Dementia:
A guide for caregivers

We've developed this guide to support you on your care journey and share practical ways you can live your life to the fullest while caring for a loved one with dementia.

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Caring for someone with dementia

When someone close to you has dementia, it may feel overwhelming, as there currently is no cure.

Dementia is a progressive condition; this means the symptoms will gradually get worse. As a caregiver, you will have to learn to understand and manage many symptoms, including changes in cognitive and functional abilities, emotions and mood, behaviour, and physical abilities.

Many families provide care at home for a loved one with dementia. While this can be stressful, it can also be an enriching and very rewarding experience.

Support and assistance are very important for the entire time that you are a caregiver. You will need occasional respite—a break from the daily responsibility of caregiving. Help from friends, other family members or community agencies is invaluable in allowing you to continue to provide your loved one with good care without becoming exhausted, frustrated or simply burned out.

Communicating about dementia with healthcare providers

Good communication with healthcare providers can directly affect your and your loved one's wellbeing.

Be sure to:

- Communicate your concerns clearly
- Describe any changes that you observe

You may need to keep a journal or a checklist, which you can bring to an appointment; that way, you can be sure that all relevant information is captured. This will help your healthcare provider understand what further investigations or interventions are needed. Visit TevaCanada.com/Caregivers for downloadable checklists that can help you prepare for a visit to a doctor or pharmacy.

Tips

- Keep a log of new or changing symptoms, and outcomes of medical visits.
- Be prepared to advocate for your care partner to access needed assessments, services and therapies. You are allowed to have a voice.
- Be sure that you understand and are involved in treatment plans.
- Record and report any changes in behaviour or mental state.
- Be clear about your boundaries—let others know what you can and cannot do.

Keep a journal or a checklist, which you can bring to an appointment.

Changing needs as cognitive impairment increases

Caregivers of persons with dementia often live through the full progression of the condition, from mild cognitive impairment to advanced dementia and end of life.

Though symptoms are not predictable for any one person with dementia, they typically progress through specific stages of cognitive impairment. As the disease advances, the person will become increasingly dependent on caregivers and will need different health and social care for optimal quality of life.

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Take care of yourself

The person with dementia needs you to be a healthy care partner. An effective partnership depends on the physical and emotional wellbeing of the both of you.

- Make time for your own health needs such as physical exercise, a healthy diet and regular medical examinations.
- Find downtime and get enough rest.
- Stay involved in activities that have meaning for you, including maintaining social ties.

Seek emotional support

Caregivers often think that they can—and should—handle everything alone. The best way to avoid burnout is to have the practical and emotional support of other people.

Beyond seeking support from your family and friends, consider participating in a caregiver self-help group. If you don't have time to go to group meetings, explore online caregiver support resources.

If you're experiencing disturbing emotions or thoughts, consider seeking out the guidance of a counsellor or therapist.

Communicate effectively

Take time to sort out your feelings, then schedule some time to clearly and calmly discuss them. Not expressing your feelings can lead to a range of emotions, including guilt, numbness, anger and resentment.

Understand that the emotional and cognitive symptoms of dementia are often distressing. If the symptoms of the person in your care are disrupting your daily activities, consult a healthcare professional.

The best way to avoid burnout is to have the support of others.

Ask for support before you feel overwhelmed.

Burnout from caregiving

Some studies have found that, because of the demands of dementia symptoms, this condition has a higher likelihood of overwhelming caregivers.

Dementia is associated with long care hours and physically demanding caregiving. Caregivers face many challenges in balancing caregiving with other demands, including parenting, career and relationships. This sometimes leads caregivers to neglect their own needs and self-care. They are at increased risk for stress, depression and a variety of other health complications, including:

- Cardiovascular problems
- Lower immunity
- Poorer immune response to vaccine
- Slower wound-healing
- Higher levels of chronic conditions (such as diabetes, arthritis, ulcers and anemia)
- More doctor visits and use of prescription medications
- Decreased engagement in preventative health behaviours such as exercise and eating well
- Greater likelihood of drinking alcohol or smoking
- Poor sleep patterns

Caregivers sometimes gradually lose social contact and support. This happens because they may begin to sacrifice their leisure pursuits and hobbies, to restrict time with friends and family, and to give up or reduce employment. If this happens, they can end up feeling isolated.

Remember that you're allowed to ask for support before you feel overwhelmed.

Caregiver stress symptom checklist

Caregivers sometimes develop feelings of inadequacy, guilt and self-blame despite their commitment to their loved one. They might struggle to stay organized and perform care tasks effectively.

The following are signs of caregiver burnout. If you recognize these symptoms in yourself, talk to your healthcare provider about strategies and resources to help you manage. Be sure also to remind them that you are a caregiver to someone who has dementia.

1. **Denial** about the disease and its effect on the person who has been diagnosed
2. **Anger** at the person with dementia or frustration that the person can't do the things they used to be able to do
3. **Social withdrawal** from friends and activities that used to make you feel good
4. **Irritability** or agitation toward others
5. **Anxiety** about the future and facing another day
6. **Depression** that breaks your spirit and affects your ability to cope
7. **Sadness,** feeling tearful or dissatisfied with life in general
8. **Exhaustion** that makes it nearly impossible to complete necessary daily tasks
9. **Sleeplessness** and/or disturbing dreams
10. **Lack of concentration** that makes it difficult to perform familiar tasks
11. **Health problems** that begin to take a mental and physical toll

Talk to your healthcare provider about strategies to help you manage.

Be realistic about dementia and acknowledge your limits.

Day-to-day tips to keep you healthy and happy

Be realistic about dementia

It can be hard to admit that your loved one has a progressive disease. But when you accept this, it will be easier to be realistic about your expectations.

Acknowledge your limits

Caring for someone with dementia takes time and energy. There will be limits to what you can do, and you will have to prioritize. It may be difficult to admit that you cannot do everything, and you will need to get comfortable with saying "no" to some things.

Accept your feelings

When supporting someone with dementia, you will experience many different feelings. You may feel contented, angry, frustrated, guilty, happy, sad, loving, embarrassed, afraid, resentful, hopeful and hopeless. These feelings may be confusing and difficult to handle, but they are normal.

Share your feelings

Try not to keep your feelings and problems to yourself. Find someone you are comfortable with and talk about how you feel and what is troubling you. Joining a support group where you can listen and share experiences is helpful and will reassure you that you are not alone.

Look for good things

Your attitude can make a big difference in the way you feel. Try to look at what your loved one is still able to do rather than what they cannot. You can still create happy times together.

Take care of yourself

Caregivers often neglect their own health. Take care of yourself by eating proper meals and trying to exercise regularly. Find ways to relax and make sure you get the rest you need. Make regular appointments with your doctor for check-ups.

Take time for yourself

As a caregiver, you need time for your interests outside of caregiving. Take the time and keep up with things that are important to you–before you become exhausted. This will give you strength to continue and help prevent feelings of loneliness and isolation.

Dealing with common dementia-associated behaviours

Wandering

People with dementia may walk aimlessly, for a variety of reasons, such as boredom, medication side effects, or to look for "something" or someone.

- Make time for regular exercise to minimize restlessness.
- Consider safety-proofing the house by installing new locks that require a key, adding "child-safe" plastic covers to doorknobs, and installing a home security system or monitoring system.
- Provide an ID bracelet and sew ID labels in clothes.

Incontinence

The loss of bladder or bowel control often occurs as dementia progresses.

- Establish a routine for using the toilet and schedule fluid intake to avoid dehydration. Limit fluid intake in the evening before bedtime.
- Consider putting a commode in the bedroom at night for easy access.
- Purchase incontinence pads and products.
- Provide easy-to-wash and easy-to-remove clothing.

Agitation

Agitation refers to a range of behaviours, including irritability, sleeplessness, and verbal or physical aggression. Often these types of behaviour progress with the stages of dementia, from mild to more severe.

- Reduce noise, clutter, or the number of persons in the room.
- Maintain structure by keeping the same routines.
- Reduce caffeine intake, sugar, and other foods that cause spikes in energy.
- Try gentle touch, soothing music, reading, or walks to quell agitation.
- Do not try to restrain the person during a period of agitation.
- Keep dangerous objects out of reach.

Repetitive speech or actions

People with dementia often repeat a word, question or activity over and over. While usually harmless, this behaviour can be stressful to caregivers.

- Try distracting with a snack or activity.
- Avoid reminding your loved one that they just asked the same question.
- Try ignoring the behaviour or question, and instead try refocusing the person into an activity.
- Don't discuss plans until immediately prior to an event.

Paranoia

Seeing a loved one suddenly become suspicious, jealous, or accusatory is unsettling. Remember, what the person is experiencing is very real to them. It is best not to argue or disagree—and try not to take it personally.

- Help your loved one look for the "missing" object and then distract them with another activity.
- Try to learn where their favorite hiding places are for storing objects, which are frequently assumed to be "lost."
- Take time to explain to other family members that suspicious accusations are a part of the illness.

Sleeplessness/sundowning

With dementia, restlessness, agitation and disorientation often get worse at the end of the day and into the night—a behaviour commonly called sundowning.

- Increase daytime activities, particularly physical exercise. Discourage inactivity and napping during the day.
- Avoid giving the person sugar or caffeine later in the day.
- Plan for the afternoon and evening hours to be quiet and calm.
- Keep a nightlight in your loved one's room, hallway, and bathroom.
- Block off stairs with gates, lock doors and put away dangerous items.

Problems with eating/nutrition

Ensuring that your loved one is consuming enough nutritious foods and fluids can be a challenge, as they begin to forget to eat and drink.

- Schedule meal and snack time around the same time every day.
- Create a calm atmosphere.
- Finger foods support independence. Provide assistance only when necessary and allow plenty of time for meals.
- Sit down and eat with your loved one.

Hygiene issues

People with dementia often have difficulty remembering "good" hygiene, such as brushing teeth, toileting, bathing, and regularly changing their clothes.

- Maintaining your loved one's past bathing routine may provide some comfort.
- If they have always been modest, make sure doors and curtains are closed.
- Use safety features such as non-slip floor bath mats, grab-bars, and bath or shower seats, and consider a hand-held shower.
- Never leave a person with dementia unattended in the bath or shower.

Ask for help

You may be a spouse, partner, child, family member or friend providing care on a regular basis to someone with dementia. Your role as a caregiver is an important one.

Accept that you may need help with everyday household and caregiving tasks. Family and friends can be vital members of your circle of care. Tell your friends and family that you need their help. Most people want to help, but they don't know what you need. Friends often worry that offering help might seem intrusive, so let them know their help is welcome. Don't hesitate to be specific with your support needs.

Keep a list of projects, errands and services that others can do. Then, the next time someone offers to help in some way, you can guide them on how to best support you.

People with dementia often need significant help with daily care. In many cases, family and friends may not be able to do it alone, and additional help may be needed. Talk with your medical team or your local Alzheimer's Society to determine what additional professional care is available. This additional help may be covered by the government or private insurance.

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Additional resources

Huddol

Visit the largest online caregiver support network in Canada, where you can learn, share and connect with experts and other caregivers.

huddol.com

Dementia Friends Canada

Dementia Friends Canada is a national campaign that helps Canadians learn about dementia, and then turn that understanding into simple actions that can improve the lives of people living with dementia.

dementiafriends.ca

Alzheimer Society of Canada

The Alzheimer Society of Canada offers information on Alzheimer's disease, dementia, research and treatments available in Canada.

alzheimer.ca

Helping Canadians live better days

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We're committed to caring for caregivers.

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