

Care for the Caregiver

Taking care of yourself is one of the most important things you can do as a caregiver

Providing care for an individual with Alzheimer's disease or other dementias can be rewarding as well as challenging. As the disease progresses, caregiving needs will increase which will require more time and energy. It is not unusual to feel overwhelmed at times.

Caregiving can however lead to a stronger relationship with the person receiving care. It is not unusual for caregivers to report that:

- They appreciate life more as a result of their caregiving experience.
- Caregiving has made them feel good about themselves.

It is important to recognize that as the caregiving needs increase, caregiving stress, which is normal, can place a burden on your physical and emotional health. Caregiving can become more manageable and rewarding for you if you recognize and take steps to reduce the effects of stress.

Recognizing the signs of stress

The Alzheimer Society of Canada has identified 10 Warning Signs of Stress:

- **Denial...**about the disease and its effect on the person with the disease.
- **Anger...**at the person with Alzheimer's disease, yourself and others.
- **Withdrawing socially...**you no longer want to stay in touch with friends or participate in activities you once enjoyed.
- **Anxiety...**about facing another day and what the future holds
- **Depression...**you feel sad and hopeless much of the time.
- **Exhaustion...**you barely have the energy to complete your daily tasks.

- **Sleeplessness...**you wake up in the middle of the night or have nightmares and stressful dreams.
- **Emotional reactions...**you cry at minor upsets; you are often irritable.
- **Lack of concentration...**you have trouble focusing and you find it difficult to complete complex tasks.
- **Health problems...**you may lose or gain weight, get sick more often (colds, flu), or develop chronic health problems (backaches, high blood pressure).

You need to take care of yourself in order to be an effective caregiver. You may feel guilty about needing or wanting time out for rest, socializing and fun although everyone deserves regular and ongoing breaks from work, including caregivers.

Managing your stress:

- Know your strengths and limitations. Try and put supports in place for those aspects of caring that create the most stress for you. We all have different limitations and abilities.
- Know your own warning signs, and act to make changes. Don't wait until you are overwhelmed.
- Identify sources of stress. Ask yourself, "What is causing stress for me?" Sources of stress might be that you have too much to do, family disagreements, feelings of inadequacy, or the inability to say no.
- Identify what you can and what you cannot change. Remember, we can only change ourselves; we cannot change another person. When you try to change things over which you have no control, you will only increase your sense of frustration.
- Take action. Identify which stress reducers work for you. Taking walks, gardening, meditation etc.

Some practical caregiving tips:

Learn all you can:

- About dementia and the progression of the disease.
- Plan ahead.
- Learn about caregiving resources available in your community.

Ask for and accept help:

- Develop a 'Circle of Care' or support system made up of family members and friends to help with some specific caregiving tasks. If they offer help, don't refuse. Prepare a list of things that need to be done and then ask them what they would like to do.
- Ask them to sit with the person who has dementia while you take a break for yourself.

Find out about local community support services and how to access their programs.

- Adult day respite programs provide an opportunity for the person with dementia to socialize in a safe setting and also provide you with a break from caregiving.
- Home maintenance services such as housekeeping, home delivered meals and transportation services for medical appointments could make your life easier.

Talk to others who are going through similar circumstances.

- Join a support group. Besides being a great way to make new friends, you can also pick up some caregiving tips from others who are facing the same challenges.
- Keep in touch with family and friends. Help them understand more about what you are going through and reassure them that you do need their support.

Give yourself a break.

- Respite care provides short-term breaks that can relieve your stress, restore energy, and promote balance in your life.
- Take advantage of community programs that provide respite and relief from caregiving.
- For more information, refer to the Fact Sheet: **"Taking a Break. Why it's Essential"**. <http://www.alzheimer.ca/en/pei/First-Link/Resources/Caregiver-Fact-Sheets>

Communicate constructively.

- Learn how to say "No" to the demands of others when you are overwhelmed or need a break. It is your right to say "No" to extra demands on your time without feeling guilty
- It is important to set boundaries in your caregiving role and the ideal time to discuss this with the person who has dementia is in the early stages of the disease.
- Using "I" statements rather than "you" statements is more effective and allows you to express your own needs and desires while respecting the needs and desires of others.
- Remember that persons with dementia often react more to our feelings than the words.

Take care of yourself.

- See your doctor for a checkup. Tell them that you are a caregiver and about any symptoms of depression or sickness you may be having.
- Try to be physically active on most days of the week, eat a healthy diet, and get enough sleep.
- Make time to do something that you want to do.

A word about feeling guilty

It is normal to experience feelings of guilt during caregiving. These feelings may be triggered by: thinking that you could be a better caregiver; thinking that you should not take any breaks for yourself; feeling angry and frustrated with the one you are caring for; or when you are thinking about placement

in a residential care home. If you do experience feelings of guilt, you need to say to yourself:

- I am doing the best I can.
- There are some things I cannot control.
- It is the disease that causes behaviours to happen. Not my caregiving.
- I will enjoy the peaceful moments we share together.
- I will ask for help when things get out of control.

Remember... Be realistic about what you can expect of yourself, and recognize that taking care of yourself is the most important thing you can do as a caregiver.

The good news is you are not alone. Reach out and contact your local Alzheimer Society. They will provide you with information and support on your caregiving journey.

This Fact sheet is provided courtesy of the Alzheimer Society of Ottawa and Renfrew County

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Further information on this topic

Visit the following websites:

- www.alzheimer.ca
- <http://www.alzheimer.ca/pei>
- <http://www.alzheimer.ca/en/pei/We-can-help/Resources/Resources-for-caregivers>

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