



UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE
DE L'UNIVERSITÉ D'OTTAWA

Living Well as a Caregiver



TIPS, TOOLS, AND RESOURCES FOR CAREGIVERS AND FAMILIES

Acknowledgements

This guide is for caregivers and families of people with heart disease. It contains tips, tools, and resources to support you in your role, and strategies for taking care of your mental, physical, and emotional health.

This guide was carefully developed by members of our care team in collaboration with patients and caregivers with lived experience. Thank you to everyone who shared their ideas and suggestions with us so we could develop a guide that is as helpful and relevant as possible.

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This document is also available in French under the title: | *Cette publication est aussi disponible en français sous le titre : Mieux vivre comme proche aidant*

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The Living Well as a Caregiver guidebook



Nearly 30% of Canadians provide care to family members or friends with a long-term health condition, disability, or problems associated with aging.

Cardiovascular disease is a leading health issue in Canada that often requires caregiving. For some people, the need to provide care can happen overnight, such as when a loved one has a heart attack. For others it occurs gradually over time.

If you are a caregiver, you may help your loved one with a variety of tasks, including helping with grocery shopping and cleaning, managing prescriptions and medical appointments, assisting with mobility and transportation, running errands, performing activities of daily living (such as personal hygiene and eating), and providing emotional support.

As your loved one's health condition changes, the caregiving tasks you undertake may change as well. Certain transitions, such as coming home from the hospital or returning to work, may bring about additional caregiving challenges. Caregiving experiences are also different depending on for whom you are providing care (for example, a spouse or a parent) and whether you live with or near that person.

All caregivers at any phase in the caregiving journey are a vital support to their loved one.

This “Living Well as a Caregiver” guide is designed to support caregivers of patients with cardiovascular disease. This guide presents tips for providing high-quality care for a loved one, and tools for taking care of yourself. In this guide and on our website, you will find several resources to inform your specific self-care needs, including information about physical activity, stress, and sleep. You will also find additional resources designed for caregivers, offered by the University of Ottawa Heart Institute and beyond.



If you would like **additional tips and strategies** to improve your skills, knowledge, and confidence as a caregiver, the following courses are free and available to caregivers.

- **Provincial Geriatrics Leadership Ontario: Caregiving Strategies**

Topics covered in this free online course and handbook include caring for the caregiver, pain, staying active, nutrition, bladder health, medication management, and changes in thinking and social engagement. New resources designed by caregivers and health experts are available.

Visit rgps.on.ca/caregiving-strategies

- **Champlain Hospice Palliative Care Program: Practical Caregiving Training**

A five-week workshop series for caregivers to help reduce stress and make caring safer. The program is intended to increase your skills and knowledge and strengthen your support network. This training is free and currently offered in English.

Visit champlainpalliative.ca/practical-caregiver-training

- **Living Healthy Champlain: Support for Caregivers**

Offered free of charge and in both English and French. *Powerful Tools for Caregivers* includes six sessions to help you develop self-care tools. The *Living a Healthy Life* workshops aim to help individuals take charge of their health while living with chronic conditions.

Visit livinghealthyhamplain.ca/en/supportforcaregivers

- **Institut universitaire de gériatrie de Montréal — MeSSAGES** (French only)

An online seven-week program that provides French-speaking caregivers with training, education and tools about caregiving and stress management.

Visit ciusss-centresudmtl.gouv.qc.ca/soins-et-services/personne-proche-aidante/formation-proches-aidants-gestion-du-stress

You may also consider contacting a support line designed for caregivers. Here are some recommended suggestions:

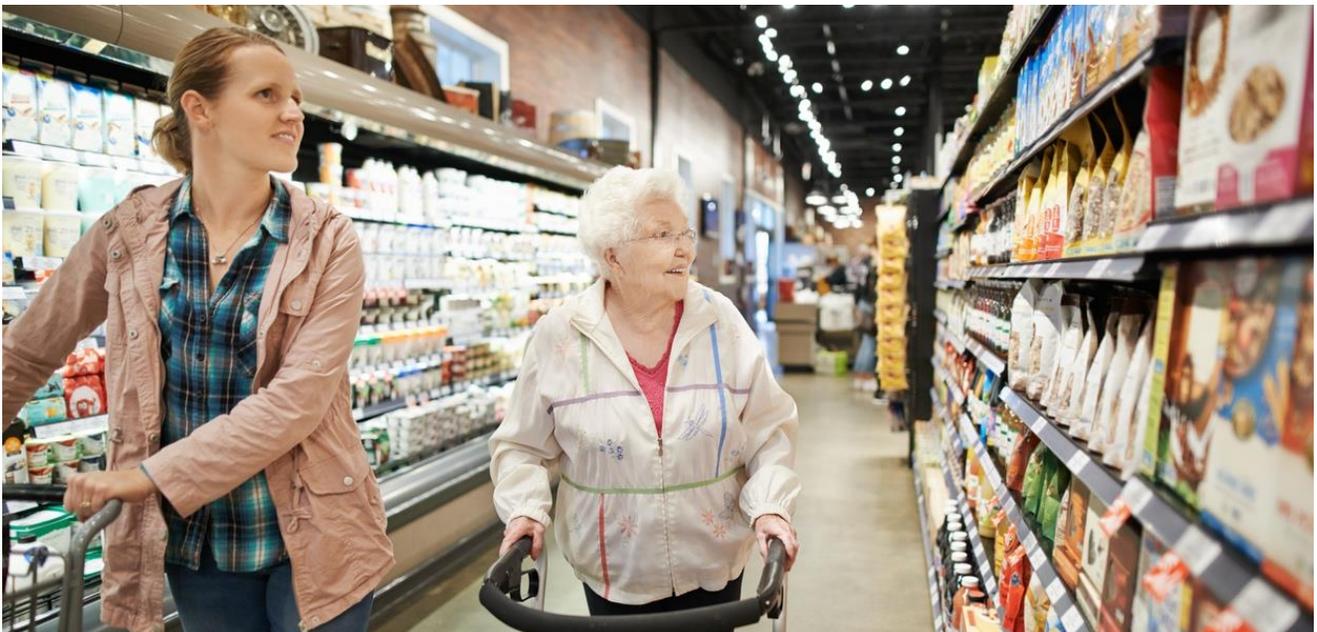
- **The Ontario Caregiver Healthline (available 24/7)**
1-833-416-2273 (CARE)
Live chat: ontariocaregiver.ca/helpline
- **Caregiver Support Service – Quebec**
1-855-852-7784
- **Proche aide Québec**
A collection of community organizations supporting caregivers.
514-524-1959
procheaide.quebec



Top 10 tips for caregiving

- 1 Take care of yourself:** Exercising regularly, getting a good night's sleep, and eating properly will boost your mood and give you more energy to help your loved one. Monitor your mental health. Keep up with your own appointments and medication. Speak up if you feel you need a break or that your own health is worsening. Protect some of your time (even if it is short) to explore a passion or engage in activities that bring you joy. Doing what you love will give you some respite and allow you to recharge.
- 2 Keep organized and informed:** Write down your questions or concerns before meetings with healthcare providers. Take notes during appointments. Educate yourself about your loved one's condition. Keep your loved one's medical information organized and stored in a consistent, secure, and easily accessible place.
- 3 Seek and accept outside help:** You are not alone. There are resources in the community designed to support caregivers. If you do not feel comfortable accessing these resources yourself, ask a healthcare provider to connect you. Give yourself permission to ask and accept offers of help from friends and family.
- 4 Connect with others:** Staying socially and emotionally connected with others will help to reduce stress. Supportive others can offer advice, encouragement, or answer your questions. Consider connecting with another caregiver who understands what you are going through. Be sure to spend time with the person you care for in a personal way, not just in a way that is related to caregiver tasks.

- 5 Communicate clearly:** Patients and caregivers that are communicative, accessible, and responsive to each other are better able to adapt to the upheavals and uncertainties of heart disease. Be clear when communicating your needs and feelings.
- 6 Be open to change:** Tackling lifestyle changes together can improve your health and strengthen your relationship. Communicate with your loved one about changing family dynamics. Collectively decide on new household roles and responsibilities.
- 7 Give control back:** Letting your loved one take back some of the activities of daily life is an important part of the recovery process. This can offer your loved one a greater sense of control and lessen the burden on you.
- 8 Talk about and plan for the future:** When managing heart disease, understanding what is coming next can help you to prepare now and reduce stress later. Speaking about the future beyond your loved one's health condition or your role as a caregiver is also important. Set personal goals. Establish family priorities. Make plans to engage in meaningful activities.
- 9 Recognize your strengths:** Caregiving can be a rewarding and positive experience. Recognize your limitations but be sure to acknowledge your strengths and capabilities. Be gentle with yourself. Give yourself credit for doing the best job that you can.
- 10 Acknowledge the rollercoaster of caregiving:** There are many twists and turns in the caregiving journey. Recognizing caregiving will be full of ups and downs will help you to anticipate and prepare for bumps in the road, appreciate the highs, and identify the lows.





1 Take care of yourself

Caregiving is not easy. It is full of daily challenges that can be emotionally and physically demanding. Caregivers who are occupied with caring for a loved one may have fewer opportunities for exercise and restful sleep. They may neglect their own diets and emotional health. Feeling stressed, especially for long periods of time, is not good for your health. Ignoring your needs negatively affects you. It can limit the care you are providing to your loved one.

As a caregiver, are your responsibilities impacting your ability to:

- Meet your exercise/physical activity goals?
- Make healthy food choices, especially during times of stress?
- Keep up with your own appointments and medication?
- Feel emotionally well and socially connected?
- Take breaks?
- Engage in activities you enjoy?



It is common for caregivers to answer “yes” to any or all these questions, but it signals you could consider building more time for self-care. **Remember, everyone benefits when you take care of yourself.** It is important to recognize that *filling your own cup* allows you to be a more patient and loving caregiver.

Below are strategies to help you take care of yourself. On pages 30 to 34 of this guide, you will find our **top 10 tips** for physical activity, healthy eating, managing stress, emotional health, and sleep. You will also find a link to several helpful resources.



Engage in physical activity

Exercise regularly, even if only for 10 minutes at a time. When possible, consider exercising at the same time as your loved one. Exercising does not need to be strenuous. It can involve taking a walk, gardening, cleaning the house, or even stretching.



Make healthy food choices

Food can impact your mood and energy levels. Remember, healthy eating is about more than just the food you eat. Take time to eat. Involve others in planning and preparing meals. Enjoy your food.



Reduce stress

Caregiving for a loved one can be stressful. Short-term stress can make you more alert and able to deal with the situation, but long-term stress is not good for you. Although most of us can't eliminate stress from our lives completely, we can learn to manage our stress better. The first step is to identify what you can and cannot change and focus on what you can. Remember to speak with your healthcare provider if you feel you are having a difficult time coping or if your stress is not improving.



Prioritize your emotional health

You may experience varying emotions and your mood may change from time to time. Maintaining your emotional health may include reducing negative emotions, like anxiety or feelings of depression. It is also important to think about ways to improve your positive emotions as well, such as feelings of optimism and a sense of purpose. Remember, it is common to experience changes in your mood. However, if these changes are impairing your ability to function, please contact your doctor or mental health professional (for example, a psychologist, psychiatrist or psychotherapist).



Take breaks and sleep well

Taking breaks is crucial and will make you a more compassionate and attentive caregiver. When you notice signs of fatigue or frustration, it may be time to take a break from caregiving. Allow yourself to ask for help. Your downtime should also include quality sleep. It may be difficult for you to find the time to sleep. The stress you feel from caregiving may disrupt your sleep. Fortunately, there are effective ways to deal with sleeping problems.



2 Keep organized and informed

Keeping up with the practical demands of caregiving may be difficult. You may need to assist your loved one at several appointments, help with the management of their medication, and uphold regular household tasks. Balancing these responsibilities can feel overwhelming. Developing an organizational plan may be helpful. For example, store your loved one's medical information in a consistent and secure place. Keep a separate calendar of your loved one's appointments. Set up reminders for yourself. If you have a cell phone or computer with internet access, consider downloading an app or program to help you stay organized. Keep a list of the names and contact information of your loved one's healthcare providers. Store this list in an accessible place.

Before a medical appointment

Many caregivers choose or need to accompany their loved one to health appointments. *It is important to first obtain permission from your loved one to attend these appointments.* Prior to the appointment, you and your loved one could discuss the concerns you would like addressed. It may be helpful to educate yourself about your loved one's condition. Note any questions to ask the healthcare provider. Write down these talking points. Bring this list with you to the appointment. Bring a list of medication your loved one is taking. Include the dosage and schedule.

Below is a list of patient guides available to patients and families. Each guide is tailored to a specific diagnosis or treatment plan. Guides are available online at ottawaheart.ca.

- Atrial Fibrillation
- Coronary Artery Disease
- Diabetes Medications (videos)
- Heart Failure
- Cardiac Catheterization and Angioplasty
- Complex Ablation
- Electrophysiology Studies and Standard Ablation
- Heart Transplant
- Implantable Cardioverter Defibrillators (ICDs)
- MitraClip
- Pacemaker Implantation
- Pulmonary Thromboendarterectomy
- Recovering from Cardiac Surgery
- TAVI: Transcatheter Aortic Valve Implant
- Therapeutic Hypothermia
- Waiting for Cardiac Surgery
- A Guide to Women’s Heart Health
- Cardiac Rehabilitation: Physical Activity
- Heart-Healthy Living
- Your Guide to the University of Ottawa Heart Institute

Parking at hospitals and clinics can sometimes be frustrating. If it’s possible for you, consider taking a taxi, public transit, or asking a family member or friend to drive you. Depending on your loved one’s ability and access to transportation, you may be eligible for ParaTranspo, a shared ride, book in advance, public transit service. Contact Lifemark Health Group at 613-218-8417 to receive an application form by mail.

During the appointment

It may be helpful to take notes at the appointment. If your loved one has not asked a question you both planned for, you may prompt your loved one by saying, “[patient name], do you still want to ask about...?” It is important your loved one is provided the space to answer the healthcare provider’s questions first. Try to avoid having a two-way conversation with the healthcare provider and yourself. Also, you may be asked to leave the room for privacy reasons. If the appointment is virtual, ask the healthcare provider if a speaker phone or a shared video screen may be used during the appointment.

After the appointment

Review your notes together. Write down any additional questions you may have. Write whether these questions need answers right away or if they can wait until the next appointment. Be sure to add dates to your notes. Write down the next steps to follow up on, including any medication changes and future appointments. Add this information to your calendars or other organizational tools.



3 Seek and accept outside help

Many caregivers feel they need to do it all and to do it alone. Although this is a common feeling, this approach can contribute to higher levels of stress and can lead to caregiver burnout.

It can be difficult to ask others for help because you feel you are responsible for the health and happiness of your loved one. The first step is to acknowledge that you are not alone. In fact, there are likely many people in your life who would love to help. There are also many resources in the community available to support you and your loved one. Give yourself permission to ask for help. Seeking and accepting support from others allows you to:

- Build connections with family, friends, and community members
- Learn new approaches for caring for your loved one
- Take a break and recharge
- Engage in self-care

Others may be glad to help but are unsure how. Be specific with the tasks others can help. Let them know that their help is appreciated.

In some situations, help from family or friends is not possible. There are many organizations and services available to support caregivers. The UOHI webpage, ottawaheart.ca/caregiver-resources, provides detailed information to support caregivers with:

- Convalescent care and respite care
- Driving/transportation
- Snow removal
- Employment insurance, sickness benefits and compassionate care benefits
- Finding a family doctor
- Home care/support
- Meals
- Medications
- Oxygen
- Personal emergency response/MedicAlert
- Physiotherapy
- Power of attorney
- Substitute decision-making
- Travelling for care
- Wills
- General resource listings

You and your loved one may also ask for a referral to a social worker at the Heart Institute who may be able to help navigate these resources with you.



4 Connect with others

When caregivers have a strong social support network, they are better able to care for themselves and their loved one. It is important to maintain social connections to feel less isolated and avoid burnout. One can connect with others informally, such as through a phone or video call to a family, friend, or neighbour. You can also socially connect through more formal networks whether online or in-person. Your workplace, community organizations, religious centres, or health facilities may be great places to start if you are looking for opportunities to expand your social network.

Options for connecting with others can include:

- Physical activity classes or sports teams
- Walking groups
- Special-interest clubs or events
- Religious, faith-based, or spiritual community groups
- Social media special-interest groups (for example, Facebook)

Social support groups can be helpful for building connections, learning new information, and providing or receiving emotional support from others. It is important, however, that you *save important questions about your loved one's health condition (and your own) for healthcare providers.*

The University of Ottawa Heart Institute hosts many support groups for patients that caregivers are welcome to attend. These groups provide opportunities for patients and caregivers to share their experiences, discuss challenges and strategies for recovery, and to connect on a personal level.

Support groups for patients and caregivers

Patients of the University of Ottawa Heart Institute and their families or caregivers have access to several free support groups that focus on health topics and conditions, such as the Aortic Diseases Support Group, the Heart Failure Support Group, the ICD Support Group, and the Women's Heart Health Education Group. You can confirm the group's meeting time, location, and video link (if applicable) on the Heart Institute's online event calendar. Visit ottawaheart.ca/calendar.



There are also several **online caregiver support groups** available outside the Heart Institute. For example:

- **Care Supporters' Community:** Moderated by Heart and Stroke, this online community provides social and emotional support for caregivers in Canada.
Visit heartandstroke.ca/heart-disease/recovery-and-support/the-power-of-community
- **HeartLife Foundation:** A group for patient and family carers in Canada to talk freely and share experiences about heart failure in an online environment.
Visit heartlife.ca/caregivers
- **Well Spouse Association:** A non-profit organization that offers peer support and education about the special challenges and unique issues facing spousal caregivers.
Visit wellspouse.org



5 Communicate clearly

Good communication skills are critical to effective caregiving. Problems sometimes arise when there is a misunderstanding or poor communication. Effective communication skills involve **active listening** and **expressing yourself clearly**.

Active listening

Active listening is listening to what someone is saying and understanding their meaning and the intent behind their words. This involves many techniques. Be fully present in your body language (for example, maintain eye contact). Ask open-ended questions (for example, “*How do you feel?*” rather than “*Do you feel sad?*”). Notice non-verbal cues (for example, looking down or away or fidgeting). Withhold judgment or advice. Reflect and repeat what has been said to the speaker.

An example of active listening:

Patient: *I’m sorry to dump this on you, but I don’t think I want to go on this vacation.*

Caregiver: *Really? Can you tell me a bit more about how you are feeling?* (Open-ended question.)

Patient: *I feel uneasy being that far from a hospital. What if something happens to me?*

Caregiver: *It makes sense you would feel more comfortable staying home.* (Withholding judgment.)

Patient: *I’d feel bad for making you stay home. I know you want to go on this vacation. And I don’t want to stop living. I wish I wasn’t so scared.*

Caregiver: *I can see you are feeling a lot of emotions right now, including guilt and fear. (Reflecting.) Is there something I can do to make things better?* (Open-ended question.)

There are many **barriers** to good listening. Feelings of fatigue, worry, and frustration may make it difficult to listen to what your loved one is saying. We may also have preconceived ideas that can interfere with listening with an open mind. It may be helpful to ask yourself what makes it difficult to listen to your loved one. Consider your own needs, emotions, attitudes, and environmental barriers. Address these factors as best you can. For example, avoid addressing issues when you are distressed or tired. You might consider waiting to have a discussion until you are free of distractions or refreshed after a small break or good night's sleep.

Expressing yourself clearly

When your communication is clear, assertive, and constructive, you are more likely to get the responses you want. You can use these following techniques when speaking with your loved one, family members and friends, as well as healthcare providers.

- Share your own thoughts to get the conversation started.
- Use “I” messages rather than “You” messages (“I feel angry” rather than “You make me feel angry”).
- Ask for clarification if you aren’t sure what the other meant.
- Be specific and straightforward.
- Avoid phrases that may shut down the conversation (for example, “Don’t worry about that”).
- Focus on the topic at hand.
- Remain calm and try to be positive (for example, emphasize what you can do rather than what you cannot do).
- Check in to make sure you are understood.
- If at first you don’t succeed, try again.



For **more tips** on communicating effectively as a caregiver, please visit:

- **The American Heart Association’s communication tips for caregivers**
heart.org/en/health-topics/caregiver-support/communication-tips-for-caregivers
- **Family Caregiver Alliance’s “Communicating Constructively”**
caregiver.org/resource/taking-care-you-self-care-family-caregivers/#tool-4



6 Be open to change

Living with heart disease can prompt many changes to your loved one's life and your own. In addition to making lifestyle changes (diet, smoking, etc.), patients may experience career changes or disruptions and shifting roles or tasks within the family unit. These changes impact caregivers as well. Sometimes, caregivers can find adjusting to these changes difficult.

Below are strategies to help you adjust to these changes. Keep in mind that not all changes are bad. Some caregivers report their loved one's heart event or diagnosis led to many positive changes in their lives.

Adjusting to lifestyle changes

Encouraging your loved one to make lifestyle changes is important. Consider tackling them together. This can improve your relationship and your health.

The first step is to acknowledge you can make changes to your life. Start small. Only add one new change at a time. Plan with your loved one and write it down along with some of the challenges you may encounter and how you will address them.

Remember, it is common to experience setbacks. Try not to be discouraged when you have a setback or if you are not achieving your goals. Focus on what you have achieved. Reward yourself (and each other) when you meet your goals.

Adjusting to family role changes

Communicate with your loved one about changing family dynamics. Collectively decide on new household roles and responsibilities. Your roles may change as your loved one's health condition changes.

Check in with each other frequently and at important transitions (for example, discharge from the hospital, going back to work). Ensure you are both on the same page about your roles and responsibilities.

It is common for caregivers to try to take on too much. It is important to recognize what your loved one *can* do. Contributing to household tasks and to the needs of the family can give your loved one a sense of satisfaction and purpose.

Adjusting to relationship changes

Positive spousal and family relationships are so important for your health and wellbeing. People react in different ways to stress.

Some caregivers may become more closed off or shut down when facing a loved one's health challenge and may try to avoid the situation. Other caregivers may want to be close and may seem overprotective of the patient. Recognize relationship strain is a typical part of adjusting to chronic illness. Be open about changes you've experienced in your relationship. Work together to handle these changes.

Amid these changes, it is important to maintain a connection with one another by setting aside deliberate moments to be together. Sexual activity is often a great concern for both patients and their partners after a cardiac event. You or your partner might fear sexual activity will cause further heart problems. Speak to your healthcare provider if you have this concern. For more information and resources about healthy relationships and sexual health, visit ottawaheart.ca/living-well-caregiver.

Adjusting to career or financial changes

Some caregivers take time off work to help their loved one adjust to their heart condition. In many cases, caregivers will go back to the same sort of work they used to do. But, in some cases, caregivers will work fewer hours or may feel they need to switch jobs to care for their loved one.

Talk to your employer about any suggestions a healthcare provider has given you with respect to your caregiving duties. Changes to your employment may put stress on your finances, especially if your loved one is also not able to work in the same capacity as they could before. As with other adjustments, it is important to be open and honest with your loved one about your concerns. It is important to make decisions together.



To **learn about financial supports**, you may request a referral to a social worker. If the patient needs assistance navigating returning to work, they may be referred to a vocational rehabilitation counsellor experienced in cardiac rehabilitation.

Heart and Stroke has a list of available financial support programs. Visit heartandstroke.ca/services-and-resources/financial-support to learn more.

In addition, many companies offer benefits, such as confidential counselling services for employees to address problems that affect their work, finances, health, mental and emotional wellbeing. Counselling is typically short-term.

Note: Federal employees, members of the Canadian Forces, and individuals covered by Veterans Affairs Canada Assistance Service are covered for many services. In some cases, coverage extends to immediate family members and dependents.

Call 1-800-268-7708 or 1-800-567-5803 or visit canada.ca/en/health-canada/services/environmental-workplace-health/occupational-health-safety/employee-assistance-services/employee-assistance-program.html to learn more.

Non-insured health benefits for First Nations and Inuit

Coverage for a variety of health benefits including counselling services.

1-800-567-9604

sac-isc.gc.ca/eng/1572537161086/1572537234517



7 Talk about and plan for the future

Experiencing a heart event or diagnosis is a life-changing event for the whole family. You may find yourself trying to understand what happened to your loved one and questioning what to do next. Feelings of confusion and uncertainty are common. In the immediate weeks and months following the heart event or diagnosis, you and your loved one will be focusing on taking it one step at a time.

Although it is important to focus on the present, it is also helpful to have discussions about what to expect, shared goals, and wishes for the months and years ahead. Talking about and planning for the future can help patients and caregivers feel a sense of optimism for things to come (an upcoming trip, retirement, etc.). This helps patients and caregivers recognize their lives do not need to be defined by heart disease.

Talking about and planning for the future isn't solely about solving a problem and moving on. It can give your loved one the space to express themselves and share their stories and thoughts. By doing so, you can both get a better picture of what's important. Start small, go slow, and talk often. A single conversation is rarely enough.

Talking about the future, especially related to **care plans**, can feel daunting, uncomfortable, or upsetting. We sometimes put off conversations about care until we are in a pressure situation. As your loved one recovers from their heart condition, use this opportunity to have discussions about their future care. This can feel difficult in the beginning, but there are many benefits to planning ahead.

- It can give both of you peace of mind for the future.
- You can make arrangements ahead of time.
- Knowing their wishes means they are more likely to be met.
- You can find out what's important to your loved one and avoid family arguments and stress.

There are several things you can do now to feel more at ease, knowing that your loved one's wishes are understood. This includes organizing your important documents; completing a will; discussing care homes and advanced care plans, including the use of assistive breathing or feeding devices, and desires for resuscitation; final arrangement preferences (for example, cremation, burial site, funeral/celebration of life), and communicating wishes about organ, tissue, or body donation.



The following are **resources** to help support these important discussions.

- **Ministry of the Attorney General: Make a Power of Attorney**
ontario.ca/page/make-power-attorney
1-800-891-0504
- **Government of Quebec: Power of Attorney**
quebec.ca/en/finance-income-and-other-taxes/power-attorney-legal-protection/power-attorney
1-877-644-4545
- **Harvard Medical School: Survival Tips for Current and Future Caregivers**
health.harvard.edu/healthbeat/survival-tips-for-current-and-future-caregivers
- **The Conversation Project: Free Conversation Guides on Wishes for Care through the End of Life**
theconversationproject.org/get-started

If you wish to discuss or explore future planning informally, you and your loved one may request a meeting with a social worker.



8 Give control back

There are often power dynamics in patient-caregiver relationships. In some cases, caregivers control many aspects of their loved one's life, leading to a power imbalance. Sometimes caregivers may make decisions without consulting their loved one, feeling they are acting in their loved one's best interest. To help prevent power imbalances, regularly check in with your loved one. It can be helpful to set aside a scheduled time each week to talk about any changes to care plans or needs. Consider enlisting nursing, social work or psychological support to help navigate family dynamics and decision-making.

Recovery from a cardiac event is a challenging process. Both you and your loved one may be thrust into unfamiliar roles and dealing with unaccustomed tasks. It can be frustrating and frightening. There is a natural tendency to want to do everything you can for your loved one. Letting your loved one take back some of the activities of daily life is an important part of the recovery process. This can offer your loved one a greater sense of control and lessen your responsibilities.

It may be difficult to pinpoint what and when certain tasks can be transferred back to a loved one. You may be worried they are not yet ready to take on certain tasks (for example, driving, carrying the groceries). As a caregiver, it is common to feel overprotective. Overprotection comes from a good place. You worry about your loved one and want them to be safe. For patients, overprotection may lead to anxiety, resentment, and tension in the relationship. Be sure to include your loved one in any decision-making and involve a healthcare provider if you need more information or to provide reassurance.

A family meeting may help decide how to share caregiving responsibilities and to give some control back to the patient. These meetings give the patient, caregiver, and other family members or providers the opportunity to discuss concerns, identify problems and solutions, and negotiate the sharing of tasks. It can also reduce misunderstandings and clarify each person's expectations.



For **more information** on family meetings or shared decision-making, please consult the following resources.

- **Family Caregiving Alliance: Holding a Family Meeting**
caregiver.org/resource/holding-family-meeting/
- **Daily Caring: Caregiver Family Meetings — Five Keys to Success**
dailycaring.com/5-keys-to-successful-caregiver-family-meetings/
- **The Ottawa Hospital: Patient Decision Aids**
decisionaid.ohri.ca/decguide.html



9 Recognize your strengths

Caregivers are mentally and physically strong, but they do not always feel it. Focusing on your strengths rather than your perceived weaknesses can help you to create positive thinking patterns, which may improve your mood, increase your confidence, and reduce your stress. Once you recognize the internal strengths, you can develop an action plan to use them to address challenges and difficulties. Below is a list of exercises that may help you to identify your caregiving strengths.

Exercise one

In the last week, think of a time when you demonstrated:

- Patience
- Organization
- Acceptance
- Flexibility
- Creativity
- Humour

In the last week, think of a time when you felt:

- Optimistic
- Grateful
- Courageous
- Resilient
- Self-compassion
- A sense of purpose



Place a checkmark next to the behaviours and feelings you had over the past week. For every check-marked item, be specific about the event or occurrence. Revisit this list, especially during times of low-confidence and stress.

Exercise two

Set aside a few minutes for personal reflection. Ask yourself the questions below. If it helps, write down your responses and revisit these answers when you are feeling stressed or down. You can also ask your loved one to answer these questions about you.

- What gives me energy?
- What do I do well?
- What comes naturally to me?
- What are my best character traits?
- What things do I look forward to doing?
- When faced with challenges, what strengths do I bring?
- What do I handle well?

Remember, there are no right and wrong answers. Do not judge or filter your responses — just record them as they come. Identifying and being aware of your strengths will serve both you and the loved one for whom you are providing care.



Below are **resources** to help you identify your strengths and focus on the positive.

- **The Berkeley Well-Being Institute: Strength Findings — 57 Questions, Exercises & Activities**
berkeleywellbeing.com/strength-finding.html
- **Mind Over Mood: Change How you Feel by Changing the Way You Think**
by D. Greenberger and C. Padesky



10 Acknowledge the rollercoaster of caregiving

The care you provide for your loved one will change throughout the caregiving journey. The support needs that are often required of caregivers in each phase are listed below.

Initial phases of caregiving

- Notifying others of the event or diagnosis
- Learning about the disease, expectations for prognosis, and treatment
- Assisting in the coordination of care with healthcare providers
- Preparing for discharge and integration back home
- Providing emotional support

Intermediate phases caregiving

- Assisting with activities of daily living
- Assisting with rehabilitation needs
- Learning self-care or preventative health behaviours
- Assisting with medication management
- Assisting with clinic appointments and follow-up appointments
- Preparing for upcoming surgeries
- Providing emotional support

Long-term caregiving

- Assisting with follow-up appointments
- Providing ongoing medication management
- Encouraging preventative health behaviours
- Navigating life transitions (for example, career and financial changes)
- Providing emotional support

End of life

- Decision-making about treatment options
- Assisting with advanced care planning
- Proxy decision-making
- Making end of life arrangements (funeral, celebration of life, etc.)

Post death

- Bereavement
- Transition to post-caregiving role

Keep in mind that although there are often distinct phases to caregiving, there are many twists and turns and ups and downs along the way — some you can predict and some you cannot.

There may be bumps in the road that caregivers and patients experience over time. Caregiving can be challenging during periods of transitions, including during hospitalization, when a loved one receives a diagnosis, discharge from the hospital, resuming work or leisure activities, or rehospitalizations and follow-up appointments. The emotions experienced at each phase may also vary. They may include many highs and lows. Caregivers may experience fear, uncertainty, anger, guilt, hopelessness, grief, and loneliness as well as feelings of relief, optimism, determination, and gratitude.

It may be helpful to envision caregiving as a rollercoaster ride during which each turn, hill, and loop brings new responsibilities, priorities, and emotions. Acknowledging the rollercoaster of caregiving allows caregivers to anticipate the bumps in the road and to prepare. It also encourages caregivers to cherish the highs when they happen and to recognize the lows are temporary. Remember, on the caregiving rollercoaster, it is completely natural to want to take a few deep breaths, close your eyes, or even scream. Prioritizing your own health, taking a break, and expressing your emotions are healthy responses.



Top 10 tips for physical activity

1. **Remind yourself** that it's important to prioritize your health to help your loved one.
2. **Start small** and gradually increase your intensity to suit your needs and ability. Listen to your body.
3. **Choose an activity that you enjoy** and that fits with your lifestyle.
4. Exercise with a **buddy**.
5. **Keep an exercise log**. This way you can see your progress and keep track of how you feel.
6. **Set SMART* goals** and talk about them with important people in your life.
7. **Reward yourself** when you reach your goals.
8. **Track your progress**. Focus on effort rather than the result.
9. **It's normal to slip out of your exercise routine**. When you notice it happen, start from where you left off.
10. **Plan your activity** for the cold winter months (for example, mall walking).

*For the definition of a SMART goal, visit ottawaheart.ca/document/heart-healthy-living-guide.



For additional information and resources about physical activity, visit ottawaheart.ca/living-well-caregiver.

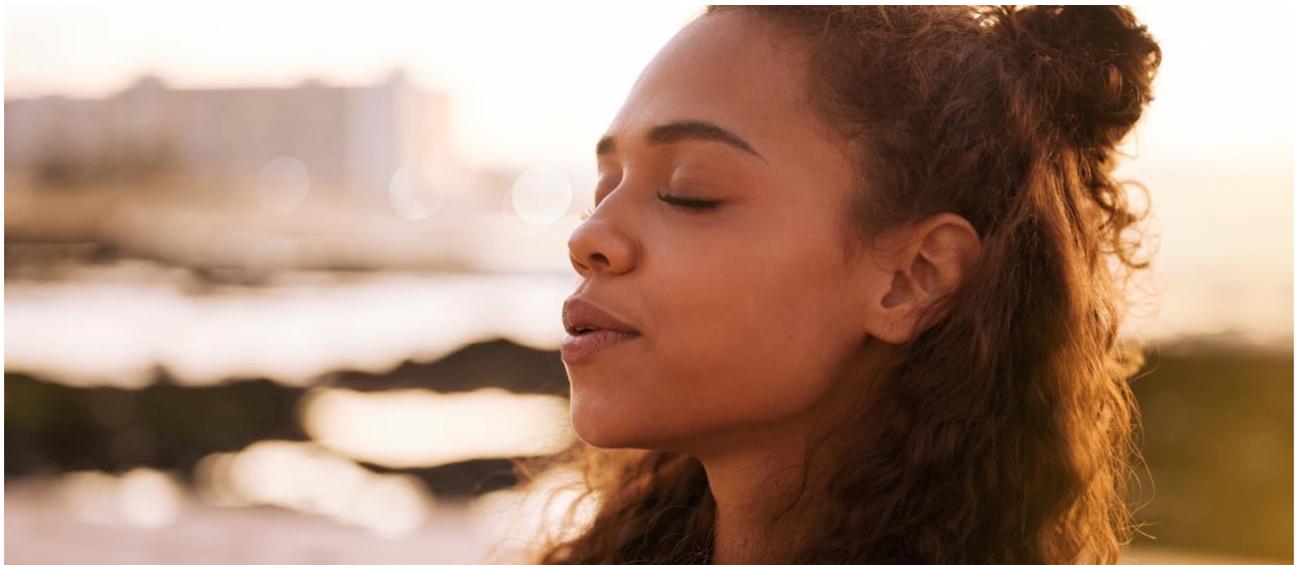


Top 10 tips for healthy eating

1. **Cook at home more often.** Cooking at home makes it easier to avoid processed foods. It can be as simple as scrambled eggs, whole-grain toast, tomato, and cucumber slices.
2. **How you eat is as important as what you eat.** Enjoy mealtimes and the food you eat! Enjoy your food without distractions like your smart phone or TV. Sit and enjoy a meal at the table. If you live with others, eat together.
3. **Listen to your body.** Eat when you're hungry and stop when you feel satisfied.
4. **Eat at regular times.** Eat breakfast within one to two hours after waking up. Don't wait too long between your meals. It's harder to make healthy choices when you're hungry.
5. **Plan healthy snacks.** Try whole-grain crackers and peanut butter or hummus, a piece of fruit and a few unsalted nuts, or frozen berries and plain yogurt.
6. **Eat a variety of vegetables and fruit at every meal.** Enjoy brightly coloured whole vegetables and fruit. Fresh or frozen, try them in different ways — raw, roasted, or sautéed.
7. **Eat whole grains more often.** Switch to brown rice, whole wheat pasta, dark rye bread or oatmeal. Try something new in your soup, salad or casserole like quinoa, bulgur or barley.
8. **Eat fish at least twice a week.** Trout, salmon, tuna and sardines are some tasty options. Try fresh, frozen or canned.
9. **Include legumes like beans, chickpeas, lentils, nuts and seeds more often.** Add them to salads, soups and grain dishes such as rice, quinoa or couscous. Legumes can replace meat in your meals. Try a vegetarian chili.
10. **Don't be afraid of fat.** You need fat for good health, and it adds flavour to your cooking. Use plant-based fats such as olive or canola oil.



For additional information and resources about healthy eating, visit ottawaheart.ca/living-well-caregiver.



Top 10 tips for managing stress

1. **Exercise regularly.** Exercising at least three to five times a week helps to relax and condition your body and mind.
2. **Breathe deeply.** Take a few deep breaths. Notice how it changes how you feel.
3. **Be aware of quick fixes.** Try to avoid the tendency to consume more alcohol and non-prescribed drugs in stressful times.
4. **Notice your thoughts.** Reflect on how you think about what's causing you stress. A trusted person or a counsellor can help you see things in a new way.
5. **Relax the muscles in your body.** Stress can make your body tense. Try to relax the areas where you carry the most stress.
6. **Reflect** on what you can control and let go of things you can't.
7. **Take a break.** Give yourself permission to nap, listen to music, read, meditate or just have some quiet time.
8. **Make time for things you enjoy.** Set time aside for hobbies or learning something new.
9. **Avoid exposure to stress.** When possible, avoid unnecessary triggers for stress, such as distressing TV shows.
10. **Evaluate your commitments.** Consider how you spend your time and letting go of some commitments.



For additional information and resources about managing stress, visit ottawaheart.ca/living-well-caregiver.



Top 10 tips for emotional health

1. **Practise deep breathing.** Deep breathing relaxes your body and lowers your blood pressure and heart rate.
2. **Name your emotions.** Naming your emotions helps you be more aware and decide how you will react.
3. **Try not to judge your emotions.** Judging our emotions can make them seem worse.
4. **Know your emotional triggers.** Knowing what makes you angry, sad or anxious will help you be better prepared.
5. **Be more mindful.** Be aware of what is around you and try to notice your thoughts and feelings.
6. **Move your body.** Physical activity decreases anxiety and improves mood and self-esteem.
7. **Talk to someone you care about. Humans are social.** Make time to talk and connect with others.
8. **Sleep well.** Sleep is important for your mind and body.
9. **Stop “shoulds” in their tracks.** Don’t put too much pressure on yourself about what you “should” or “shouldn’t” be doing.
10. **Do the things that make you happy.** Identify the things that make you happy and make time for them.



For additional information and resources about emotional health, including grief and bereavement, visit ottawaheart.ca/living-well-caregiver.



Top 10 tips for sleep

1. **Get up at the same time every day and get up early.** Doing this every day, even on weekends, sets your biological clock. It's the most important change you can make to improve your sleep.
2. **Exercise, but not right before bed.** Exercise stimulates us, which can make it hard to sleep afterwards. Avoid exercise two to three hours before bed.
3. **Avoid late naps.** Napping late in the day can disrupt your nighttime sleep. If you do nap, do so before 2 p.m.
4. **Only go to bed when you are sleepy.** Going to bed before you are drowsy is a common mistake. Only go to bed when you're tired enough to fall asleep within 15 minutes.
5. **Create a bedtime routine.** Create a routine that lets you get everything done an hour before bed and then wind down gradually.
6. **Relax before going to bed.** Your body needs to be relaxed to fall asleep. Plan an hour of calming activities, like meditation, colouring, or reading before you sleep.
7. **Take racing thoughts to another room.** Rather than stay in bed, take your worries to a comfortable place where you can sit and relax.
8. **Clear your mind.** To help clear your mind, write down what your worry is, how you will address it, and when you will do it.
9. **Talk to your doctor about snoring.** Snoring can be a sign of obstructive sleep apnea. If you do snore, talk to your doctor.
10. **Use your CPAP device.** If you do have obstructive sleep apnea, make sure you use your CPAP device. Left untreated, obstructive sleep apnea damages your brain and heart.



For additional information and resources about sleep, visit ottawaheart.ca/living-well-caregiver.

Crisis and distress phone numbers by region

Ontario

- **Ottawa Distress Line** (not for mental health emergencies)
In Ottawa: 613-238-3311
Outaouais Region: 1-866-676-1080
- **Ottawa Crisis Line** (call 911 for immediate life-threatening emergencies)
In Ottawa: 613-722-6914
Champlain Region: 1-866-996-0991

Quebec

- **Info-Social** (mental health support)
811
- **Suicide Prevention and Help**
1-866-APPELLE (277-3553)

Nunavut

- **Kamatsiaqtut Nunavut Helpline**
In Iqaluit: 867-979-3333
In Nunavut (toll free): 1-800-265-3333

Canada-wide

- **Mental Health and Crisis Line:** 1-888-893-8333
- **Talk Suicide Canada:** 1-833-456-4566 or text to 45645

Mental health resources

The following resources are **general recommendations and examples only**. There are many great resources across the region that are not listed below. Please consider this a reference guide to begin finding the support or services right for you. We also suggest you speak to your healthcare provider.

Suicide.ca

Professional and confidential support if you are thinking about suicide, if you are worried about someone thinking about suicide, or you are grieving a loss by suicide.

suicide.ca

Info-Social

Provides advice, answers questions, and makes referrals to appropriate resources for psychosocial issues. *Must be in the province of Quebec to call.*

811

quebec.ca/en/health/finding-a-resource/info-social-811

AccessMHA

Mental health and substance use/addictions supports in Eastern Ontario.

accessmha.ca

Hope for Wellness Helpline

For Indigenous people across Canada. Available in Cree, Ojibway, Inuktitut, English, and French.

hopeforwellness.ca

Health Coaching

Free phone support program to help you manage and take control of your health.

livinghealthyhamplain.ca/en/healthcoach

Kelty's Keys

Free online self-help modules for a variety of mental health needs.

keltyskey.com/self-help

Togetherall

A digital support group and recovery service for people living in Ontario who are stressed, anxious, or having difficulty coping. Guided by trained professionals who are online 24/7.

togetherall.com/en-ca

Counselling Connect

Quick access to a free phone or video counselling session.

counsellingconnect.org

The Walk-in Counselling Clinic

Immediate free counselling for individuals, couples, and families.

walkincounselling.com

Psychologists

Psychologists can be located by searching the College of Psychologists of Ontario's website.

cpo.on.ca

Low-cost counselling services

Fees are free or on a sliding scale based on income. Services are offered by social workers or graduate students (Masters or Doctorate students) and are supervised by licensed psychologists.

Centre for Psychological Services and Research

University of Ottawa

613-562-5289

socialsciences.uottawa.ca/centre-psychological-services-research/client-services

The Wabano Centre for Aboriginal Health

299 Montreal Road, Ottawa

613-748-0657

wabano.com

Counselling and Pastoral Services

St. Paul's University (Ottawa)

613-782-3022 or 613-782-3023

ustpaul.ca/en/centre-for-counselling-home_360_120.htm

Clinique de services psychologiques de l'UQO

Université du Québec en Outaouais (Gatineau)

819-773-1679

uqo.ca/cspuqo

Family Services Ottawa

312 Parkdale Avenue, Ottawa

613-725-3601

familyservicesottawa.org

Counselling and Family Service Ottawa

310 Olmstead St., Ottawa

613-233-8478

cfsottawa.ca

Jewish Family Services of Ottawa

2255 Carling Ave., Ottawa

613-722-2225

jfsottawa.com

University of Ottawa Heart Institute programs

The University of Ottawa Heart Institute provides programs that include **caregivers**. For a list of classes offered, visit ottawaheart.ca/patient-and-caregiver-classes. Browse the calendar of events at ottawaheart.ca/calendar. The programs listed below **welcome** or **directly involve participation from caregivers**. For each program, you can call the Heart Institute's main line, 613-696-7000, press 0, and ask to be connected to the program.

24-hour nurse coordinator

The Heart Institute has a nursing coordinator who can help answer questions or direct you to resources that may assist you. **Contact the nurse coordinator by calling [613-696-7000](tel:613-696-7000), and then press 0.**

CardioPrevent

A personalized heart health program that helps people with cardiovascular risk factors lower their chances of developing cardiovascular disease. The program accepts individuals who are at moderate to high risk for cardiovascular disease. CardioPrevent health coaches guide and support participants through a customized program.

Participation requires referral by a physician or a nurse practitioner.

Visit ottawaheart.ca/cardioprevent-program to learn more.

FrancoForme

This is a three-month program focused on your personal heart health goals. The program is open to Franco-Ontarians only. You will have regular phone calls with a mentor as you complete an individualized home exercise program. This ensures flexibility for those unable to participate in a hospital-based program. Participation requires referral by a physician or a nurse practitioner.

Visit francoforme.ca to learn more.

Heart Wise Exercise

Heart Wise Exercise partners with community organizations to develop programming and designate facilities, programs, and classes where individuals can exercise regularly to prevent or limit the effects of living with a chronic health condition. There are a variety of Heart Wise Exercise program options from which to choose. There are walking programs, free exercise options and a variety of gym settings. All programs offer training workshops and have a defibrillator on-site.

Visit heartwise.ottawaheart.ca/locations to learn more.

Virtual drop-in education classes

- Atrial Fibrillation
- Electrophysiology Catheter Ablation
- Coronary Artery Disease and Recovery from a Heart Attack
- Recovering from Heart Surgery
- Nicotine Dependence
- Waiting for Cardiac Surgery
- Heart Failure Discharge Class
- Hypertension Education Group
- While You Wait for Your Cardiac Rehabilitation Program

Visit ottawaheart.ca/calendar to learn more about our virtual drop-in education classes.

Nutrition 101 and 201

- **101:** A one-hour introduction to heart-healthy eating. Learn how to read food labels and get the facts about fat, cholesterol, fibre and salt.
- **201:** Learn about trends in nutrition, including superfood, supplements and the Mediterranean diet.

Visit ottawaheart.ca/healthy-eating to learn more.

“Living Well as a Caregiver During COVID-19 and Beyond” webinar

A one-hour online webinar hosted by Heart Wise, profiling the lived experiences of a caregiver, up-to-date caregiving research, and resources available in the Ottawa community.

Visit ottawaheart.ca/living-well-as-a-caregiver-webinar to learn more.

Occupational therapy

Resources and individual skills training for patients and caregivers about general home safety, bathroom safety, car transfers, and methods to conserve energy are offered by an occupational cardiac rehabilitation therapist. Also available is a list of suppliers for specialized equipment (mobility aids, bathroom safety aids, and self-care equipment).

Visit ottawaheart.ca/inpatient-rehab-program to learn more.

Spiritual care at the University of Ottawa Heart Institute

Hospital chaplains are available to provide patients and families with spiritual counselling, emotional support and resources for addressing ethical and religious concerns.

Visit ottawaheart.ca/amenities-and-services to learn more.

CPR/AED certification

Heart and Stroke publishes a list of certification courses available in the area. The *Heartsaver* and *First Aid* courses are recommended for members of the public.

Visit cpr.heartandstroke.ca/s/courses?language=en_US to learn more.

Provincial and national associations providing resources for caregivers

Ontario Caregiver Coalition

A non-profit organization that advocates for the needs of caregivers. They include a list of the several different organizations, groups and websites in Ontario that can provide support and resources to family caregivers.

1-833-416-2273

ontariocaregivercoalition.ca

The Ontario Caregiver Organization

Aims to improve the lives of caregivers in Ontario by providing a one-stop resource for where caregivers can go to seek local support and services.

1-833-416-2273

ontariocaregiver.ca

Caregiving Matters

The internet-based Canadian charity that provides education and support to caregivers through monthly newsletters, educational events and technology-based resources (for example, webinars, videos, DVDs and podcasts).

905-939-2931

caregivingmatters.ca

Carers Canada

A national caregiver coalition that provides a list of Canadian and international non-governmental organizations that support caregivers. They also provide a free downloadable book, titled “Work & Care: A Balancing Act.”

carerscanada.ca

Heart and Stroke

Provides a list of national and provincial resources for caregivers as well as a series of articles written by caregivers, for caregivers.

1-888-473-4636

heartandstroke.ca/services-and-resources/care-partner-support

Canadian Psychological Association’s “Psychology Works” Fact Sheet on Caregiver Stress

Provides recent data on caregiver stress in Canada, strategies to reduce caregiver stress, and key resources for caregivers experiencing stress.

cpa.ca/psychologyfactsheets

American Heart Association

Resources for caregivers, including tips on communication strategies, emotional support, and learning how to care for someone before heart surgery, after a heart attack or stroke, and/or living with heart failure.

1-800-242-8721

heart.org/en/health-topics/caregiver-support/resources-for-caregivers

Additional online resources for caregivers

Caregiver Exchange

Caregiver Exchange provides extensive practical insights for busy caregivers.

519-660-5910 ext. 5929

caregiverexchange.ca

Global News: Caregivers

Providing the latest news on caregiving through news articles and videos.

globalnews.ca/tag/caregivers/

Caregiver Solutions

A national magazine providing information, resources, and support for caregivers.

caregiversolutions.ca

Healthing: Caregivers

Provides articles and webinars about the latest caregiving news across Canada.

healthing.ca/category/caregivers

