

Building caregiver resilience

Strategies for self-care



Supporting a person living with Alzheimer's disease or another form of dementia is a challenging responsibility that can feel overwhelming at times. Caregiving is very stressful and can take its toll on your physical and emotional health. Studies have shown approximately 30 per cent of caregivers die before the person they are caring for, potentially leaving the person living with dementia without a caregiver. By maintaining good care for yourself, you enable yourself to provide improved and continued care for the person living with dementia.

There are steps you can take to reduce caregiver stress; but first, you must recognize the signs of stress and assess if you hold any attitudes that may be contributing to your stress.

Signs of caregiver stress

- **Denial** about the disease and its effect on the person with the disease.
"Everyone is overreacting. I know Mom will get better."
- **Anger** at the person living with dementia, yourself and others.
"If he asks me that question once more I will scream!"
- **Withdrawing socially:** You no longer want or feel able to stay in touch with friends or participate in activities you once enjoyed.
"Even if I did have the time, I don't feel like meeting up with friends anymore."
- **Anxiety** about facing another day and what the future holds.
"I'm worried about what will happen when I can no longer provide care."
- **Depression:** You feel sad and hopeless much of the time.
"I don't care anymore. What is wrong with me?"
- **Exhaustion:** You barely have the energy to look after your own basic needs, such as preparing a meal for yourself.
"I don't have the energy to do anything anymore."
- **Sleeplessness:** You wake up in the middle of the night or have nightmares and stressful dreams.
"I rarely sleep through the night, and don't feel refreshed in the morning."
- **Emotional reactions:** You cry at minor upsets; you are often irritable.
"I cried when there was no milk for my coffee this morning. Then I yelled at my son."
- **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).

Do any of the above experiences resonate with you? Stress over time can negatively affect your physical and mental health. Self-care is not selfish; it is necessary in order to continue taking care of someone else.

Identifying personal barriers to self-care

The first step in taking care of yourself is to identify attitudes and misconceptions that stand in your way and then try to modify them. Below is a list of attitudes and beliefs frequently held by caregivers which have the potential to inhibit one's ability to practice self-care.

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| <ul style="list-style-type: none">• I feel selfish putting my own needs first.• If I don't do it, no one will.• I have trouble asking for what I need.• I put my own wellbeing last.• I do not feel that I deserve a break.• I feel inadequate if I ask for help. | <ul style="list-style-type: none">• I constantly worry about the person I am caring for, even if I only take a little bit of time off.• I feel too tired or I have no time to make an effort to be good to myself.• I assume sole responsibility for solving all the problems.• I do not know what help is available or how to get it. |
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How true are the above statements for you? What expectations do you have for yourself that may be contributing to your stress? What expectations do you have for others? How realistic are these expectations?

For many caregivers, failing to make self-care a priority is a part of a life-long pattern of putting the needs of others before your own. However, as caregivers we must try to change these old patterns for our sake and the sake of the person we are taking care of. Remember that your life also has value. It is not selfish to want to do things to maintain your well-being and that improve your quality of life.

Steps to managing stress

Some effective ways to manage caregiver stress include:

- **Learn about dementia.** Knowing as much as you can about the disease and care strategies can help prepare you for the progression of the disease.
- **Be realistic.** Being realistic about the disease and how it will affect the person over time can help you to adjust your expectations for yourself and others.
- **Accept your feelings.** When caring for a person living with dementia, you will have many feelings. In a single day, you may feel content, angry, guilty, happy, sad, embarrassed, afraid and helpless. These feelings may be confusing. But they are normal. Recognize that you are doing your best.
- **Make space for the positives.** While there will be hard days, try not to let this be your focus. Choose to create positive memories with the person by focusing on what you and the person living with dementia can do, as opposed to what you cannot do.
- **Look for humour.** While dementia is serious, you may find certain situations have a bright side. Don't be afraid to laugh at a situation if the person you're caring for can laugh along with you.
- **Practice being mindful.** Practicing mindfulness can help you to focus on how you're feeling in the moment and allow you to accept your thoughts without judgement. Being kind and compassionate to yourself can make it easier to cope with the demands of caregiving.

Building caregiver resilience

Strategies and tips

Managing your stress while you are caring for a person living with dementia can improve your quality of life and allow you to be more effective as a caregiver. Your health is important, for your own well-being and for the person with dementia. Below are some strategies for maintaining your health and well-being.

Stay healthy

- Make it a point to develop a healthy diet and a regular exercise schedule to ensure that you maintain a good quality of life.
- Make sure you get enough sleep.
- See your doctor on a regular basis to check up on your health. Make sure they are aware of any stress or concerns that you are experiencing.

Get emotional support

Every caregiver needs support and people with whom they can discuss their feelings. You can get different types of support from your family and friends, caregiver support groups and online discussion forums. If stress becomes overwhelming, seek help from an understanding professional, such as your doctor or a counsellor.



Take time for yourself

Do something that is unrelated to caregiving. Make sure that you have some time to relax every day or to maintain a hobby that is just for you. As a caregiver, you have the right to follow your own interests. In fact, it is essential that you do. This will help give you strength to continue providing care.

- Put aside some time each day for yourself: have a cup of tea, read the paper, listen to music, do the crossword puzzle or go for a short walk.
- Make a point to get out of the house, even if it is only for a half an hour.
- Get out every week to meet a friend, to pursue an interest or to take part in activities that you enjoy.

Get help from family and friends

- Provide your family and friends with information about dementia. This will help them understand the person's behaviour and your need for help.
- Try to accept help from friends or neighbours when they offer it. If you decline they may not think to ask again. Prepare a list of things that need doing. The list might include errands, yard work or a visit with your loved one. Let the "helper" choose what he/she would like to do.
- Be prepared for hesitation or refusal. Try not to take it personally when your requests are turned down. The person is turning down the task, not you. They may be happy to help another time.
- Try to involve other family members right from the start so that the responsibility doesn't entirely rest with you. Even if they can't offer day-to-day care, they may be able to look after the person while you have a break or they might be able to contribute financially to the cost of care.

Be kind to yourself

At times, caregiving can feel like a thankless task. The person living with dementia may no longer seem to appreciate your efforts and others may be unaware of how much you do.

Pat yourself on the back for:

- Managing to cope, day in and day out, with a very difficult situation.
- Becoming ever more flexible, tolerant and finding new strengths that you did not know you possessed.
- Being there for someone who needs you.

Affirmations

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| 1. I am doing the best I can. | 4. Each day I am learning to be kinder to myself. |
| 2. I am competent as a caregiver and as a person. | 5. I need and deserve time for myself. |
| 3. I can handle this. | 6. I am appreciated and I am not alone on this journey. |

Be mindful

Mindfulness, a non-judgmental attention to your experience and feelings in the present moment, is a skill that can be learned and practiced. This heightened awareness has been scientifically proven to be effective in stress reduction for caregivers.

Some techniques to practice mindfulness:

1. Start and end your day with a few minutes of mindfulness or relaxation exercises.
2. Practice recognizing, naming, and acknowledging your emotions.
3. Practice being kind and loving to yourself.
4. Share the joys and struggles with other care partners like you.
5. Ask for help.

Incorporating mindfulness in your routine has also been proven to lead to more positive experiences for the person you are caring for. There may be days when taking a break seems near impossible, however self-care does not need to be another big task on your “to do” list. Start with small, manageable steps. Sometimes all it takes is a minute to yourself to enable you to continue to be there for someone else.

Resources

Ask an Alzheimer Society staff member for a **community resource guide** for a list of resources available in your community, such as counselling support, health services, support services, meal delivery programs, transportation options, community programs, financial/legal assistance, and grief support services.