

Self-Care for Caregivers

Supporting a person with Alzheimer's disease or another form of dementia is a challenging responsibility that can feel overwhelming throughout the different stages of the disease. This edition of the In Touch bulletin will focus on an area of caregiving that is frequently overlooked – self-care for caregivers. Although it may be difficult to prioritize your own needs, it is important to think about your own well-being in order to positively impact the quality of life of both yourself and the person for whom you are caring.

Taking Breaks

Taking a break is important – for families and caregivers

Caring for someone with dementia can be physically and emotionally tiring and stressful. Families and caregivers can easily become isolated from social contacts, particularly if they are unable to leave the person for whom they are caring. Regular breaks mean that you can have a rest, go out, attend to business or go on a holiday.



Taking a break is important – for people with dementia

Most people take breaks of some sort, perhaps pursuing hobbies that they enjoy, or weekends and holidays away. This gives us something to look forward to, and experiences to look back on. Breaks are

important for the same reasons for people with dementia. Taking a break can give the person an opportunity to socialize, meet other people, and engage in meaningful activities.

What stops caregivers from taking a break?

- Putting their own well-being last
- Feeling that a break is not deserved
- Not knowing what is available, or how to get help organizing a break
- Being too tired to make the effort
- Wanting a break, but the person being cared for doesn't
- Feeling that it's all too much trouble
- Believing that it is their responsibility to provide all the care, all the time

How to take a break

There are lots of ways to take a break. It depends on what suits you and your family. Friends and other family members may be happy to help out – often it's just a matter of asking.

Breaks can be:

- Time for the person with dementia to enjoy themselves with new or familiar experiences
- Time to relax and recharge in whatever way suits you
- Taking time together away from the usual routines

Adapted from Alzheimer's Australia fact sheet

Protect Yourself against Caregiver Burnout

Caregiving can be extremely demanding. Take the test below and see if you may be suffering from **Caregiver Burnout**.

Note: this is not a diagnostic tool

Answer True or False:

	True	False
I am always tired.	<input type="checkbox"/>	<input type="checkbox"/>
I don't sleep well.	<input type="checkbox"/>	<input type="checkbox"/>
I get sick more than usual.	<input type="checkbox"/>	<input type="checkbox"/>
I have gained/lost weight unintentionally.	<input type="checkbox"/>	<input type="checkbox"/>
I have back pain, headaches, feelings of fatigue and depression.	<input type="checkbox"/>	<input type="checkbox"/>
I don't have time for myself.	<input type="checkbox"/>	<input type="checkbox"/>
I have given up hobbies and reduced contact with friends and family.	<input type="checkbox"/>	<input type="checkbox"/>
I have a short temper and outbursts of anger.	<input type="checkbox"/>	<input type="checkbox"/>
I cry easily.	<input type="checkbox"/>	<input type="checkbox"/>
I worry about not having enough money to make ends meet.	<input type="checkbox"/>	<input type="checkbox"/>
I feel I don't have enough knowledge/experience to give proper care.	<input type="checkbox"/>	<input type="checkbox"/>

If any of the above statements are true, you may be experiencing caregiver burnout. Perhaps it's time to ask for help.

Examples of where to seek help:

- **Family and friends.** They may be able to provide you with emotional support, assist with daily tasks, and allow you to take some time for yourself.
- **Adult day centres.** These facilities provide a variety of activities for people with dementia during the day, providing caregivers with a break.
- **Home and Community Care.** Contact your local health authority to find out about services offered in your area.
- **Home delivered meals.** Various organizations provide nutritional programs; for example, Meals on Wheels.
- **Transportation services.** These services can provide transportation to and from medical appointments or other services; for example, HandiDart.
- **Contact the Alzheimer Society of B.C.** to learn more about the different types of support available in your community.

Adapted from: Veterans Affairs Canada

A Caregiver's Bill of Rights

I have the right....

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of the person with dementia.
- To seek help from others even though the person with dementia may object. I recognize the limits of my own endurance and strength.
- To maintain areas of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can do for this person, and I have the right to do some things for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempt by the person with dementia (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken for me to meet the needs of the person I am caring for.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when the person with dementia no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made toward aiding and supporting caregivers.



Source: Wendy Lustbader *Caregiving: Helping an Aging Loved One*

Dealing with Guilt

People who care for someone with dementia often talk about feeling guilty, even when others reassure them that they are doing the best they can. Here are some examples of common things that can trigger guilt in dementia caregivers:

Other caregivers seem to manage better than you do. Remember that it's alright to make mistakes - no one can get it right all the time. There is no such thing as the 'perfect caregiver', and it's important not to be too hard on yourself. Are you setting realistic limits to what you can achieve? If not, can you reduce any of the demands you make on yourself, or ask for more help? See **Asking for Help** worksheet on the next page.

How you treated the person before they were diagnosed. Many caregivers feel bad about how they behaved towards the person before they were diagnosed with dementia. You may have reacted with irritation or criticism, or you may wish that you had made more of the time you spent with the person when they were well. Try to remember that everyone gets frustrated with their partner or family members from time to time. You didn't know they had dementia, and you couldn't have foreseen what the future held.

You sometimes get angry or irritated. If you feel angry and frustrated, you might occasionally have angry outbursts towards the person with dementia. Many caregivers find it hard to forgive themselves in this situation. Try to remember that caring can be very stressful, and anger or frustration are natural in this situation. Look for ways of expressing your irritation away from the person by finding the space or time to have a good shout, punch a cushion, or through

some other outlet. If you can identify the particular situations or times of day when you are more likely to become irritated (for example, at the end of a long day), you may be able to develop strategies to defuse the tension or to get extra support.

You sometimes want time for yourself.

You may feel guilty about having time to yourself. If you still enjoy doing things that you used to share with the person you are caring for, you may feel that you are being disloyal. Everyone needs to recharge their batteries now and again, and it's very important for caregivers to enjoy some time away from their caring role. Many caregivers find that giving themselves some time apart, and doing things that make them feel happy and positive, makes them more able to fulfill their role. This can improve their relationship with the person with dementia.

You've decided that the person needs to move into residential care. Caregivers often feel that moving the person into a care facility is the 'ultimate betrayal'. You may have previously promised the person that you would always look after them at home, and now feel forced to break that promise. Remember that any promises were probably made in a completely different situation, when neither of you had any idea of all the strains and stresses that lay ahead. It may help to talk to other caregivers, but don't let those who are still caring at home add to your sense of guilt. Everyone's situation is different. The move to a facility doesn't need to mean that you give up your caregiving role completely - it's just a different way of caring. Your involvement is still very important. Some caregivers feel that residential care helps them to have a better relationship with the person, as their time together can be more special, less stressful, and more like it used to be before the constant worry about practicalities.

Adapted from Alzheimer's Society of UK factsheet

Self-care Checklist

Are you taking good care of yourself—body, mind, and spirit? Review the list below. Put a check mark next to the things you are currently doing, and circle the items that you would like to improve on.

How well do you care for your physical health?

- Eat a well-balanced diet
- Get adequate sleep
- Have periods of physical rest and relaxation
- Get regular physical exercise
- Keep your weight at a healthy level
- Get regular mental exercise (e.g., reading, music, puzzles)
- Attend to your own health needs

How well do you care for your emotional health?

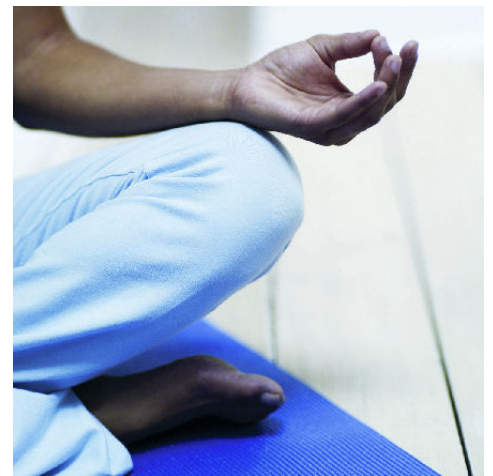
- Talk about your feelings, both positive and negative
- Use coping strategies for stress, anxiety, and frustration
- Remind yourself of the good things in your life
- Laugh a lot
- Practice being a positive, encouraging person
- Find balance between your work and personal life
- Take time for rest and relaxation

How well do you care for your interpersonal well-being and friendships?

- Have close friends and confidants
- Take time to enjoy activities with others

How well do you care for your spiritual health?

- Pay attention to your spiritual needs
- Spend time thinking about the things which bring peace, beauty and serenity to your life
- Follow your own spiritual path (religious or not)



Source: University of Michigan

Maintaining Social Relationships

One of the most common complaints of caregivers has to do with the reduction in their social contacts and activities. Caregivers find that they are unable to visit with friends and relatives, go out, or do the things they enjoy as much as they would like. As a result, they often begin to feel socially isolated.



The power of social support

As a caregiver of a person with dementia, most of your attention is probably spent on them. You may find that you rearrange other commitments and areas of your life to be with them and to provide the care they require. Often, friends and relatives are neglected because you are too busy, don't want to burden others with your problems, or don't think they will understand. You may

also feel as though friends have limited their calls or visits, which may be the result of their own discomfort with the person's illness, not knowing what to say to you, or feeling like they will be in your way. Much of this can be changed through proper communication and allowing yourself some time to spend with friends. You need the support and love of your friends and family to feel less alone and to cope better with the challenges of caregiving.

Tips for maintaining social relationships:

- ✓ Reassure your friends and family that although you may be busy, you do need and appreciate their support.
- ✓ Be open and share your experiences as a caregiver with your friends and family so that they can try to understand what it is like for you.
- ✓ Explain the diagnosis to those who are not familiar with it.
- ✓ Invite friends and family over to visit or to help with daily tasks (for example, cooking a meal) while you are caring for the person.
- ✓ Take the time to call and catch up with those friends and relatives with whom you have lost touch. Be sure to ask them about their lives rather than just talking about your situation. This can serve as a great way for you to take a break.

Adapted from: You have needs too! Booklet from www.netofcare.org

Thoughts on friendship:

"A friend is someone who knows the song in your heart and can sing it back to you when you have forgotten the words."

-Unknown

"A true friend never gets in your way unless you happen to be going down."

-Arnold H. Glasow

Notes and Events

DEMENTIA HELPLINE

Alzheimer Society
BRITISH COLUMBIA

1-800-936-6033
(Lower Mainland 604-681-8651)

Helping people with dementia, their friends, and their family members to build the confidence to maintain quality of life when facing dementia.



Our Vision

Our ultimate vision is to create a world without Alzheimer's disease and related dementias.

Our Mission

The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer's disease and related dementias, to promote public awareness and to search for the causes and the cure.

The Alzheimer Society of B.C. relies on the generosity of individuals and the community to ensure families have access to the knowledge, skills and tools they need to live well with dementia. Your donation will help make the journey easier for families impacted by Alzheimer's disease or related dementias.

Free Telephone Workshops



Thursday, September 23, 2010, 7 pm Understanding Dementia

Family caregivers can prepare for the journey with dementia by understanding the way Alzheimer's disease progresses. This workshop will focus on the kinds of symptoms and reactions that are likely to arise throughout the different stages of the disease.

Thursday, October 28, 12 noon Living Safely with Dementia

This workshop offers strategies for ensuring the safety of the person with dementia in the home. Caregivers will learn ways to prevent the person with dementia from getting lost and what to do in the event of a wandering incident. Information about products that may help keep the person with dementia safe will also be provided.

To see a list of the upcoming workshops or to register, go to www.alzheimerbc.org and click on **We Can Help**. You can also register toll-free at 1-866-396-2433 (Mon-Fri, 6am to 2pm P.S.T.)

In Touch is published by:

Alzheimer Society
BRITISH COLUMBIA

#300 – 828 West 8th Avenue
Vancouver, B.C. V5Z 1E2
Tel: 604-681-6530
Toll-free: 1-800-667-3742
Fax: 604-669-6907

Email: info@alzheimerbc.org
Website: www.alzheimerbc.org