

THE PROGRESSION OF ALZHEIMER'S DISEASE - MIDDLE STAGE

Introduction

Alzheimer's disease is the most common of a large group of disorders known as "dementias". It is a disease of the brain, characterized by deterioration of thinking ability and of memory, caused by the progressive degeneration of brain cells. The disease also affects mood and emotions, behaviour and one's ability to perform activities of daily living. The disease typically follows certain stages which will bring about changes in the person's and family's lives.

The Progression Series

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 middle 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 - Early 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.

The middle stage - what to expect

Typically, for the person in the middle stage (also referred to as "moderate Alzheimer's disease") there is an increasing loss in cognitive and functional ability although many people will still have some awareness of their condition. For families and caregivers, it is the point where their involvement increases substantially and may include moving the person to a care facility. With the increasing challenges faced by persons with Alzheimer's disease and their family, this stage often seems the longest and everyone involved will need help and support.

Even though the middle stage of the disease brings with it increasing challenges for the person with the disease, there are strategies that the person can use to help make life easier. See the "Helpful Strategies" chart and the "More suggestions" section in the *Early Stage* sheet. The suggestions below are primarily directed at those who support the person.

Common Symptoms	Helpful Strategies
<p>Cognitive abilities:</p> <ul style="list-style-type: none"> • Memory problems become more pronounced, for example: <ul style="list-style-type: none"> - Remembers own name but not address or phone number - Forgets recent events and own history - Has difficulty identifying family and friends, but still recognizes familiar faces - Loses or misplaces possessions and takes things belonging to others • Declining ability to concentrate • Confusion - difficulty organizing thoughts or following logic • Disorientation to time and place 	<ul style="list-style-type: none"> - Use reminders and cues including notes, pictures, signs or seasonal objects - Offer information if the person is struggling, for example, "Hi mom, it's me Bill and I've brought your granddaughter, Ann, to visit you." - Gain the person's attention and maintain eye contact while talking; limit distractions such as the radio or television - Speak slowly and clearly; use simple language and repeat the message if necessary - Stick to concrete vs. abstract ideas ("Isn't it a nice day?" rather than "What do you think about the weather today?") - Use physical gestures to reinforce your messages - Remember that the person is not intentionally being difficult - Limit number of choices to one or two

<ul style="list-style-type: none"> • Problems understanding and expressing spoken and written language • Difficulty making choices 	
<p>Moods and emotions:</p> <ul style="list-style-type: none"> - Mood shifts may include anxiety, suspiciousness, sadness, depression, frustration, anger, hostility, apathy and agitation - Pervading sense of loss or insecurity 	<ul style="list-style-type: none"> - Try to identify, acknowledge, and address underlying emotions being expressed, which may be missed if focus remains solely on the person's words - Use strategies and maintain activities that support the individual's independence and that focus on what they can still do - Encourage a healthy lifestyle including physical activity, healthy eating, and familiar and meaningful activities - Avoid disagreeing, arguing or trying to convince the individual that what they believe is untrue or inaccurate - Reassure and comfort the person - Try reminiscing as a helpful strategy
<p>Behaviours:</p> <ul style="list-style-type: none"> - Apprehensiveness, withdrawal or passiveness - Restlessness (pacing, wandering) - Repetitive questioning or actions - Delusions (believing things that aren't true) - Hallucinations (hearing, seeing, smelling, or tasting things that aren't there) - Uninhibited behaviour (from overtly sexual behaviour to aggression) 	<ul style="list-style-type: none"> - Remember that all behaviour is a form of communication – try to determine what the person is trying to express eg. fear, discomfort, frustration - Watch for behaviour changes that may result from physical illness such as a urinary tract infection or the flu - Consider whether the behaviour is mostly annoying or actually dangerous or anxiety causing - Identify and avoid situations that trigger disconcerting reactions (is the behaviour triggered by noise, too many people, too many expectations? Is the person hungry or in pain?) - Offer the person choices - Try gentle persuasion - Remain calm, reassure and distract to a more pleasant topic or location - Contact the Alzheimer Society to register the person with the Safely Home® Registry; learn strategies to prevent wandering - Speak to a physician about whether there may be medications that can help
<p>Physical abilities:</p> <ul style="list-style-type: none"> - Assistance required for activities of daily living including dressing, eating, bathing, using the toilet - Changes in sleep/wake patterns - Changes in appetite - Spatial problems that can affect movement and co-ordination 	<ul style="list-style-type: none"> - Know the person's preferred tastes and past routines - Keep things simple: clothes that are easy to put on, simple hairstyles etc. - Adjust scheduled activities to times best suited to the person - Adapt activities to accommodate lost abilities and make the most of remaining ones - Identify and adapt any potential hazards in the home, for example rugs that could be tripped on. Grab bars in the tub or shower can help. - Consult an occupational therapist for advice on routines, activities, and adapting the home to make it as safe and accommodating as possible - Seek homecare support

Consult with a physician on treatment options for the disease. As well, pay attention to other issues of daily health (eg. regular medications, dental needs, etc.) Although the middle stage requires some additional and different strategies than for the earlier stage, some of the same strategies will still apply. See “Suggestions for the early stage - for the family” in the Early Stage sheet.

More suggestions—taking care of yourself and planning for the future

Despite your best efforts, providing care will become more difficult as the disease progresses, and the person you are caring for becomes more dependent on you. This is a time when many family members need increased support for themselves. The following tips are to help family members take care of themselves and plan 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 living with the day-to-day issues of Alzheimer’s disease and facing practical challenges, grief and loss.
- Watch for signs of stress and how it can affect your health and ability to provide care.
- Be aware that you may already be grieving the gradual losses caused by the disease.
- Seek professional help if feelings of depression or anxiety are overwhelming.
- Be flexible about routines and expectations.
- Try to be positive and use humour as a part of care strategies.
- Make time for yourself by using respite care options, including adult day programs, professional homecare services, other family members or friends, volunteer caregivers and friendly visiting programs.

Planning for the future: Refer to and follow any documents that the person with the disease has established to address his or her financial, legal and care wishes. If plans are not already in place, start the process as soon as possible.

- Arrange financial, legal and care matters and establish who will be responsible for these functions.
- Follow the person’s wishes, if you know them. Otherwise, decisions will need to be based on the person’s lifelong values and desires and what you think the person would want.
- Learn about the services that will be available as the disease progresses and both your needs change (homecare, respite care, community programs like Meals on Wheels and care facilities).
- Learn what to look for in a care provider or facility.
- Plan for your own future. There are many changes throughout the disease process that may affect how you will live your own life in the coming years.
- Your local Alzheimer Society can advise you on the above issues and the kinds of professionals who can help to address them.

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 - Late 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 us at 416-322-6560 or visit our website at www.alzheimertoronto.org.

Resources:

1. Alzheimer Society. www.alzheimer.ca (of particular interest: "I Have Alzheimer's Disease", "Forums" and "Resources" sections). The following can also be obtained by contacting your local Alzheimer Society or by visiting www.alzheimer.ca.
2. Alzheimer Society of Canada. (1999). *Guidelines for Care*.
3. Alzheimer Society of Canada. *Safely Home Program*.
4. Alzheimer Society of Canada. (2001). *Shared Experiences - Suggestions for those with Alzheimer Disease*.
5. Alzheimer Society of Canada. (2007). *Heads Up for Healthier Living*.
6. Alzheimer Society of Canada. (1998). *The Alzheimer Journey: On the Road, workbook and video (Module 2)*.
7. Alzheimer Society of Canada. (2007). *Day to Day information sheet - Caregiving Options: Considering Long-Term Care*.
8. Alzheimer Society of Canada. (2008). *The Progression of Alzheimer's Disease - Overview; Early Stage; Middle Stage; Late Stage; and End of Life information sheets*.
9. *By Us For Us* © Guides: *Memory Work Out; Managing Triggers; Enhancing Communication* (2006, 2007) were 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>
10. *Early Stage Support Groups in the North/Central Okanagan Region of the Alzheimer Society of B.C.* (2000). *Memory problems?*

Note:

This information 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.

© December 2008 Alzheimer Society of Canada