

## The Caregiving Role

### Possible experiences through the series of stages of Alzheimer's disease and other dementias

Each person experiences Alzheimer's disease or other dementias in their own way. It can be helpful to think of the way the disease progresses as a series of stages, although not everyone with dementia goes through the stages in the same way. The following information is provided as a guide only.

**Mild Stage** is characterized by a loss of memory. This can result in forgetfulness, communication difficulties, and changes in mood and behaviour.

#### Caregiving role in the mild stage:

- While the person is still able, help plan their future care options including legal and financial issues.
- Make up a schedule of appointments and activities to help as a reminder. Promote as much daily routine as possible.
- Encourage social connections including physical activities as they are able.
- Encourage independence as long as safety is maintained. If required, provide specific instructions for tasks, one at a time as well as verbal cues and prompts when appropriate.
- Be flexible. What works well one day may not work at all the next day. Provide positive encouragement and support to the person.
- Learn about dementia and 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).
- Contact the local Society for information and support for both the person with dementia and yourself.

**Middle stage** is characterized by increasing forgetfulness and inability to manage daily tasks. As this stage progresses, there will be decreased ability to

perform self-care which may result in moving the person to a care facility. You will need to obtain support from family, friends, and/or community organizations to manage care needs in the home.

#### Caregiving role in the middle stage:

- Contact the local Alzheimer Society for information and support. Learn strategies on how to support the changing needs of the person with dementia and connect with other caregivers who are on the same journey.
- Ensure safety. Assess safety concerns in the home, driving issues, and also safety issues regarding increasing inability to cook, shop, or pay bills. Staff at the Alzheimer Society can connect you with the appropriate professionals who can help you with these concerns.
- Plan activities for the person with dementia that are appropriate and promote satisfaction and achievement.
- Develop a plan for providing care as the needs of the person with dementia change and enlist the help and support of others, such as family and friends.
- Arrange for appropriate community services as care needs increase. Try to maintain the person in his or her current residence as long as possible.
- Register the person with the *Medic Alert Safely Home* program.
- Assess the need for increasing professional care and possibility of moving into a care facility.
- Take care of yourself. Refer to the fact sheet "**Care for the Caregiver**" (<http://www.alzheimer.ca/en/pei/Living-with-dementia/Caring-for-someone/Self-care-for-the-caregiver>).

**Late stage** is characterized by gradually becoming totally dependent on others for physical care. Twenty-four hour care will be required either in the home or a care residence. Loss of memory may become very pronounced and the person may start to walk unsteadily, eventually becoming dependent on a wheelchair for mobility.

### Caregiving role in the late stage:

- Professionals will take over your primary caregiving role and you will become a valuable resource to the health care team. Your knowledge of the person is crucial in providing quality care.
- Be prepared for the adjustment that needs to take place for both you and the person with dementia if you move the person into a care facility. The person with dementia is moving to a new home with new faces. You are adjusting from being the person providing hands-on care to being a “partner in care.” This adjustment period will take time. For more information, please refer to a series of fact sheets entitled “**Long-term Care**” available at <http://www.alzheimer.ca/en/Living-with-dementia/Caring-for-someone/Long-term-care>.
- Keep in touch with the doctor and/or care facility staff about the person's condition, care and treatment; attend care planning meetings in a care facility when invited, keep lines of communication open between you and the care staff.
- The need for companionship and belonging remains. Help the person with dementia remain stimulated with appropriate activities such as reading, sharing photographs, reminiscing, and listening to music.

**End stage** is characterized by decreasing physical and cognitive abilities. The person’s inability to cope with

infections and other physical problems is more pronounced as end-of-life approaches.

### Caregiving role in the end stage:

- Providing comfort and dignity is a priority.
- Some abilities remain, although many are lost as the disease progresses. The person may still keep their sense of touch and hearing, and their ability to respond to emotion, even in the final stages.

### Factors affecting your caregiving role:

- The nature and strength of your relationship with the person with dementia.
- The personalities of both the person with dementia and yourself.
- The ability of each of you to adapt to changes caused by the disease including your physical, emotional, psychological and financial resources.
- Day-to-day expectations that you have, such as being an employee, parent, volunteer, your place of residence in relation to the person with dementia.

### A word about setting boundaries

You are most effective as a caregiver when you know where your boundaries are and you protect them. This can be challenging. Caregivers live their day-to-day lives perilously close to their boundaries. The first step is recognizing your boundaries and understanding that it is all right to have them. In fact, it is healthy to give yourself a break now and then. Decide how much time you need for renewal and schedule it. Learn to say “no” when you feel overwhelmed. For more information, refer to the fact sheet, “**Care for the Caregiver**” (<http://www.alzheimer.ca/en/pei/Living-with-dementia/Caring-for-someone/Self-care-for-the-caregiver>).

You will adjust more readily to transitions in your caregiving role if you:

- Learn about dementia, its impact and what the major transition points are in the caregiving journey.
- Connect with others going through similar situations in order to share feelings and learn new strategies of coping.
- Know your boundaries in your caregiving role.
- Look after yourself, try to be positive and find joy in everyday things.

**Remember, you are not alone. Reach out for help and support!**

#### Resources:

- Respite Care Fact Sheet:  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=140](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=140)
- Respite as an Outcome:  
[www.ccc-ccan.ca](http://www.ccc-ccan.ca)

#### Further information on this topic

Visit the following websites:

- <http://www.alzheimer.ca/en/pei>
- [www.fightdementia.org.au/](http://www.fightdementia.org.au/)

(July 2013)