It is also important to do something about them.

HOW? STRATEGIES FOR DAY-TO-DAY LIVING

Be realistic - about the disease

It is important, though difficult, to be realistic about the disease and its effects.

First of all you have to admit that the person has a progressive disease. Once you accept this, it will be easier to be realistic about what you expect of him.

The person's needs change as the disease progresses. The basic needs for overall health and security, stimulation, connection, self-esteem and affection remain. At the forefront of a person-centred approach to care is the belief that each individual with Alzheimer's disease deserves to be treated with dignity and respect. Although a person loses many abilities as the disease progresses, it is important to focus on the abilities that remain. You may have to learn to see him as he is today, and not as you have known him in the past.

Be realistic - about yourself

It is also important to realize that caring for someone takes time and energy. There will be limits to what you can do. You will have to decide which things are most important to you. Which do you value most? A walk with the person you are caring for, time by yourself, activities you have always enjoyed with others, or a clean and tidy house? There is no "right" answer to this question; only you know what matters most to you at any particular time.

Besides making choices, you will have to set limits on what you do in a day. It may be difficult to admit that you cannot do everything. It is not easy to say "no." To be realistic, you will need to think carefully about how much you can do.

Accept your feelings

When taking care of someone with Alzheimer's disease, you will have a lot of mixed feelings. In just one day, you may feel contented, angry, frustrated, guilty, happy, sad, loving, embarrassed, afraid, resentful, hopeful, and hopeless. These feelings may be confusing and difficult to handle, but they are normal.

It is frustrating to live with someone who often forgets who you are and what you say. It is normal to be angry when you have to postpone your plans. Feeling sad when you are going to lose someone you love is natural.

One of the hardest feelings to deal with is guilt. People often feel guilty when they are impatient or short-tempered. They feel guilty when they want time for themselves. Feeling guilty about not being perfect will only make you feel worse.

Negative feelings do not mean that you are not a good caregiver. They mean you are human. Tell yourself you are doing the best you can. Remember that feeling grief and loss, through all stages of Alzheimer's disease, is normal. And everyone will grieve differently. Get the practical help and emotional support you need from your local Alzheimer Society.

“Even I wonder why I can sit daily by his side as I play music, relate bits and pieces of news, hold his hand, tell him I love him. Yet I am content when I am with him, though I grieve for the loss of his smile, the sound of my name on his lips.”

Share your feelings

Do you keep your feelings and problems to yourself? Many people do. It is really important to share your feelings with others. Find someone you are comfortable with, and talk about how you feel and what is troubling you. This person may be a close friend, a family member, a counsellor or someone you met at an Alzheimer support group. Joining a support group where a number of people who are caring for someone with Alzheimer's disease share their experiences is helpful.

Look for good things

Your attitude can make a great difference in the way you feel. Try to look at the positive side of things. Look at what the person is still able to do rather than what he cannot. For example, even though the person cannot prepare dinner, he may still be able to peel potatoes. That can be helpful.

Try not to focus on your losses and problems too much. Give yourself credit for the care you are providing.

Try to make good times happen. There are still moments that are good and worthwhile. Perhaps you had a nice walk to the store or he was happy when he looked at pictures of a trip you took together. The good moments are still there; they may be less frequent but they are there.

Take care of yourself

Your own health is important. Do not ignore it. Eat proper meals and try to exercise regularly. Find ways to relax and make sure you get the rest you need. Make regular appointments with your doctor for check-ups. These things will help you deal with stress and allow you to continue giving care.

Take time for yourself

You need regular breaks. You need relief so that you can have interests outside of caregiving. Do not wait until you are exhausted to plan this. Take time and keep up with things that are important to you. This will give you strength to continue and help to prevent you from feeling lonely and isolated.

To get time to yourself, you will need someone else to look after the person with Alzheimer's disease. Prepare for this by inviting the new caregiver in for a short visit. This will help the new caregiver become familiar with the individual, your house, and your daily routines. It will make your time away easier for everyone.

Look for humour

Alzheimer's disease is serious, but you do not have to take yourself seriously all of the time. Your sense of humour will help get you through difficult times. Seeing humour in your situation does not lessen the sincerity of your care.

People with Alzheimer's disease do not necessarily lose their sense of humour or desire to have fun. Taking care of someone will be more pleasant if you can share a joke and laugh together.

Explaining the disease

You will need to become a teacher. It will be important for you to explain Alzheimer's disease and its effects to your family and friends. Tell them what you have learned about communicating and giving care. With this knowledge, they will be more comfortable when visiting and more able to help you give care.

GETTING HELP

Practical help

Many people have a hard time asking for help and a hard time accepting it; they want to be very independent. Some feel that asking for help is a sign of failure. It is important to realize that you cannot take care of a person with Alzheimer's disease alone.

You may need help with everyday household and caregiving tasks. Figure out exactly what kind of help you could use and then let people know. Most people would really like to help, but sometimes they just do not know how.

There are community agencies and services to help you. The names of the agencies and services they provide are not the same in each province in Canada. Call the local Alzheimer Society, Public Health Unit, or your doctor to find out what is available in your area.

Support

You will also need the support that comes from sharing thoughts and feelings with others. The "others" may be people from your church choir or bowling team. They may be your neighbours, your friends, your family or someone in your Alzheimer support group.

If caregiving becomes emotionally stressful, you may need to meet with a counsellor. Such a professional can help you understand your situation, deal with your feelings and give you support.

One service which can be very valuable is an Alzheimer support group. It will provide you with a group of people who understand the disease and who know just what you are going through. The group can offer you hands-on suggestions about caregiving and information about the resources available in your community. It also gives you a chance to share your own experiences and to help others. Call your local Alzheimer Society to find out the time and place of these meetings.

The other way to share your experiences, exchange information and useful tips or learn more about the dementia or your role as a caregiver is to use the online Message Board of the Alzheimer Society of Canada.

To learn more about the various forums or if you wish to register as a user, please visit <http://www.alzheimer.ca/en/We-can-help/Alzheimer-society-message-board> or call the Alzheimer Society of Canada.

THE FUTURE

As soon as you start caring for a person with Alzheimer's disease you need to plan for the immediate future and consider what is ahead for both of you. Include family members and the person, if possible, in your planning.

This handbook has tried to show you some of the more immediate things you need to think about when you live with a person with Alzheimer's disease. It is also important to realize that, over the course of the disease, your needs and abilities will change just as the person's will change. There may come a time when you can no longer provide care in your home. The person may need to be cared for in a care home. There are no rules to say when this will be, but it is helpful to recognize that it can occur. As a caregiver you should not view this move as a sign of failure. It should be seen as a stage in the overall progression of the disease. A care home is one more service available to you as a caregiver.

YOU ARE IMPORTANT

You are the most important person in the life of the person with Alzheimer's disease. He is relying on you for his care. He is depending on you to interpret life for him.

What you are doing is vital, so take care of yourself.

There are things you can do to help maintain your health and well-being:

- Learn about the disease and care strategies and understand how the disease affects the person in order to comprehend and adapt to the changes
- Be realistic about the disease, about yourself
- Accept your feelings
- Share information and feelings with others
- Be positive and make every day count
- Look for humour
- Take care of yourself
- Ask for help
- Plan for the future

We know it can be done. People we know have done it. They have grown and learned from their experiences. They have shared with us some of the information found in this handbook.

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.

Do you need further information?

If you need further information, please refer to the following Alzheimer Society publications:

Alzheimer's disease:

What Is Alzheimer's disease?

Risk factors

Other dementias:

Creutzfeldt-Jakob disease

Lewy body dementia

Frontotemporal dementia

Vascular dementia

Daily living:

Communication

Personal care

Meal time

Shared experiences

Caregiving options

Reducing caregiver stress

Ambiguous loss and grief in dementia for individuals and families

The progression of Alzheimer's disease:

Overview

Early stage

Middle stage

Late stage

End of life

Tough issues:

Driving

Quality of life

Decision-making

Locating devices

Living alone

Intimacy and sexuality

Restraints

Please visit our website at www.alzheimer.ca to learn more about Alzheimer's disease and other dementias or contact your local Alzheimer Society.

WHERE TO CALL?

The following is a list of Alzheimer provincial Societies across the country. They can help you find your local Society:

Alzheimer Society of Canada

20 Eglinton Avenue West, 16th Floor
Toronto, ON M4R 1K8
Tel: (416) 488-8772 • Fax: (416) 322-6656
Toll-free: 1-800-616-8816
E-mail: info@alzheimer.ca
Web: www.alzheimer.ca

Alzheimer Society of Alberta and Northwest Territories

10531 Kingsway Avenue
Edmonton, AB T5H 4K1
Tel: (780) 488-2266 • Fax: (780) 488-3055
Toll-free: 1-866-950-5465
E-mail: info@alzheimer.ab.ca
Web: www.alzheimer.ab.ca

Alzheimer Society of British Columbia

828 West 8th Avenue, Suite 300
Vancouver, BC V5Z 1E2
Tel: (604) 681-6530 • Fax: (604) 669-6907
Toll-free: 1-800-667-3742
E-mail: info@alzheimercb.org
Web: www.alzheimercb.org

Alzheimer Society of Manitoba

120 Donald Street, Unit 10
Winnipeg, MB R3C 4G2
Tel: (204) 943-6622 • Fax: (204) 942-5408
E-mail: alzmb@alzheimer.mb.ca
Web: www.alzheimer.mb.ca

Alzheimer Society of New Brunswick

320 Maple Street, Suite 100
Fredericton, NB E3A 3R4
Tel: (506) 459-4280 • Fax: (506) 452-0313
Toll-free: 1-800-664-8411
E-mail: info@alzheimernb.ca
Web: www.alzheimernb.ca

Alzheimer Society of Newfoundland and Labrador, Inc.

835 Topsail Road, Unit 107
Mount Pearl, NL A1N 3J6
Tel: (709) 576-0608 • Fax: (709) 576-0798
Toll-free: 1-877-776-0608
E-mail: alzheimersociety@nf.aibn.com
Web: www.alzheimernl.org

Alzheimer Society of Nova Scotia

6009 Quinpool Road, Suite 300
Halifax, NS B3K 5J7
Tel: (902) 422-7961 • Fax: (902) 422-7971
Toll-free: 1-800-611-6345
E-mail: alzheimer@asns.ca
Web: www.alzheimer.ca/ns

Alzheimer Society of Ontario

20 Eglinton Avenue West, 16th Floor
Toronto, ON M4R 1K8
Tel: (416) 967-5900 • Fax: (416) 967-3826
E-mail: staff@alzheimeront.org
Web: www.alzheimer.ca/on

Alzheimer Society of Prince Edward Island

166 Fitzroy Street
Charlottetown, PE C1A 1S1
Tel: (902) 628-2257 • Fax: (902) 368-2715
Toll-free: 1-866-628-2257
E-mail: society@alzpei.ca
Web: www.alzheimer.ca/pei

La Fédération québécoise des sociétés Alzheimer

5165, rue Sherbrooke Ouest, bureau 211
Montréal, QC H4A 1T6
Tel: (514) 369-7891 • Fax: (514) 369-7900
Toll-free: 1-888-636-6473
E-mail: info@alzheimerquebec.ca
Web: www.alzheimerquebec.ca/federationquebecoise

Alzheimer Society Of Saskatchewan

2550 - 12th Avenue, Suite 301
Regina, SK S4P 3X1
Tel: (306) 949-4141 • Fax: (306) 949-3069
Toll-free: 1-800-263-3367
E-mail: office@alzheimer.sk.ca
Web: www.alzheimer.ca/sk



Alzheimer Society