

Alzheimer Society

A HANDBOOK FOR CARE



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.

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Finding out that someone close to you has Alzheimer's disease or another dementia can be overwhelming, as these conditions currently have no cure. It is important, however, for you to know that there are many things that you can do to make life easier and more enjoyable for the person with dementia. Not only is there information to help you to better understand the disease and how to provide the best "tailor-made" care to the person, but there are people and services in your community to provide you with practical help and support. This handbook is for you - a person who is supporting someone with Alzheimer's disease or another dementia.

A note about the terms we use:

You may be supporting your spouse, partner, parent, sibling, neighbour or friend. In this handbook, we refer to you as the "caregiver" or "family" which includes anyone in the supportive network of people with dementia. Where appropriate, we talk about "dementia" instead of any one particular type of dementia, like Alzheimer's disease.

This handbook is based on 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 to be done. This holistic approach to care takes into account the specific needs and preferences of each person; it is grounded in mutually beneficial relationships 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 wellbeing of their relative.

This handbook does not replace the services of a doctor or other trained health professional. You should seek their advice and support, as needed.

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 providing care while also taking care of yourself. After all, you know yourself and the person you care for better than anyone.

WHAT IS DEMENTIA?

Dementia is an overall term for a set of symptoms that are caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language, severe enough to reduce a person's ability to perform everyday activities. A person with dementia may also experience changes in mood or behaviour.

Dementia is progressive, which means the symptoms will gradually get worse as more brain cells become damaged and eventually die.

Dementia is not a specific disease. Many diseases can cause dementia, the most common being Alzheimer's disease and vascular dementia. Some of the other causes of dementia include Lewy Body disease, fronto-temporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease and Huntington's disease. These conditions can have similar and overlapping symptoms. To learn about other types of dementias, please visit <http://www.alzheimer.ca/en/About-dementia/Dementias> or speak with the staff at your local Alzheimer Society.

Some treatable conditions can produce symptoms similar to dementia, for example, vitamin deficiencies, thyroid disease, sleep disorders, or mental illness. It is therefore important to arrange for a full medical assessment as early as possible. Getting a timely diagnosis can help you access information, resources and support through the Alzheimer Society, benefit from treatment, and plan ahead.

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 may slow its progression.

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. Understanding the various stages and the challenges they typically present can help you learn strategies to plan for and respond to these situations, reducing stress for everyone.

IMPORTANCE OF EARLY DIAGNOSIS

Early diagnosis is important. Individuals or their family members should consult a family physician when they begin to notice symptoms such as loss of memory, judgment and reasoning, difficulty with day-to-day tasks and changes in communication abilities, mood and behaviour.

Finding out the cause of the symptoms can help the person get the proper care, treatment, support and plan for the future. To read about the 10 warning signs of Alzheimer's disease, please visit www.alzheimer.ca/10warningsigns.

EFFECTS OF DEMENTIA

Alzheimer's disease and other dementias are fatal conditions which eventually affect all aspects of a person's life: how they think, feel and act. Each individual is affected differently. It is difficult to predict which symptoms they will have, the order they will appear, or the speed of their progression. The following are some of the typical changes you may expect as the disease progresses.

Remember: Despite all the changes that dementia brings over time, a person with dementia will be able to hear, respond to emotions and be aware of touch right through until the end of life.

Changes in cognitive and functional abilities

Dementia affects a person's ability to understand, think, remember and communicate. At first you may not be aware of the small subtle changes. You may notice that the person gradually becomes unable to learn new things and make decisions. They may forget how to do the simple tasks they have done for years. They may have trouble remembering people's names, where they are, or what they were about to do. They may have difficulty understanding what is being said and making themselves understood. Eventually the difficulties will increase over time.

Changes in emotions and mood

As the disease progresses, a person with dementia may have less expression, be less lively and more withdrawn. At the same time, they may lose the ability to control their moods and emotions. These may vary, change rapidly and become harder to predict. Sometimes they may become sad, angry, laugh inappropriately, or worry a great deal over small things. At other times they may be suspicious of people close to them. Other times, they will appear to have little or no reaction at all to people or their surroundings.

Changes in behaviour

Behaviours associated with dementia or other neurological conditions include agitation, wandering, pacing, repetitive actions, disturbed sleep, use of inappropriate language and outbursts. These apparent changes in the personality of the person with dementia can be a major source of distress both to the person who is expressing the behaviours and to their caregivers. It is important to understand that all behaviours have meaning and may be a response to the person's current environment. As a person's ability to express themselves verbally deteriorates over time, the only way the person may be able to make their needs or wishes known will be through their behaviour (e.g. disrobing in public when they need to use the toilet). Learn more about recognizing and understanding the person's actions and behaviours by reading 'Shifting focus: Guide to understanding dementia behaviour' at <http://alzheimer.ca/en/Home/Living-with-dementia/Understanding-behaviour/guide-to-dementia-behaviour>.

Changes in physical abilities

Changes in the brain of a person with dementia may also result in decreased physical ability. You may see a difference in the way they move and in their co-ordination. Over time, they may have difficulties with daily activities such as eating, dressing or bathing. They may become incontinent. It is therefore important to adapt activities to accommodate lost abilities and make the most of remaining ones.

BRAIN HEALTH

The human brain is one of our most vital organs. It plays a role in every action and every thought, and just like the rest of our bodies, it needs to be looked after. It's never too soon, or too late, to make changes that will maintain or improve your brain health, changes that may also help reduce the risk of developing dementia.

Alzheimer's disease and other dementias develop when the risk factors for the disease combine and reach a level that overwhelms the brain's ability to maintain and repair itself. By making healthy lifestyle choices, you may be able to reduce your risk and improve your brain's ability to sustain long-term health. To read more about brain health, please visit www.alzheimer.ca/brainhealth. To learn more about risk factors, please visit www.alzheimer.ca/riskfactors.

THERE IS HELP

There is a growing body of knowledge about care strategies that can help you care for the person with dementia. Learning continues every day, 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 dementia. In Chapter 3, you will find suggestions about how to take care of yourself. There is no doubt that caring for a person with dementia can be rewarding but also tiring and difficult at times. Your experience can be made easier if you are armed with reliable information and support throughout the course of the disease.

The staff at your local Alzheimer Society are there to help. Find your local Alzheimer Society by visiting www.alzheimer.ca/helpnearyou or by calling 1-800-616-8816. You are not alone.



Taking care of someone with dementia 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 their actions may seem out of place to you, you may realize that they make sense to them. For example, if they throw their dishes in the garbage, it may be because they are trying to get rid of something dirty. They are trying to help and no longer understand that this is not appropriate. Although taking care of the person 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 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 dementia does not stop needing what made them feel happy and contented in the past. They need to stay in contact with family and friends. They need 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 their 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 them to the toilet, or whether or not you talk about them to others when they are 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 restricted 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 (art, meditating, listening to music, praying, gardening, etc.) and you should encourage them to express themselves in their own unique way.

Loss and grief

People with dementia are likely to experience feelings of loss and grief over their diagnosis and throughout the progression of the disease, as their own abilities gradually change. There is also ambiguity and uncertainty about how the disease will progress, whether slowly or quickly, and how it will affect relationships with family and friends, daily life and plans for the future.

Talking openly with family, friends, healthcare providers, Alzheimer Society staff or peers in a support group about your fears, feelings and concerns can help to normalize the feelings you have about the disease and caregiving. Knowing you're not alone – and that caring people are listening – makes the caregiving role easier. To learn more about ambiguous loss please visit www.alzheimer.ca/ambiguousloss.

How relationships change

Dementia does not change the need for companionship, friendship, love and affection, but it does change many aspects of all relationships. You may feel you've lost the companionship of someone who has been close and important to you.

It can also affect sexual relationships. 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 their 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.

A person with dementia may be overly affectionate at the wrong time or place or to an 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 dementia may no longer be able to recognize their partners. In these situations, the partner will benefit from support and understanding. If the person with dementia develops a close relationship with another person, this can be very hard to understand. It is important to remember that the person is enjoying the company of a new companion and may no longer appreciate how this may appear to others.

Similarly, partners often feel that they have lost the person even when the person is still alive. It is normal for partners to look elsewhere for companionship that they are missing from the person with dementia. It may be difficult to balance your needs with those of the person you care for. Find ways of meeting your needs that make you comfortable.

At a later stage of the disease, you might make the decision to move the person you have been caring for to a long-term care home. This may be one of the most difficult decisions you will ever 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. For more information about moving to long term care please visit www.alzheimer.ca/longtermcare.

If any problems with your relationship become difficult to handle, discuss them with someone. You might 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 dementia may be a challenge. In order to keep them in touch with the people around them, you will have to try to focus on their remaining abilities.

Knowing how to communicate is important. You will need different ways of getting your message across, as the person gradually becomes less able to express their ideas in words and less able to understand what is said to them. Gentle touch, body movements, expressions on your face, and tone of your voice can all convey messages to which a person with dementia may respond. At the same time, the person can communicate with you through actions and expressions when they are 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 - turn it off.
2. **Get their attention.** Approach the person slowly and from the front. Gently touch the person's hand or arm to help get their attention. Don't start talking until you know they are ready to listen.
3. **Make eye contact.** If possible, sit facing them or stand in front of them and keep eye contact. This makes it easier for them to understand what you are saying.
4. **Speak slowly and clearly.** Use simple words and short sentences. If the person has hearing problems, face them 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.** Their reaction to what you say can give you some idea of how much they are understanding. Pay attention to the expression on their face. Respond to their moods and feelings.
- 7.** If the person has not understood the message the first time, be patient and repeat the information.
- 8. Show and talk.** Show them what you mean as well as tell them. For example, if it is time to wash their hair, have the shampoo and towel at hand to help you explain.

DAY-TO-DAY LIVING

Each one of us likes to be independent. As the disease progresses, the person with dementia will need help with day-to-day tasks. As a caregiver, you will have to adjust to many losses. At the same time, you should try to let them function as much as possible by themselves.

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 them to know what to expect and when.

Each person with dementia is a unique individual and the challenges you may face as their caregiver will be specific to your situation. Don't try to manage this caregiving role alone, there is much help available. Contact your local Alzheimer Society to learn how they can support you.

ON THE SAFE SIDE

At home

Safety is an important part of caring for an individual with dementia.

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. As the disease progresses, you will need to become 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 to use? Are there bannisters and grab bars? (note: do not use a gate across the top of the stairs as they may try to climb over it)
- Is the person 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 has a cigarette? Should I control the use of the lighter and matches?
- Do I need to put alarms on certain 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?
- 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? For more information, contact Canadian Association of Occupational Therapist at 1-800-434-2268 or visit www.caot.ca/site/findot

Health

Keeping the person with dementia in good health is important. Providing them 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 can also develop problems like colds or toothaches. They can also suffer from serious diseases such as cancer or diabetes. As the disease progresses, the person may not understand what is wrong or even be able to tell you if they have 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 dementia 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 the person. Common side effects include: rashes, upset stomach and drowsiness. The person with dementia may experience some of these but the medicine may also affect their 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 dementia, report any unexpected changes to your doctor.

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 dementia 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 dementia, there will come a time when the person is no longer safe to drive. People with dementia 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 and thus can be very difficult for everyone involved. Contact your local Alzheimer Society for information about provincial regulations for reporting potentially unfit drivers, the role of your family physician 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 dementia has increasing difficulty when they are 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 them to do what they can for themselves, 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 their life. Give them the chance to make choices as long as they are able, although it will eventually become necessary to limit choices. As their abilities change, you will have to make the decisions for them.

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 dementia to know what to expect and to continue to do things on their own for as long as they are able. Doing so will make them feel better about themselves.

It will be easier if you continue the routines that they have used most of their life. For example, if they are 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 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 them to eat, or signs on a cupboard to tell them what is inside. If they no longer understand words, perhaps colour cues or pictures could be used. Cues such as a toothbrush on the counter will remind the person to brush their teeth. Clothes laid out in the order they are to be put on will make it easier for them to get dressed. Regular reminders might be needed to encourage the person to go to the bathroom.

THINGS TO DO

It can be a challenge to engage the person with dementia in meaningful and enjoyable activities throughout the day.

Keep in mind the things they liked to do in the past, respect their wishes and ensure that the activities are meaningful and achievable based on their abilities.

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 them a chore that they are 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 them.

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

BEHAVIOURS

Dementia changes a person's behaviour. This is not intentional as it sometimes seems; it is part of the disease. Remember, all behaviour has meaning. You need to know the person and their history to understand why they may be acting this way.

When there is a change in behaviour, there may be an underlying medical condition such as an infection or the person may be feeling pain. Consult with your family doctor.

As dementia 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 dementia. They may be confused and think that they see or hear things which are not there. They may get up and wander in the night and then become confused when they don't know where they are.

Make sure that the person is active during the day, so they 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 per night. Avoid caffeine; if they have trouble sleeping, don't give them as much coffee, tea, or chocolate, especially before bed time. These all contain caffeine, which can keep people awake.

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

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

If they do get up in the night, give them a gentle reminder to return to bed. Night lights in the bedroom and bathroom will help them find their way. Try to position the bed so they can easily see the toilet. If you do have to get up with them, help them to understand what is happening. Use their name, tell them who you are and what time it is. This is often all they need to go back to sleep.

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

Wandering

We all have the desire to move about freely however, difficulties occur when the person becomes lost (even in a familiar area) or goes out at inappropriate times of the day or night. 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 they are 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.

Some caregivers decide to lock or bolt doors to prevent the person with dementia from leaving the house. It is important to remember that you should never lock a person with dementia in the home if they are alone. As a less restrictive option, consider installing alarms or chimes which ring to let you know when a door is open. Try different approaches that may work for both of you and always be mindful of the person's safety. Regular walks and exercise may help to make them less likely to wander.

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

Be sure you have all the information you need to identify them if they do 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, a name tag or carry a card containing their name and contact information. 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, please call 1-855-581-3794 (toll-free) or visit www.medicalert.ca/safelyhome.

Toileting

A person who has dementia may sometimes soil or wet themselves.

These accidents may happen because the person:

- Is unable to find the bathroom
- Cannot get their clothes off in time
- No longer understands when they should go to the bathroom
- Has a urinary tract or bladder infection
- Cannot control their bladder or bowel

You can reduce accidents by regular reminders to go to the toilet. Identify the bathroom with a sign or picture on the door. If accidents continue to happen, notify your doctor and ask them to check for an infection.

When the person becomes unable to control their 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 dementia are able to use the toilet if they have some help. When accidents happen, a calm and reassuring response is best.

Repeated actions / restlessness

Dementia may cause a person to repeat words and actions over and over again. This is not intentional, though it may appear to be. They 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. They may be able to fold clean clothes, dust, prepare vegetables, sand, or polish something. This will help both of you.

The person with dementia 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 they tend to pace and be more restless late in the afternoon, try to arrange your schedule to have someone with them at this time to engage in activities.

Suspicion

A person with dementia may lose the ability to understand what is going on around them. They may think that you or others are trying to hurt them. They may accuse you or others of stealing if they misplace something.

It is important for you to remember that it does not help to argue. Agree with them that they have a right to be upset. Assure them that they are safe and that no one is trying to hurt them or steal their belongings. Then distract them.

If they accuse 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 dementia can get upset in situations which they could have handled easily in the past, such as: adjusting to a new place, new people, large groups, a loud noise, a fall, or not knowing how to do something. These situations may cause them to become annoyed and frightened. They may show these feelings by loud crying or laughing. They may become angry and aggressive. They may scream, push or strike out at you. These outbursts can be frightening both for you and for the person.

Remember, you do not need to put yourself at risk. If the person becomes aggressive, it is important to get the help you need to protect both of you. These outbursts are not wilful or intentional but are the result of the disease.

The following may help you in dealing with these reactions:

- Be calm and reassuring. The person will often respond to your mood.
- Stop the activity. Give them space and a chance to calm down.
- Distract them or remove them 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
- Being aware of situations which cause stress

“Assume people are scared. They live in a world that doesn’t make sense to them. They don’t know whom to trust and they are looking for reassurance. That explains a lot of the behaviours. If you think about that each time you see someone who looks like they are behaving uncharacteristically or aggressively, you’ll do fine”

*– Professor Lisa Gwyther, Alzheimer’s Research Center, Duke University
Source: HealthCare Interactive: Online Dementia Training*

PLANNING AHEAD

As the disease progresses, you will become more and more responsible for the person you are caring for. This is not always easy. 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.

Some important areas to consider are as follows:

Legal

Dementia raises many legal issues. People with dementia gradually become less and less able to make decisions. You must be sure that someone trustworthy has the legal authority to make the decisions for the person when they are no longer able to do so themselves. It will help to talk about this with the person, when they are able, as well as with family members. It may also be helpful to consult with a lawyer.

It’s human nature to try to avoid talking about sad and difficult topics like end of life. But by taking an active role in preparing for this stage, individuals and families can get on with their day-to-day lives knowing they have taken important steps to ensure that the care provided at the end of life will reflect the person’s wishes, beliefs and values. For more information about end of life please visit www.alzheimer.ca/endoflife.

Finances

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

Know where the following are and how to access them:

- Bank accounts and safety deposit boxes
- 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

Emergencies

Emergencies happen when we least expect them, so it's best to be prepared.

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

Know what to do in an emergency so that you can continue to care for the person with dementia.

THERE IS HELP

Every community has agencies and services to help you. They might provide 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 you provide care. Others bring meals to your home or accompany the person for

a walk or an outing. Services vary from province to province and region to region. Finding out what is in your area may be helpful -now and in the future.

Begin by talking to someone at your local Alzheimer Society and to your doctor.

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



WHY IS CARING FOR YOURSELF IMPORTANT?

Caring for a person with dementia is a marathon -not a sprint. You are the most important person in the life of the individual with dementia. They are relying on you for their care as the disease progresses and they may be depending on you to interpret their surroundings for them.

Providing care for someone with dementia can be a demanding task. It requires time and energy. Even if you are looking after someone you love, it can be difficult at times. Even if you are young and in good health, it can be hard on you. If you wish to continue to provide 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. When you accept this, it will be easier to be realistic about your expectations.

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 or another dementia deserves to be treated with dignity and respect regardless of the stage of the disease. Although a person loses many abilities as the disease progresses, it is important to focus on the abilities that remain.

Be realistic - about yourself

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 might need to set limits on what you can 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 supporting the person with dementia, 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 when facing the ups and downs that the disease can bring.

It can be frustrating to support 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 feel you are losing

someone you love is natural. Not all relationships are loving and close. Sometimes the relationship with the person has been a stormy one. Remember, it is also natural to be sad about not having had a more positive relationship with the person.

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 the 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 a support group. Joining a support group where a number of people who are caring for someone share their experiences can provide you with practical tips and also reassure you are not alone.

Look for good things

Your attitude can make a big 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 they cannot. For example, even though

the person cannot prepare dinner, they may still be able to peel potatoes. That can be helpful for you both.

Try not to focus on your losses and problems. 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 they were happy when they 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 providing care.

Take time for yourself

Everyone needs regular breaks from their usual responsibilities. As a caregiver, you need time for your interests outside of caregiving. Do not wait until you are too exhausted to plan this. Take the time and keep up with things that are important to you. This will give you strength to continue and help to prevent feelings of loneliness and isolation.

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

Look for humour

Dementia is serious, but you do not have to take yourself or your situation 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 dementia 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 now and then and laugh together.

GETTING HELP

Practical help

Many people have a hard time asking for help and a harder time accepting it; they want to appear independent and capable at all times. Some feel that asking for help is a sign of failure. It is important to realize that it is not a good idea to try to take care of a person with dementia 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. These organizations can vary from one province to another. Contact your local Alzheimer Society, Public Health Unit, or your doctor to find out what is available in your area.

Support

You will benefit from the support that comes from sharing thoughts and feelings with others. The “others” may be people from your bookclub, choir or bowling team. They may be your neighbours, your friends, your family or someone in your support group.

If caregiving challenges become tiring and stressful, you may find it helpful to meet with a counsellor. Such a professional can help you understand your feelings, consider your options and provide support.

One service which can be very valuable is an Alzheimer Society 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 when these meetings take place.

THE FUTURE

As soon as you start caring for a person you need to plan for the immediate future and consider what is ahead for both of you. Include members of your supportive network and the person, if possible, in your planning.

This handbook has shown you some of the more immediate things you need to think about when you care for a person with dementia. 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. In fact, most people with dementia will eventually need the care that a long-term care home provides. There are no rules to say when this will be, but it is helpful to recognize that it may well occur. As a caregiver, try not to view this move as a sign of failure. It is a fairly predictable 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 dementia. They are relying on you for their care. They are depending on you to interpret the world around them.

What you are doing is vital, so it is important to 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. Understand how the disease affects the person in order to comprehend and adapt to the changes you will see in the person.

- Be realistic about the disease and what you can do
- Accept your feelings
- Share information and feelings with others
- Be positive and make every day count
- Use humour to make the day brighter
- 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.

You are not alone. The Alzheimer Society is here to help. 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.



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

Conversations about:

Driving

Living alone

Intimacy and sexuality

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

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

14925 - 111 Avenue NW, Suite 308
 Edmonton, AB T5M 2P6
 Tel: (780) 761-0030 • Fax: (780) 761-0031
 Toll-free: 1-866-950-5465
 E-mail: info@alzheimer.ab.ca
 Web: www.alzheimer.ca/ab

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@alzheimerbc.org
 Web: www.alzheimer.ca/bc

Alzheimer Society of Manitoba

120 Donald Street, Unit 10
 Winnipeg, MB R3C 4G2
 Tel: (204) 943-6622 • Fax: (204) 942-5408
 Toll-free: 1-800-378-6699
 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.alzheimer.ca/nb

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: info@alzheimernl.ca
 Web: www.alzheimer.ca/nl

Alzheimer Society of Nova Scotia

112-2719 Gladstone St.
 Halifax, NS B3K 4W6
 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
 Toll-free: 1-800-879-4226
 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.alzheimer.ca/fr/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: info@alzheimer.sk.ca
 Web: www.alzheimer.ca/sk





Alzheimer Society

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20 Eglinton Avenue West, 16th Floor, Toronto, Ontario M4R 1K8
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