

Progression

FEDERATION OF QUEBEC
Alzheimer Societies

EARLY STAGE

This document is one in a five-part series on the stages of Alzheimer's disease and is written for the person with the disease, their family and caregivers. The early stage of the disease is featured in this sheet. For information on the other stages of the disease, please see the following sheets in the series: *The Progression of Alzheimer's Disease – Middle Stage*; *Late Stage*; and *End of Life*. For a general overview of the disease, its stages and the approach to care, please see *The Progression of Alzheimer's Disease – Overview* sheet.

What is Alzheimer's disease?

Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgment and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person's ability to work, maintain relationships or carry out everyday activities.

Alzheimer's disease is the most common form of dementia. Other forms of dementia resemble Alzheimer's disease in that they also involve a progressive degeneration of brain cells that is currently irreversible. They include Vascular Dementia (the second most common dementia after Alzheimer's disease), Frontotemporal Dementia, Creutzfeldt-Jakob Disease, Lewy body Dementia, Huntington disease, and Parkinson's disease.

Alzheimer's disease is a disease of the brain, characterized by deterioration of thinking ability and of memory, caused by the progressive degeneration of brain cells. The disease also affects mood and emotions, behaviour and one's ability to perform activities of daily living. There is currently no cure for Alzheimer's disease nor can its progression be reversed. However, present treatment options and lifestyle choices can often significantly slow the progression of the disease.

Alzheimer's disease typically follows certain stages which will bring about changes in the person's and family's lives. Because the disease affects each individual differently, the symptoms, the order in which they appear and the duration of each stage vary from person to person. In most cases, the disease progresses slowly, and the symptoms of each stage may overlap, often making the move from one stage to another quite subtle.

The early stage - what to expect

The early stage of Alzheimer's disease (also referred to as "mild Alzheimer's disease") marks a beginning that will bring with it significant changes for you and the people who care about you. You will likely retain many of your abilities and require minimal assistance during this stage. You may have insight into your changing abilities and therefore, can inform others of

your experience of living with the disease and help to plan and direct your future care. You may also be feeling overwhelmed and apprehensive about the future. It is normal for both you and your family to have many mixed emotions including feelings of grief and sadness. Many people are concerned about how the changes will affect them, how they will plan for the future and get the help and information that they need. The following are suggestions for living life to the fullest throughout the progression of the disease.

Please note that the term “early stage” refers to people of any age who have mild impairments as a result of Alzheimer’s disease. This differs from the term “early onset” which refers to people who have been diagnosed with Alzheimer’s disease at a younger age than usual, typically in their 50’s or very early 60’s.

| Common Symptoms | Helpful Strategies |
|---|--|
| Forgetfulness | <ul style="list-style-type: none"> - Use labels, notes, calendars, alarms/timers, pill dispensers - Create a “memory station” by the phone to post emergency numbers |
| Difficulty learning new things and following conversations | <ul style="list-style-type: none"> - Break tasks into steps - Acknowledge your limits - Keep group sizes to what is manageable - Tell people what you need in order to participate in conversations - Take breaks or rests - Write things down while in conversation |
| Difficulty concentrating or limited attention span | <ul style="list-style-type: none"> - Pick activities that are manageable - Do one thing at a time - Listen to talking books and CDs or watch DVDs - Take breaks or rests - Follow routines - Avoid overstimulation |
| Problems with orientation, getting lost, not being able to follow directions | <ul style="list-style-type: none"> - Register with the MedicAlert® Safely Home® program - Ask friends and family for rides - Use cabs - Be realistic about your ability to drive (consult your doctor) |
| Communication difficulties | <ul style="list-style-type: none"> - Take your time and tell others that you need more time to express yourself - Take someone with you to doctors’ appointments to help communicate and clarify information |

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|--|---|
| Difficulty handling problems at work | <ul style="list-style-type: none"> - Be realistic about your abilities - Talk to your manager about reduced hours or different tasks or opportunities - Plan for a time when you will not be able to work |
| Mood shifts, depression | <ul style="list-style-type: none"> - Keep physically active - Eat nutritiously - Stay socially connected - Attend early stage support groups facilitated by the Alzheimer Society - Acknowledge and share your thoughts and feelings with someone you trust - Try meditation or other stress-reduction techniques - See your doctor, if necessary, and take medications as prescribed - Do things that bring you pleasure and meaning - Take one day at a time |
| Passiveness, withdrawal | <ul style="list-style-type: none"> - Ask your family to watch for this and encourage you to participate in manageable activities |
| Mild co-ordination problems | <ul style="list-style-type: none"> - Use safety features like handrails and grab bars - Remove items that may cause tripping hazards - Increase lighting to improve visibility especially around stairs, hallways and entrances |
| Impaired ability to perform challenging cognitive tasks | <ul style="list-style-type: none"> - Realize your abilities and limits - Get help with tasks - Focus on activities that you can manage and enjoy |

Modified from Global Deterioration Scale, Reisberg, 1982

More suggestions for the early stage - for the person with the disease

1. Consider sharing your diagnosis with others who can help

You may feel that you want to keep your diagnosis confidential. This is a personal decision and one that should be made with the potential positive and negative consequences in mind. It may be useful to discuss this issue with someone who knows your diagnosis and can give helpful input. If you decide to be open about having Alzheimer's disease, it can help you begin to make plans for the future and open doors for others to support you. Family, friends, faith leaders, legal/financial advisors and/or the staff at your local Alzheimer Society may be able to assist you during this time.

2. Focus on what you can do

It is important to focus on your strengths and what you can do to develop strategies for successfully managing the activities that you now find more challenging. Try to keep a sense of humour and a positive attitude.

3. Maintain a healthy lifestyle

Making healthy lifestyle choices can help you feel better, may help slow the progression of the disease and improve your ability to cope with the changes that you are experiencing. Healthy choices include:

- staying socially connected
- choosing healthy food
- being physically active
- reducing stress
- avoiding head injuries
- seeking support to break harmful habits such as smoking
- exploring treatment options with your physician and scheduling regular checkups with him or her
- getting adequate sleep
- participating in a fitness and social program

4. Give your brain a work out

Studies have shown that mental stimulation improves brain activity and may help maintain brain health throughout life. Many people with Alzheimer's disease agree that it is important to put your brain to work every day. Challenging your brain doesn't have to be difficult. It can be as simple as dialing the phone with your less dominant hand or as complex as learning a new language. For extensive information and exercises on improving memory, concentration and problem-solving, see the *By Us For Us*® *Guide: Memory Work Out*¹ written by people with dementia for people with dementia.

5. Manage triggers

Many people with the disease talk about "triggers" - situations that cause agitation, increased stress or more difficulty thinking. Understanding triggers and how to respond to them is important in reducing the incidence of these situations and their impact. A number of specific triggers and solutions are detailed in the *By Us For Us*® *Guide: Managing Triggers*² written by people with dementia for people with dementia.

6. Plan for the future

There will be many decisions that will have to be made as you live with Alzheimer's disease and a time when you will need to depend on others to make decisions for you. Making some of these decisions now can give you and your family members a sense of control and peace of mind.

Work: if necessary, speak to your manager about reduced hours and/or tasks. Start to plan for a time when you cannot work.

Safety: be realistic about your ability to drive and start to consider alternate forms of transportation. Register yourself with the MedicAlert® Safely-Home® program and talk with Alzheimer Society staff about other safety options.

Daily living: seek information on getting assistance with daily tasks and consider your preferences for future living arrangements.

Financial, legal and care matters:

- make your wishes known about how you would like your financial, legal and care matters to be handled when you are no longer able to make decisions for yourself
- discuss these wishes with your family and write them down
- appoint someone who will take care of your financial and legal matters
- appoint someone to be your substitute decision-maker regarding issues of your future care, such as what type of future living arrangement you would prefer, kinds of medical interventions you would want etc.
- your local Alzheimer Society can advise you on what issues will need to be addressed and the kinds of professionals who can help with them

7. Living alone

Many people with the disease continue to live successfully on their own for some time. Some suggestions include:

- arranging housekeeping, meal preparation, transportation and bank-at-home services
- arranging closets, drawers etc. so areas are uncluttered and items easier to find
- leaving a set of house keys with a trusted neighbour
- using electrical appliances that shut off automatically
- using labels, notes, alarms as reminders
- keeping only one diary or calendar for appointments and keeping it in the same place
- asking for and accepting help when you need it

8. Get involved

People in the early stage of Alzheimer's disease are in a strong and unique position to have their voices heard. As people are diagnosed earlier in the course of the illness and able to take advantage of medications and other means of slowing down the disease, they are able to continue to contribute meaningfully to their communities. Helping to change some of the stereotypes about people who have Alzheimer's disease can have a powerful impact on public attitudes and on your own. Think about asking the Alzheimer Society in your community if they need people like you to raise awareness of the disease in your community or for public speaking or other volunteer tasks.

Suggestions for the early stage—for the family

Learning about the experiences of people living with Alzheimer's disease can be helpful to those who support them. The following are some suggestions from people with the disease from *Memory Problems?*³, written by the Early Stage Support Groups in the North/Central Okanagan Region of the Alzheimer Society of B.C.:

- Please don't correct me. I know better -- the information just isn't available to me at that moment.
- Remember, my feelings are intact and get hurt easily.
- I usually know when the wrong word comes out and I'm as surprised as you are.
- I need people to speak a little slower on the telephone.
- Speak to me clearly, one thought at a time; don't ask a question when you can provide a statement.
- Try to ignore off-hand remarks that I wouldn't have made in the past. If you focus on it, it won't prevent it from happening again. It just makes me feel worse.
- I may say something that is real to me but may not be factual. I am not lying, even if the information is not correct. Don't argue; it won't solve anything.
- If I put my clothes on the chair or the floor, it may be because I can't find them in the closet.
- If you can anticipate that I am getting into difficulty, please don't draw attention to it, but try to carefully help me through it so nobody else will be aware of the problem.
- At a large gathering, please keep an eye on me because I can get lost easily! But please don't shadow my every move. Use gentle respect to guide me.
- Sometimes you give me the message that you think I am faking these problems. What you don't see is my terrible confusion and my hurt knowing how you feel.
- I don't mean to frustrate you. I know you get impatient and tired of telling me things, three times in a row. Please be patient.
- Ask me what I think or want. Don't assume that you know.
- Believe I still love you, even if I am having trouble showing it.

More suggestions for the family - taking care of yourself

A diagnosis of Alzheimer's disease can be difficult for everyone involved and family members will need to take care of themselves throughout the disease process. The following are some tips for self care and planning for the future.

- Avoid isolation and loneliness by maintaining social activities and contacts as much as possible.
- Take care of your own health.

- Learn about the disease.
- Join a caregiver support group to connect with others.
- Be aware of the signs of stress and how it can affect your health and ability to support the person with the disease.
- Seek professional help if feelings of depression or anxiety are overwhelming.
- Be flexible about routines and expectations.
- Try to be positive and find some joy in the everyday.
- Start planning for the future with the person you support. For the types of planning necessary, see point 6 in “More suggestions for the early stage—for the person with the disease”.

What’s next?

Because Alzheimer’s disease is progressive, you will continue to need more information and support. You may want to take time in the early stage of the disease to think about what is important to you in the years that you live with Alzheimer’s disease. The next sheet in this series is *The Progression of Alzheimer’s Disease – Middle Stage*. Learning how the disease progresses and the changes that it will bring can help you to make plans for the future. However, only you can decide when is the right time to seek more information.

Help and support from the Alzheimer Society

Living with Alzheimer’s disease at any stage can be very challenging. Whether you are the person with the disease or someone who supports them, it is normal to feel a variety of emotions including grief and loss throughout all stages of the disease. It is important to acknowledge your feelings, care for yourself and seek the practical help and emotional support that you need.

The Alzheimer Society in your community can provide educational resources to help you learn more about the disease, referrals to help you access the practical support you need, and one-on-one and group support to help cope with the emotional impact of the disease. Contact your local Alzheimer Society or visit www.alzheimer.ca.

References

- ¹ *Memory Work Out*, By Us For Us® Guide (2006) created for people with dementia by people with dementia. Available through the Murray Alzheimer Research and Education Program, <http://www.marep.uwaterloo.ca/products/bufu.html>
- ² *Managing Triggers*, By Us For Us® Guide (2007) created for people with dementia by people with dementia. Available through the Murray Alzheimer Research and Education Program, <http://www.marep.uwaterloo.ca/products/bufu.html>
- ³ *Memory problems? Early Stage Support Groups in the North/Central Okanagan Region of the Alzheimer Society of British Columbia* (2000)

Useful resources

The Progression of Alzheimer's Disease - Overview; Early Stage; Middle Stage; Late Stage; and End of Life information sheets. Alzheimer Society of Canada (2013)

Guidelines for Care: Person-centred care of people with dementia living in care homes, Alzheimer Society of Canada (2010)

Shared Experiences - Suggestions for those with Alzheimer's Disease. Alzheimer Society of Canada (2013). Also available in audio files at <http://www.alzheimer.ca/en/Living-with-dementia/I-have-dementia/Shared-experiences>

All About Me. Alzheimer Society of Canada (2013). This fillable PDF booklet gives information about the individual's needs, preferences, likes, dislikes and interests

Day-to-Day Series - Communication. Alzheimer Society of Canada (2010)

Day-to-Day Series - Personal Care. Alzheimer Society of Canada (2010)

To learn more about the **MedicAlert® Safely-Home® program** or to register, please visit <http://www.alzheimer.ca/en/Living-with-dementia/Day-to-day-living/Safety/Safely-Home>

The Alzheimer Society of Canada offers a wide variety of free information sheets and brochures. To learn more, please visit our resources section at <http://www.alzheimer.ca/en/We-can-help/Resources/Alzheimer-Society-brochures-and-publications>

Note: This information sheet provides guidance but is not intended to replace the advice of a health care professional. Consult your health care provider about changes in the person's condition, or if you have questions or concerns.

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