

# Caring for the Caregiver



Caregivers are family members, partners, friends or neighbours who provide personal, social, physical, and psychological support to someone in need, without getting paid.

Every caregiver's journey is unique and not always easy. Caregivers may experience joy and connection, but can also feel stress. In this chapter, let's focus on you, the caregiver.

This chapter provides strategies and resources for you to use to take care of yourself. You can use this chapter to:

- Check in to see how you are managing.
- Discover your strengths.
- Identify strategies, resources, courses, and books that are relevant to your situation.

*This information is not intended to replace the advice of a health care professional. Please consult a health care professional for advice about a specific medical issue. This chapter offers general suggestions – not rules – that may be adapted to meet your current and future needs.*

## Reminders for the Caregiver

Every caregiver is unique in their experience and comfort level with providing care and in their relationships with the people they provide care for.

- Sometimes your past relationship with the person you are caring for can influence the current caregiving experience.
- All families function differently, and some caregivers have to balance family dynamics when providing care.
- Having unrealistic expectations of yourself or comparing yourself to others may cause feelings of stress, anxiety, guilt, shame, anger, and resentment.

## Caregiver Wellness

Caregivers may experience stress that can impact their health. It is important to recognize when you, the caregiver, are feeling this way. Identifying and talking about stress are the first steps to feeling better.

The following are some common warning signs of stress. Do any of these statements sound familiar to you?

"I am not sleeping well."

"I have no time for myself."

"I don't have any time to socialize."

"I feel guilty if I don't meet my own expectations."

"I have not left home in a long time."

"I argue a lot more."

"I am worried about money."

"I don't know what I am doing."

"I am not doing a good enough job as a caregiver."

"I am sick all the time."

"I am at the end of my rope."

If one or more of these statements sound familiar, you may be experiencing caregiver stress.

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*"You can't care  
for someone else  
if you don't know  
how to take care  
of yourself!"*

– A caregiver from  
Hamilton, ON

### Take the Quiz!

The Ontario Caregiver Organization offers a quiz that encourages reflection on how you are feeling about the level of stress in your life. You can take the quiz here: <https://www.ontariocaregiver.ca/en/find-support/resources/Caregiver-Quiz--The-Ontario-Caregiver-Organization.pdf>

The Ontario Caregiver Organization also offers a checklist that guides you in identifying and assessing your caregiving responsibilities and prioritizes areas where you may need support. You can complete the Caregiver Checklist here: <https://www.ontariocaregiver.ca/en/find-support/resources/Caregiver-Task-List---Ontario-Caregiver-Organization-.pdf>



## Discover Your Strengths.

You may feel that your life is too busy to care for yourself, but think about how strong you are. Experienced caregivers have shared an excellent tip. They recommend that you figure out what gives you strength. Then, try to make time for the things that make you feel strong.

Many caregivers feel stronger when they:

### **Link with social supports.**

- Experienced caregivers explain that they feel stronger when family, friends, and other caregivers are around to support them.
- Think about who you would like to surround yourself with and arrange face-to-face time with those people.

### **Understand the caregiving role and feel knowledgeable.**

- Caregivers express that they feel stronger when they understand the health and well-being of the senior they are caring for and when they know what they can do to help.
- Find out who to talk to and how to share caregiving with others. Know where to find answers, what your role is within the circle of care, and how to ask for help.

### **Set boundaries and expectations.**

- Caregivers suggest that boundaries surrounding the care and support you provide should be based on what the senior wants and does not want help with.
- Understanding and respecting a person's wishes can help build a strong relationship and can decrease your feelings of stress and anxiety.

### **Connect to health care professionals.**

- Caregivers share that they feel stronger in their ability to provide care when they feel like they are being treated as a part of their person's care team by the health professionals they encounter.
- Refer to the *Helpful Tips to Communicate with Health Care Professionals* in each chapter of this Handbook.

### **Take time for self-care.**

- Experienced caregivers agree that they gain strength from self-care.
- Schedule time to relax and enjoy yourself; stay active; get together with friends; spend time with pets; find ways to get rest; and work through unpleasant emotions and thoughts with a trusted family member, friend, or therapist.

**Think about what you get out of caregiving.**

- Many caregivers feel good when they provide care for someone in need. These positive feelings make them feel energized and keep them going each day. One caregiver said, “I feel like I am giving back to someone who took care of me for so long, it makes me feel good to care for someone else.”
- Make a list of all of the good things that you get out of being a caregiver, to help you reinforce positive thinking about caregiving.

Take a moment to think about the things that make you feel strong. Incorporating these things in your life may help you to stay strong when things get tough. To guide your thinking, see [Tool 1.1: Caregiver Strengths Activity](#).

**Strategies for Wellness**

The following are strategies for self-care that may reduce feelings of stress and encourage wellness:

**Eat healthy meals and snacks throughout the day.**

- Include as many natural and “real” foods in your meals as possible (whole grains, protein, fruits and vegetables).
- Have snacks at the ready to grab and go (e.g. put them in your purse to take with you to appointments).
- Remember to stay hydrated (e.g. carry a water bottle during busy days).
- Make healthy meals in bulk (e.g. freeze individual portions for easy dinners).

**Try to stay active for two or more hours each week.**

- Add small activity into each day.

**Try to get at least seven to eight hours of sleep each night.**

- Depending on the level of support you are providing, this may be difficult. Try to find ways that will allow you to fall asleep without worrying that something might happen (e.g. Using a monitor so you can hear noises in other rooms).

**Give yourself permission to ask for help when you need it:**

- Ask someone you know to help you with a task or chore.
- Tell your health care professional that you are looking for more help with caregiving or with how you are feeling emotionally.
- Some people find it easy to ask for help, while others find it challenging. If you find it challenging, start by asking someone you trust to complete an easy task and go from there.



## Access Resources for Caregivers and Self-care

Finding the right resources to support you in your caregiving journey can be a challenge. Below are some suggested resources to get you started.

### Ask a health care professional.

Ask a person who can lead you in the right direction (doctor, nurse practitioner, nurse, pharmacist, therapist, etc.). The health care system can be difficult to figure out, and the steps will be different depending on who you talk to and where you live. There is no one way to figure out the health care system. Talking to knowledgeable people who are familiar with the resources in your area can be a good first step.

### Look Online.

**211 Ontario** is a free helpline that connects you with programs, services and resources in your area. You can call 211 or find the 211 Ontario website at:

<https://211ontario.ca/211-topics/health-care/>.

**Healthline Health Services for Ontario** provides access to local health and community services across Ontario. The Healthline Website is: <https://www.thehealthline.ca/> .

Watch the Healthline video about “Finding a Service in your Area”:

<https://www.youtube.com/watch?v=4ARBEGh6TS4>.

**A Guide to Programs and Services for Seniors** is a booklet of information on resources available for seniors in Ontario, including tax credits, health, caregiving, housing, driving and staying safe. You can download the guide here:

<https://www.ontario.ca/page/guide-programs-and-services-seniors>.

**Ontario Seniors:** for family and other caregivers is a website that offers information such as:

- Taking leave from work and the Employment Insurance compassionate care benefit.
- Respite care.
- Planning for care, care options.
- Having conversations about care.
- Understanding your role as caregiver and your role in another person’s health care.
- What to do when a loved one dies.
- Elder abuse.
- Visit the website at:

<https://www.ontario.ca/page/seniors-family-and-other-caregivers#section-0>.

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*“Give yourself  
permission  
to ask for help”*

– A caregiver from  
Cobourg, ON

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The **Government of Canada** offers a website dedicated to providing resources and guides for care options and planning for care, including:

- How to have care conversations.
- The Safe Living Guide - A Guide to Home Safety for Seniors.
- Your Emergency Preparedness Guide.
- Planning for future housing needs.
- Exploring financial options.
  - Visit the Government of Canada website at: <https://www.canada.ca/en/employment-social-development/corporate/seniors/forum/care-options.html>.
  - Watch the caregiver readiness video at: <https://www.canada.ca/en/employment-social-development/corporate/seniors/forum/caregiver-readiness-video.html>.

The **Ontario Caregiver Organization** has been created to help make it easier for family caregivers. Their focus is on raising awareness of the caregiving role, connecting caregivers to information and supports, and helping to bridge the services available so that all caregivers, regardless of age, condition or where they live will have access to the same resources. Visit the Ontario Caregiver Organization website at: <https://www.ontariocaregiver.ca>.

The **Fountain of Health** website offers strategies that are known to promote brain health and resilience. The website offers strategies and support for caregivers to try at home. Find the Fountain of Health website at: [www.fountainofhealth.ca](http://www.fountainofhealth.ca).

- Watch the short Fountain of Health video at: <https://youtu.be/FURi5aHgp1g>.

The Caregiving Matters website provides education, support, videos, and podcasts on many topics that matter to Canadian caregivers. Visit the website at: <https://caregivingmatters.ca/>.



**Hospice Palliative Care Ontario (HPCO) Caregiver Education Portal** provides information, educational resources, and support for family and friend caregivers, particularly related to the topics of death and dying and end-of-life care. Visit the website at: <http://www.caregiversupport.hpcoco.ca/>.

**The Canadian Virtual Hospice** provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators. Visit the Canadian Virtual Hospice website at: [http://virtualhospice.ca/en\\_US/Main+Site+Navigation/Home.aspx](http://virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx).

**The Change Foundation** supports improvement in Ontario's healthcare system by engaging family and friend caregivers and health care professionals to explore the health care issues of today. Visit the Change Foundation website at: <https://www.changefoundation.ca/>.

The **Alzheimer Society of Ontario** provides information and support related to the topic of Dementia. Visit the website at: <https://alzheimer.ca/en/on>.

The **Caregiver Exchange** website offers practical advice for busy Ontario caregivers. It contains many articles and videos that are free to access. You can subscribe for weekly newsletters to stay updated on what's new on the website. You can find out more about what this Ontario website offers at: <https://www.caregiverexchange.ca/>.

**CareChannel** is a website developed by the Saint Elizabeth Foundation that offers free resources for caregivers. This website offers access to over 100 helpful videos and instructional contents, supported in five different languages: English, French, Spanish, Mandarin, and Punjabi. For details, visit: <http://elizz.com/carechannel>.

## Take a Course!

### **Caregiving Strategies: Providing Care and Support for a Senior Living with Frailty**

A free online course offered by the Regional Geriatric Programs of Ontario, this eight-week course is designed for family and friend caregivers of seniors who want to learn about frailty and to develop strategies that support them in their caregiving role. You'll recognize this handbook as the complementary resource for this course.

Topics include:

- Caring for the Caregiver.
- Pain.
- Staying Active: Mobility and Fall Prevention.
- Nutrition and Bladder Health.
- Medication Management.
- Changes in Thinking and Behaviour (Delirium).
- Social Engagement.
- Bringing it all Together.

To learn more about this course, visit: [www.rgps.on.ca/caregiving-strategies](http://www.rgps.on.ca/caregiving-strategies).

### **Caregiving Essentials**

A free online course offered by McMaster Continuing Education, this seven-week course covers the following topics:

- Becoming a caregiver, (including legal and financial information).
- How to navigate the health care system and get the supports you need.
- How to take care of yourself so you can care for someone else.
- Health and medical information.

This course can be taken before or after the course mentioned above, Caregiving Strategies – Providing Care and Support for a Senior Living with Frailty, depending on your topics of interest.

To learn more about this course, visit: <https://mcmastercce.ca/caregiving-essentials>.



## Powerful Tools for Caregivers

Powerful Tools for Caregivers helps caregivers take better care of themselves while caring for a friend or relative.

This six-week course is offered through in-person classes during which caregivers develop a wealth of self-care tools to:

- Reduce personal stress.
- Change negative self-talk.
- Communicate with family members and health care professionals.
- Communicate effectively in challenging situations.
- Recognize the messages in their emotions.
- Deal with difficult feelings.
- Make tough caregiving decisions.

Participants also receive a copy of The Caregiver Helpbook, developed specifically for the course.

At this time there is not a central number to call to receive information about these workshops. Please be aware that you can access information about Powerful Tools for Caregivers workshops in your community through your local self-management programs. Information about local self-management programs can be found on the following webpage: <https://www.selfmanagementontario.ca/en/RegionalSite>

## Read a Book that Other Caregivers Recommend.

***Being Mortal: Medicine and What Matters in the End*** by Atul Gawande is a non-fiction book about the modern experience of mortality - about what it's like to be creatures who age and die. It is a recommended read for those who are aging and caregivers. New York: Metropolitan Books (2014)

***The Conscious Caregiver: A Mindful Approach to Caring for Your Loved One Without Losing Yourself*** by Linda Abbit is a non-fiction book that explores how to navigate caring for a family member or friend. Based on the author's personal caregiving experience, she shares valuable information on how to speak with the person you are caring for, handle emotional stress, finances, and care for yourself. New York, New York: Simon and Schuster (2017)

***Living With Dying: A Complete Guide for Caregivers*** by Katie Ortlip, RN, LCSW and Jahna Beecham is a caregiving guidebook that provides advice on how to:

- Have the conversation.
- Navigate the emotional and spiritual journey.
- Control pain.
- Address symptoms.
- Work with hospice.
- Care for yourself.
- Get your loved one's affairs in order.
- Ashland, Oregon: Starcatcher Press (2016)

***The Unexpected Journey of Caring: The Transformation from Loved One to Caregiver*** by Donna Thomson and Zachary White looks at how disorienting this time is for families and offers a comprehensive guide for family or friend caregivers so they can turn outward to their communities for help. Lanham, Maryland: Rowman & Littlefield Publishers (2019)

***A Guide for Caregiving: What's Next? Planning for Safety, Quality, and Compassionate Care for Your Loved One and Yourself*** by Tina Marrelli. Written specifically for family and friend caregivers, this guidebook seeks to make health care understandable and to value and respect the expertise of family, friends and other caregivers. Venice, Florida: Innovative Caregiving Solutions LLC (2017)

## Summary

As a caregiver, you may help a person with any or all of the following:

- Transportation.
- Cooking.
- Cleaning.
- Appointments.
- Bathing and dressing.
- Supporting them from a distance.
- Other.

No matter what, caring for another person requires you to take care for yourself. This chapter has shared some strategies to support you to take care of yourself. This chapter has also provided some resources available to you.

This chapter has focused on you, the caregiver. The following chapters will focus on clinical topics and caring for a senior experiencing frailty.



**Tool 1.1 - Caregiver Strengths Activity**

Take a moment to consider the questions below. By identifying your strengths, you will be better able to enhance your social network and prioritize self-care as part of your caregiving practice.

1. Experienced caregivers explain that they feel stronger when family and friends are around to support them.

- Who are some of the people you can count on for support?

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2. Caregivers share that they feel stronger in their ability to provide care when they feel that they are being treated as a part of their person’s care team by the healthcare professionals they encounter.

- What does it mean for you to feel included as part of the care team? What would an ideal caregiving team look/feel like for you?

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3. Experienced caregivers agree that they gain strength from self-care. For example, taking time to relax, enjoy themselves, stay active, spend time with friends, spend time with pets, and rest.

- What are some activities or ways that help you stay replenished?

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4. Although not the case for everyone, many caregivers express that providing care to another person makes them feel good. These positive feelings make them feel energized and keep them going each day.

- In what areas of caregiving do you find joy?

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- What areas of caregiving do you find stressful?

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5. Experienced caregivers explain that they are able to stay strong by searching inside themselves and relying on their strength of character to keep them going during difficult days. Some examples of these strengths include patience, love, faith, core values, integrity, and compassion.

- What strengths do you possess and draw from when you are faced with challenges?

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## References

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For more information on the Senior Friendly Caregiver Education Project and the Regional Geriatric Programs of Ontario, please visit [www.rgps.on.ca/caregiving-strategies](http://www.rgps.on.ca/caregiving-strategies).

