

Caregiver Guide

HURON AND PERTH

Supporting Caregivers at Every Stage of Their Caregiving Journey



Connecting the Dots for Caregivers brought together six local healthcare organizations and caregivers to create tools and resources that would help caregivers feel more supported, valued and engaged in their important role.

Welcome to the Caregiver Guide

THE HURON AND PERTH CAREGIVER GUIDE IS DEDICATED TO THE MORE THAN 3.3 MILLION ONTARIANS WHO PROVIDE UNPAID CARE, SUPPORT, ASSISTANCE, OR ENRICHMENT TO A FAMILY, FRIEND, OR NEIGHBOUR

From the beginning, we listened and learned from caregivers and healthcare providers. One theme we heard time and time again is that caregivers often have trouble finding the information they need. Sometimes this is because they don't know who to ask or where to go. Caregivers shared that they can sometimes feel overwhelmed with information – especially if they receive a lot of information all at once.

As a result, the **Caregiver Guide** was created by caregivers and healthcare providers to help guide and support you on your caregiving journey – to help give you a sense that you are not alone. It hopes to do so by:

- providing you with caregiving information, ideas, and tips;
- offering you a list of local resources which you may find useful; and
- helping to give you a sense of control.

The information found within this guide combines caregiver advice, healthcare provider experience, and research.

Within this guide, you may see numbers at the end of a sentence. This number is simply referring to the research source—or reference that the information came from. References for each section can be found at the back of each section. Within this guide, we have also provided a list of additional tools and resources that you can find on our website www.caregivershuronperth.ca.

Caregivers are an essential part of our health system—but are often not recognized as team members. We know more must be done to support you and hope you find this guide helpful.

Who is a Caregiver?

A 'caregiver' is defined as a family, friend and/or neighbour who provides unpaid personal, social, psychological and physical support, assistance and care, for family members and friends in need. This support can be provided for any length of time.

The term 'care receiver' refers to the person that a caregiver provides care for.

Understanding who caregivers are is important to both caregivers and members of the healthcare team for many reasons including:

- making it easier to support the caregiver if needed;
- helping caregivers feel recognized, valued, and important members of the health team;
- improving the overall care of the care receiver; and
- having a better understanding of the care receiver's needs, symptoms, and behaviours.

However, the reality is that caregivers often don't see themselves as a caregiver. Instead, they see themselves as "just" a spouse, a son, a daughter or a friend—someone who cares about the person and steps in to fill a need when necessary.

Types of Caregivers

Caregiving can take on many types or forms. In Canada, for instance, almost as many men are likely to be caregivers as women. While the age of a caregiver can range from the very young to the elderly, most caregivers fall between the ages of 45 to 64 years old¹.

On average, caregivers provide care between 11 and 30 hours a week. However, some caregivers spend so much time caring they are unable to guess how many hours they provide care. Caregiving can take place at any time, day or night².

The relationship between the caregiver and the care receiver can also vary from caregiver to caregiver. For example, in Ontario²:

- almost half (46%) of caregivers are looking after a parent or in-law;
- 18% provide care to a spouse or partner and 15% care for a grandparent;
- approximately 7% provide care to a child; and
- 83% of caregivers care for more than one person.

Caregiver Responsibilities

Every caregiving journey is different!

Some examples of things that caregivers might do include¹:

- provide transportation;
- perform housework;
- help with household and outdoor tasks;
- schedule appointments;

- manage finances;
- assist with medical treatments; and
- help with personal care.

Caregiving by the Numbers

Over 3.3 million people living in Ontario are caregivers¹

15% of youth (those 15 to 24 years old) in Ontario are caregivers¹

76% of Ontario's caregivers juggle caregiving and paid work³

Nearly half of all caregivers are men, representing approximately 1.6 million men in Ontario¹

Approximately \$26 to \$72 billion per year is the amount that would be needed to pay Canadian caregivers who provide care to seniors for the work they do²

The Gift and Value of Caregiving

Caregiving can be a highly rewarding experience. In fact, many caregivers share that being a caregiver has many benefits including:

- a strengthening of their relationship with the care receiver²;
- providing the ability to spend more time together⁴;
- giving a sense of accomplishment or a feeling of being proud of their caregiver role⁴; and
- allowing the caregiver to be able to fulfil a responsibility to the care receiver⁴.

Caregiving Challenges

While the vast majority of caregivers feel that they are able to cope well with their responsibilities, the ability to cope decreases as the number of hours per week spent on caregiving increases².

Some of the challenges faced by caregivers include¹:

- not being able to spend time with friends and family;
- feeling tired, frustrated, anxious, and overwhelmed;
- having trouble sleeping;
- feeling lonely or isolated; and
- having trouble juggling the demands of paid work.

While the challenges of being a caregiver can be influenced by each caregiver's unique situation, most share that the majority of their stress comes from coping with the worsening health of the care receiver. Others share that this stress comes from not being able to meet their own needs while others share that they find it difficult to manage their emotions².

¹ Statistics Canada. (2012). Portrait of caregivers, 2012. Spotlight on Canadians: Results from the general social survey. Catalogue no. 89-652-X. Retrieved from: <https://www150.statcan.gc.ca/n1/en/pub/89-652-x/89-652-x2013001-eng.pdf?st=litTqjGy>

² The Change Foundation. (2018, November). Spotlight on Ontario's caregivers. Retrieved from: <https://www.changefoundation.ca/spotlight-on-caregivers-report/>

³ The Change Foundation. (2016). A profile of family caregivers in Ontario. Retrieved from: <https://www.changefoundation.ca/profile-of-family-caregivers-ontario/>

⁴ Hermann, N. (2017). Your Health Matters: The positive aspects of caregiving for dementia. Retrieved from: <http://health.sunnybrook.ca/memory-doctor/positive-caregiving-dementia/>

Wellness

"I feel lighter, I feel freer because I have help now and someone is always doing things for us, not because they have to, because they want to."

– Huron and Perth Caregiver

Pick up any book or article about caregivers and you will undoubtedly read something about the importance of taking care of yourself as a caregiver. But why is this an important topic?

The reality is that, for some, caregiving can have a negative impact on your overall health and well-being. Examples of this include stress, anxiety, depression, poor physical health, becoming a "second patient"¹, and, in extreme cases, even early death². We also know that when caregivers have poor mental and physical health, the health of the care receiver is worse³.

The bottom line is, finding ways to make sure that you are mentally and physically healthy is vital to not only your own well-being, but also for the person you care for.

Where Do I Begin?

How do you take care of yourself when you're busy helping to take care of others? In this section, you will find a number of practical tips and recommendations in learning how to practice self-care.

Tip #1: Reducing Caregiver Burden

The more hours you provide care in a given week, the greater you are at risk for stress and burnout⁴. One way you can reduce this risk is by looking for ways to 'lighten your load.' Examples of ways you can do this include:

- **Look into local resources.** In Huron and Perth, a number of resources are available to help support you and the care receiver. Examples include adult day programs, respite, mental health support, meals, and transportation. Check out the 'Resources and Tools' section in this guide for local resources.
- **Say 'Yes' to help.** In the words of the former caregiver Katy Butler, author of "Knocking on Heaven's Door" and "The Art of Dying Well," "Right after a crisis, friends and family rush in and say, 'Is there anything I can do?' And you're often so overwhelmed you can't even think — but strike while the iron is hot and take advantage of it." Another tip? Be specific and ask for help in 'bite-size pieces.' For example, if someone asks you what they can do, ask if they can run an errand you've been putting off. If they ask if they can prepare a meal-give them a day of the week that works best for your schedule⁵.

"People genuinely want to help but often don't know how - be specific in the ways you ask for help."

– Huron and Perth Caregiver

- **Seek respite.** Respite can provide caregivers with temporary relief, for appointments, activities, overnight care, or a much needed vacation. Options can include scheduling a personal support worker in the home, adult day programs, community support services, or short stay respite in a supportive environment like a respite bed in a long-term care home.
- **Learn about the care receiver's condition.** Understanding what are 'normal changes' helps with coping and setting reasonable expectations. Speak to a member of your health team about where to find information and ask any questions you might have.

- **Join a caregiver group.** Research shows that spending time with other caregivers can be really helpful. For example, caregiver peer support has been shown to improve overall well-being, decrease symptoms of depression and anxiety, and increase support networks⁶.
- **Form a caregiver group⁷.** At first, this might seem like an impossible task—but here's the thing: often people want to help but they're not sure how⁶. If this sounds like something you think could help you, one really great resource is a book called *Share the Care: How to Organize a Group to Care for Someone who is Seriously Ill* by Cappy Capossela and Sheila Warnock. Check out your local library or online for where to find the book.

Tip #2: Plan Ahead

Regardless of what stage you are at in your caregiving journey; the importance of planning ahead cannot be overstated. There are a number of good reasons to have a plan including:

- an unexpected worsening of the condition of the person you are caring for;
- a caregiver becoming unable to provide care; and
- a community crisis such as prolonged power outages or severe weather events.

It is also important to plan for changes you can expect as a result of the care receiver's medical condition. For example, if a caregiver becomes physically or mentally unable to provide care, then arranging alternative living is needed.

Benefits of Planning

One of the most important reasons to have a plan is to help prevent a change from becoming a crisis because you are prepared. Other benefits include¹:

- identifying help and resources early on;
- having the opportunity to make decisions with all of the important people involved in the care receiver's life; and
- reducing the amount of stress and anxiety you may experience in an unexpected situation.

The Caregiver Plan

When working with caregivers to develop this guide, one thing we heard was the need for guidance on what to do when faced with an unexpected situation. For this reason, we have worked together to develop the 'Caregiver Plan'. The purpose of the Caregiver Plan is to help you prepare for unexpected situations, and to provide some guidance in moments when you're not sure what to do.

We've included this plan with this guide. After creating your plan, we recommend making copies in order to put the plan where it will be easily accessible (such as the car, a purse, or a briefcase), and share it with others if needed.

Tip #3: Look After Yourself

These are some tips on things you can do to help keep on top of your physical and mental health.

- **Physical activity.** The benefits of physical activity are well known and include having more energy, less stress, and helps prevent disease. For adults 18 years of age and older, Health Canada recommends 150 minutes of moderate to vigorous exercise per week, in bouts of 10 minutes or more. This can include participating in anything you enjoy such as swimming, biking, gardening or even vacuuming. Even something as simple as brisk walking for 30 minutes a day can have health benefits⁸.
- **Schedule Time for Yourself.** By taking care of yourself, you will be better equipped to provide care. One of the ways you can do this is to make yourself a standing appointment to do something you enjoy. For instance, meeting a friend for coffee, seeing a movie, or going for a walk.

¹ Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: health of caregivers of Alzheimer's and other dementia patients. *Current Psychiatry Reports*, 15(7), 367.

² Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282(23), pp. 2215-2219.

³ Schwarz, K. A., & Elman, C. S. (2003). Identification of factors predictive of hospital readmissions for patients with heart failure. *Heart & Lung*, 32(2), pp. 88-99.

⁴ Statistics Canada. (2012). Portrait of caregivers, 2012. Spotlight on Canadians: Results from the general social survey. Catalogue no. 89-652-X. Retrieved from: <https://www150.statcan.gc.ca/n1/en/pub/89-652-x/89-652-x2013001-eng.pdf?st=litTqjGy>

⁵ Schumann, J.H. (2019, July 14). Caregiving for a loved one? How to get the help you need. National Public Radio [online article]. Retrieved from: <https://www.npr.org/sections/health-shots/2019/07/14/741077294/caregiving-for-a-loved-one-how-to-get-the-help-you-need>

⁶ Toseland, R. W., Rossiter, C. M., & Labrecque, M. S. (1989). The effectiveness of peer-led and professionally led groups to support family caregivers. *The Gerontologist*, 29(4), pp. 465-471.

⁷ Capossela, C., & Warnock, S. (2004). Share the care. How to organize a group to care for someone who is seriously ill. New York: Fireside.

⁸ Evans, M. (2011, December 2). 23 and ½ hours: What is the single best thing we can do for our health? [Video File]. Retrieved from: <https://www.youtube.com/watch?v=aUalnS6HlGo>

Changing and Balancing Roles

The caregiving journey is different from person to person, and it is likely to change and evolve over time. For instance, when and how a caregiving journey begins and ends, the number of hours a person spends caregiving, the length of time that care is given, and how roles are shared between caregivers are all ways that can influence the caregiving journey¹. This is especially true when caring for those with a long-term health condition. For example, in the beginning, providing care for a young child with a chronic illness might simply mean monitoring their condition and taking them to their medical appointments. But, later on as the disease progresses, the caregiver may take on additional roles such as providing treatment and managing symptoms.

This particular scenario outlines a caregiving journey with a 'predictable course' meaning it is possible to guess how the caregiving journey might change over time because how the care receiver's health condition or illness will change is known^{1,2}. For many caregivers, however, it is not possible to know how your role might change. For example, caring for someone just diagnosed with cancer may result in a flurry of medical appointments such as seeing specialists, having surgery, or beginning a treatment or therapy. In the event the cancer is in a more advanced stage, the caregiver may suddenly find themselves having to help manage cancer symptoms such as pain, difficulty sleeping, or providing end-of-life care. When providing care to someone with a recent stroke, the caregiver may find themselves thrust into intensive caregiving responsibilities that can lessen over time as the care receiver's condition improves¹.

Regardless of the path you may be headed on, it is important to work with members of your health team to understand how the needs of the care receiver can change so that you can plan and adapt as needed. Some strategies include:

- gathering information about the disease/illness progression;
- meeting with others who understand the illness and can help you put strategies in place;
- managing your own expectations and abilities; for example, if you are asked to do a dressing change that you are not able to do, ask for help from a member of your medical team;
- advocating for the care receiver and yourself if you're not comfortable doing certain things;
- developing your support network, identifying at least one other person you can depend on; and
- seeking out resources in the community.

¹ Schulz, R., & Eden, J. (2016). Families for caring for an aging America. Washington, DC: The National Academies Press.

² Prohaska, T.R., Anderson, L.A., & Binstock, R.H. Public health for an aging society. Baltimore: Johns Hopkins University Press.

Advocacy and Health System Navigation

ADVOCACY

What is Advocacy?

Simply put, advocacy refers to sharing your thoughts and ideas with others to bring about change. As a caregiver, there are many examples of where you may find yourself in an advocacy role. For instance, when:

- speaking to a member of the healthcare team about a concern you have about the care receiver such as a change in their health condition or the need for more medication;
- explaining to a care provider that you are not comfortable with something; or
- writing a letter to your local government asking for better supports for caregivers in your community.

Another way to think of advocacy is simply ‘speaking up.’

"Speak up. If you're concerned, say so. If you're worried, say so. If you disagree, say so. If you do not understand, say so. If you are overwhelmed, say so." – Huron Perth Caregiver

It's Okay to be the ‘Squeaky Wheel’

Many patients and families see members of the health team as ‘the experts’ – and more often than not, they are! But they are only experts in their own work area. They are not the expert of everything that makes a person who they are. In fact, providers look to patients, their families, and their caregivers to understand what makes you “YOU”! What your wishes are, what’s important to you, and what you want to achieve together are all things that are important for your care team to know. Without this information, healthcare providers might not know that their recommendations are not the best ones for you and the care receiver. As the old saying goes, ‘the squeaky wheel gets the grease.’ In health care, this means that sometimes the only way providers know what is best for you, is by sharing information with them.

An Approach to Advocacy

For many people, finding yourself in a situation where you might need to advocate for yourself or someone else can be stressful. Fortunately, a simple tool has been developed and used in many different fields such as the military, aviation, and health care to help people communicate more effectively. This tool is called ‘SBAR’ which refers to ‘Situation, Background, Assessment, and Request* – and care receivers and caregivers can use it too²!

The SBAR Tool

Situation: Describe the situation

Background: Provide any additional details that would be helpful for the health team

Assessment: What do you think about this situation? How do you feel?

Request: What do you want? What are you asking for?

The following is an example of using the SBAR tool to communicate concerns about caring for an aging parent.

Example Scenario: You have been a live-in caregiver for your 83-year-old mother for the past two years. You are reaching the point where you feel you can no longer care for her anymore. You make an appointment with her family doctor to discuss options.

Situation: “I am finding it too difficult to continue to provide care for my mother any longer”

Background: “She has become less willing to participate in her care and is much weaker than she used to be. My family has maxed out all available resources and help”

Assessment: “I think it’s time that she be placed in residential care” OR “I’m not sure what to do anymore to help her”

Request: “Can we discuss options for finding somewhere close to us that she could live?”

Working with members of the healthcare team can be an important part of the caregiver role. To help make sure you and the care receiver don’t miss any important information during the healthcare appointment, we recommend asking the following four questions⁴:

1. What is the main concern today?
2. What needs to be done next?
3. Why is it important to do this?
4. Who can I contact if I have questions?

These questions are included on the Caregiver ID. See the Resources section at the back of this guide for more information.

“I used the questions last time I was at my family doctor’s office. In the moment that you are receiving information it’s difficult to know what to ask especially if the news comes as a shock. These questions helped me get the key facts that I needed before I left the office.”

– Huron Perth Caregiver

HEALTH SYSTEM NAVIGATION

Our health system is complex. When patients and families in Huron and Perth counties were asked about their thoughts on the health system, the ability to access care and navigate (or move through) the system were identified as key challenges. So what can you do, as a caregiver, to help find your way around the system? Here are some tips⁵ and suggestions that you can use:

- **Ask questions.** The more knowledge you have, the better equipped you will be to face the road ahead. Some questions you can ask to help you better navigate the system include:
 - Who can we speak to if we have more questions?
 - What are our next steps after this appointment?
 - Will copies of my medical information be shared with all members of the health team?
 - Are there any questions that I should be asking that I might have missed?

- **Organize, organize, organize!** One strategy to help navigate the system is to keep a binder or folder of all relevant health information that you can bring with you to your appointments. Connecting the Dots has co-designed a Healthcare Journey Binder to help manage information for yourself or the person you're caring for. Not sure where to begin? Check out the 'Resources and Tools' section of this guide for more information.
- **Ask for navigation help.** Did you know that our system is so confusing that some programs have people on staff just to help patients move through the system? Check with your health agency to see if they have a program or system navigator that can help you! You can also seek out caregivers who have had a similar journey. They are a good resource and almost always want to share their ideas and advice with others.
- **Plan ahead.** This again cannot be said enough. Check out the 'Wellness' section for planning suggestions.
- **Start as early as possible.** Don't wait to learn about and get connected to local resources. Check out www.caregivershuronperth.ca for resources in your area.

"Don't be afraid to advocate for yourself or the care receiver. If you don't understand something, ask for clarification. There are NO stupid questions."

– Huron Perth Caregiver

¹ ACT Academy National Health Service. (n.d.). SBAR communication tool – situation, background, assessment, recommendation. Retrieved from: <https://improvement.nhs.uk/documents/2162/sbar-communication-tool.pdf>

² Labson, M. (2019). SBAR – a powerful tool to help improve communication. Retrieved from: https://www.jointcommission.org/at_home_with_the_joint_commission/sbar_-_a_powerful_tool_to_help_improve_communication/

³ National Institute on Aging. (2017). Doctor's appointments. Tips for caregivers. Retrieved from: <https://www.nia.nih.gov/health/doctors-appointments-tips-caregivers>

⁴ Institute for Healthcare Improvement. (2019). Ask me 3: Good questions for your good health. Adapted with permission. Retrieved from: <http://www.ihl.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx>

⁵ The Reitman Centre for Caregivers. (2018). 10 tips for successful system navigation. Retrieved from: <http://www.dementiacarers.ca/wp-content/uploads/2018/11/SHS-10-Tips-for-System-Navigation-PRINT.pdf>

Navigating Financial & Legal Issues

Many caregivers find it difficult to understand legal issues such as privacy and consent laws, when and with whom information can be shared with, and what your options are when the person you are caring for is unable to make decisions for themselves. What's more, legal matters in health care may also be different from one province to another. No wonder people find legal issues confusing! This section reviews some basic Ontario health related legal matters that caregivers might find helpful including:

- financial matters;
- privacy and consent;
- Advance Care Planning;
- Powers of Attorney; and
- involuntary medical separation.

It is important to note that the information provided is for informational purposes only and should not be taken as legal advice.

FINANCIAL MATTERS

According to the results of a recent survey, nearly 38% of caregivers shared that caregiving had a negative impact on their finances – especially for those who provided care to a child (54%) or spouse (46%)¹. Knowing what help is out there to support caregivers financially can be difficult to find. Therefore, we've put together a brief list of resources you may find helpful.

EMPLOYMENT INSURANCE BENEFITS

In Canada, a number of benefits are available through Employment Insurance to caregivers who provide care or support to a person who is critically ill or injured, or requires end-of-life care. These include²:

- Family caregiver benefit for children. Payable up to 35 weeks for a critically ill or injured person under 18
- Family caregiver benefit for adults. Payable up to 15 weeks for a critically ill or injured person 18 or older
- Compassionate care benefits. Payable up to 26 weeks for a person of any age who requires end-of-life care

To find out if you are eligible, speak to a representative from Service Canada or go online at www.canada.ca to find out more information.

FEDERAL AND PROVINCIAL TAX CREDITS

Across Canada, you may be eligible to apply for tax credits related to caring for someone with a medical condition. At the federal level, this includes³:

- Family Caregiver Tax Credit
- Medical Expenses Tax Credit
- Disability Amount Tax Credit Transfer

For Ontario specifically, a number of credits and tax reductions are also offered to help provide some financial relief for caregivers including⁴:

- Allowable amount of medical expenses for other dependent
- Ontario caregiver amount
- Disability amount transferred from a dependent
- Medical expenses for self, spouse, or common-law partner, and your dependent children

Unsure what credits you are eligible for? The Government of Canada offers an online **Benefits Finder**⁵ (<https://benefitsfinder.services.gc.ca>). It may also be helpful to speak with your financial accountant or advisor to see if there are any credits you might be eligible for.

ADDITIONAL CONSIDERATIONS:

- Tax planning
- Bank accounts and RRSPs
- Mortgages, rent and leases
- Wills and estates
- Life insurance
- Employee or retiree benefits
- Long-term and palliative care

Depending where you are on your journey and your specific financial situation, we recommend that you seek qualified advice on any of the above considerations. For instance, you may want to consult with a financial planner, bank representative, or lawyer. If you're early in your caregiving journey, it's a good idea to make sure you know where important documents are and how to access them because it can ease the amount of work you'll have to do later. These can be difficult conversations to have, but we heard from caregivers that it's better to have them now, because delaying them will often make them harder when the situation is more complicated or the care receiver isn't able to contribute.

"Never feel pressured into a decision concerning a financial or legal matter. It is okay to take time to fully understand the impact of the decision." – Huron Perth Caregiver

PRIVACY AND CONSENT IN ONTARIO

Caregivers have shared that they sometimes cannot get the information they need to support the person they are caring for because of privacy policies. Similarly, healthcare providers are sometimes not sure they can collect health information from caregivers⁶. What's important to know is that this is not always the case.

Within Ontario there are a number of laws that make up health privacy rules including the Personal Health Information Protection Act, 2004 (PHIPA), and the Health Care Consent Act, 1996 (HCCA)¹. Though the term 'caregiver' isn't mentioned in either of these Acts, the Acts play an important role in laying out healthcare provider and patient rights and responsibilities. An understanding of how these Acts apply to caregivers can provide caregivers with the knowledge necessary to improve the experiences of patients through appropriate information sharing¹. It can be helpful to think of information sharing as falling into one of two scenarios:

- Providers sharing information with caregivers
- Caregivers sharing information with providers

The following provides some general information on both scenarios¹.

Scenario #1: Healthcare Providers Sharing Information with a Caregiver

In most cases, healthcare providers can only share information with a caregiver if their patient is willing and able to give consent. Depending on the situation, consent may be given verbally or in writing. Once the patient gives consent, the caregiver can have access to the information and health records specified by the patient. Consent may also give the caregiver the ability to participate in discussions/meetings with the provider about the patient's care. There are some exceptions to the general rule that consent is required for the healthcare providers to collect this information.

Healthcare providers may be allowed or required by law to share personal health information without consent of the patient in certain circumstances. Some examples include when there is a reasonable belief that a person can no longer safely drive, to report a child in need of protection under the Child, Youth and Family Services Act, or to eliminate or reduce a significant risk of serious bodily harm such as when there is risk for self-harm or harm to others.

Scenario #2: Caregiver Sharing Information with a Healthcare Provider

The law states that, in most cases, patient information must be collected directly from the patient. The law does allow health information to be provided from someone else, but only if the patient consents or health privacy or other laws say this can occur. In limited circumstances, if a provider cannot get information from the patient directly, then the provider can get the information indirectly from the caregiver, or other third party, even without patient consent, if they cannot get it directly from the patient in a timely or accurate way.

Want More Information?

Check out Making Privacy and Consent Rules work for Family Caregivers by the Change Foundation www.changefoundation.ca/caregiver-privacy-consent-report

ADVANCE CARE PLANNING

"Do not delay a conversation around Advance Care Planning. Though these conversations can be difficult for people to have, once a person's wishes are known, this often brings relief and feelings of being prepared for the unexpected." – Huron Perth Caregiver

What is Advance Care Planning?

Advance Care Planning is a process that allows a person to make sure their voice is heard when they are unable to speak for themselves. This could happen due to a number of situations including an accident, illness, or temporary/permanent disability. When a person is not able to make decisions for themselves, a person known as a '**Substitute Decision-Maker**' (SDM) may make health and personal care decisions on someone else's behalf⁷.

Did you know? Everyone in Ontario has an automatic SDM.

An SDM, according to the law, is the person highest on this list who is at least 16-years-old, mentally able, available, not prohibited by a court order or separation agreement, and willing to make a decision on behalf of someone else⁸:

1. A Guardian of a person with the right to make decisions for treatment
2. An Attorney named as a **Power of Attorney** for Personal Care
3. A representative appointed by the **Consent and Capacity Board**
4. A Spouse or Partner
5. A Child, Parent or Children's Aid Society
6. A Parent with right of access only
7. A Brother or Sister
8. Any other relative by blood, marriage, or adoption
9. Office of the **Public Guardian and Trustee**

It is important to know that it is possible to have more than one SDM at the same time. For instance, a parent who is not able to make a decision could have three children who would all have equal rights in making that decision. It is also important to know that if you are not satisfied with your default SDM, you can choose someone to be your SDM by completing a document known as a Power of Attorney for Personal Care².

Why is Advance Care Planning Important?

In Ontario, the law requires that health care providers get informed consent before they provide care or treatment to a person (unless it is an emergency, where special rules apply). Imagine finding yourself suddenly in a situation where you are asked to make a decision on someone else's behalf without knowing what they would have wanted. This is why it is important to plan ahead².

There are two main steps in Advance Care Planning²:

- Confirming who your Substitute Decision-Maker(s) is (are), and
- Sharing your wishes, values, and beliefs about medical and personal care with the Substitute Decision-Maker(s)

Want More Information?

Across the country, much work has been done to help people plan their care. In Ontario, one organization has created a website and workbook to help guide anyone through this planning process. Check out www.speakupontario.ca for more information.

POWER OF ATTORNEY

What is a Power of Attorney (POA)?

A Power of Attorney is a document that sets out who will be given the right to act on a person's behalf when they are unable to do so⁹.

In Ontario there are two kinds of Power of Attorney³:

1. **A Power of Attorney for Property (CPOA)** covers a person's financial matters and allows the attorney to act for that person even if the person becomes mentally incapable. The CPOA can be one of two types: "continuing" (goes into effect as soon as signed); or it will specify that it takes effect only upon a finding of incapacity.
2. **A Power of Attorney for Personal Care (POAPC)** covers a person's personal decisions, such as health care if the person is mentally incapable of making those decisions.

How are a patient's wishes captured?

Patients should consider discussing with loved ones (and documenting, such as in a Power of Attorney for Personal Care (POAPC)) what they would like to happen if they become ill and cannot communicate their wishes about treatment. In Ontario, a POAPC must be written according to specific rules. For example, it must be witnessed by two people, and it names the 'attorney' who will interpret the patient's wishes.

INVOLUNTARY MEDICAL SEPARATION

If you are the primary caregiver for a spouse or common-law partner, and you no longer live together for reasons beyond your control (such as your spouse/partner moving to a long-term care home), it is important to be aware of something called 'Involuntary Separation.' This type of separation does not mean you are legally separated or divorced, it is simply a way that allows you to qualify for higher pension benefits¹⁰.

To qualify, your spouse or common-law partner must be¹¹:

- over 65;
- living in your community or in a long-term care home, including if they live in the same semi-private room as you; and
- eligible for the Old Age Security pension and/or Guaranteed Income Supplement.

Speak to a member of your health team for more information.

¹ The Change Foundation. (2018, November). Spotlight on Ontario's caregivers. Retrieved from: <https://www.changefoundation.ca/spotlight-on-caregivers-report/>

² Government of Canada. (2019). EI caregiving benefits and leave: what caregiving benefits offer.

³ Government of Canada. (2018). Tax credits for caregivers. Available from: <https://www.canada.ca/en/financial-consumer-agency/services/caring-someone-ill/tax-credit-caregiver.html>

⁴ Government of Canada. (2019). Ontario. Available from: <https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/provincial-territorial-tax-credits-individuals/ontario.html>

⁵ Government of Canada. (2019). Welcome to the benefits finder. Available from: <https://srv138.services.gc.ca/daf/s/e0a741aa-3df1-4108-be5c-942c65d3f522?GoCTemplateCulture=en-CA>

⁶ The Change Foundation. (2017). Making privacy and consent rules work for family caregivers. Available from: <https://www.changefoundation.ca/caregiver-privacy-consent-report/>

⁷ Speak Up Ontario. (2015). Advanced care planning workbook Ontario edition. Available from: http://www.advancedcareplanning.ca/wp-content/uploads/2015/09/acp_ontario_workbook_-_03.2015_colour_final-web-form.pdf

⁸ Speak Up Ontario. (2018). Advanced care planning workbook Ontario edition. Available from: https://www.speakupontario.ca/wp-content/uploads/2018/07/ACP_Ont_workbook_2018_Eng.pdf

⁹ Ministry of the Attorney General. (2017). How Powers of Attorney work. Available from: <https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php>.

¹⁰ Family Caregivers Network Society. (2012). Involuntary separation. Available from: <https://www.familycaregiversbc.ca/wp-content/uploads/2012/12/Involuntary-Separation.pdf>

¹¹ Government of Ontario. (2019). Long-term care accommodation costs and subsidy. Available from: <https://www.ontario.ca/page/get-help-paying-long-term-care>

Preparing for the Future

Whether you're just starting out in your caregiving journey, or nearing the end, you may be wondering what life might be like if you were to no longer be a caregiver (though many will say, "once a caregiver-always a caregiver!"). If you are, this next section is for you. In it we explore caregiver grief and loss, managing emotions, finding help, and practical information on care transitions.

Caregiver Grief and Loss

Losing someone you care about is part of life.

For caregivers, however, losing your loved one can be a very difficult and complicated process. Caregivers can experience grief and loss differently than non-caregivers. This is because grief and loss can happen even before the person's death¹.

For instance, caregivers can experience something called 'chronic sorrow'. Chronic sorrow is a type of grief that happens when your loved one is still alive. This type of grief is unique because it happens over and over again as your loved one gets worse over time. Chronic sorrow happens in cycles where things become worse, but then get better as you adjust to the changes¹.

Caregivers also experience a type of grief known as 'anticipatory grief'. Anticipatory grief happens in anticipation of a future loss of someone you care about. For example, after learning that a spouse has a terminal diagnosis of cancer, you may start the grieving process well before they pass away. Caregivers can also experience anticipatory grief in other ways such as worrying about what your future will look like, loss of freedom, and loss of plans that you had for the future².

Managing Feelings of Loss and Grief

There is no right or wrong way to grieve. Below are some examples of helpful ideas that can be used to deal with loss and grief (used with permission from the Canadian Mental Health Association³).

- **Own your feelings.** It's ok to feel whatever you're feeling, to be confused or angry or sad. It's ok to laugh and to cry. Sometimes you might even feel relief that some difficult or painful part of life has ended. Accept your feelings. They may change along the way. With time, the difficult feelings will ease.
- **Express your feelings.** There may be both positive and negative feelings and memories. Find ways to express them. Try to pull them apart and understand them. Journaling, creative writing, drawing or singing may help you to get your feelings out.
- **Share your feelings.** Don't go through this alone. Talk to someone you trust. Let them know how you're feeling. Find help too by connecting with others who've experienced the loss. Sharing your grief with others at ceremonies like funerals is one way to help you make sense of your loss and move forward.
- **Find humour in life.** Enjoy a laugh as you normally would. Finding humour in life and being able to laugh can help get you through difficult times. Laughter can break the pain and help with healing. It is good for body and mind.
- **Find meaning.** For example, what can you learn from this experience? Can you find some good in this bad situation? What did the deceased mean to you? Has this experience left you with new insights or perceptions about yourself or about life? Have you learned something new about others?

- **Take care of yourself.** Coming to terms with loss is stressful. Sleeping and eating right can help you feel better. Encourage a regular sleep routine. Yoga or deep breathing can help you relax. Making healthy food choices and eating at regular times will help too. And don't forget to be kind to yourself, and do things you enjoy doing.
- **Move forward.** Bit by bit you'll be able to feel more like yourself, living in the present, planning for the future, and focusing less on your loss. Getting to the other side of grief does not mean you've forgotten your loved one. But you will be able to remember them in ways that allow you to move on with your life.

Finding Help

Sometimes after the loss of someone you care about, you may find it so overwhelming, or that it lasts for such a long time, that you might need to speak with someone to help move forward³. Speak to your family doctor or nurse practitioner about where to go to find help. As well, within Huron Perth, there are a number of resources available, including:

- For emotional support Huron Perth Helpline and Crisis Response Team: 1.888.829.7284
- Telehealth Ontario: 1.888.797.0000
- www.caregivershuronperth.ca

Moving Forward

Caregivers often experience uncertainty about how to let go after their caregiving duties end. Research also has found that caregivers are unsure about how to move on⁴. What's important to know is that moving on with your life does not mean you are leaving your old life behind - it simply means living your life differently. Below are some tips and suggestions on things you can do to begin to move forward⁵.

- Take up an activity that you used to enjoy
- Find volunteer opportunities of interest to you
- Try something you always wanted to do
- Take a course or go back to school
- Adopt a pet
- Find a local club or group of people with a similar interest (e.g. book, running, or knitting club)
- Connect with old friends that you might have lost touch with
- Travel to a place you've always wanted to go. Don't have anyone to go with? Look for travel groups with other people of similar interests

¹ Rossheim, B. N., & McAdams III, C. R. (2010). Addressing the chronic sorrow of long-term spousal caregivers: A primer for counselors. *Journal of Counseling & Development*, 88(4), 477-482.

² Holley, C.K., & Mast, B.T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist*, 49(3), pp. 388-396.

³ Canadian Mental Health Association. (n.d). Understanding and coping with loss and grief. Available from: <https://ontario.cmha.ca/documents/understanding-and-coping-with-loss-and-grief/>

⁴ Corey, K.L., & McCurry, M.K. (2018). When caregiving ends: the experiences of former family caregivers of people with dementia. *The Gerontologist*, 58(2), e87-e96.

⁵ Dresser, N., & Wasserman, F. (2010). *Saying goodbye to someone you love: your emotional journey through end of life and grief*. New York: Demos Health.

Connecting the Dots

Resources and Tools

Connecting the Dots for Caregivers was a partnership between The Change Foundation and six healthcare and community organizations in Huron and Perth counties. With caregivers, this partnership looked for ways to improve the caregiver experience. Through a process known as ‘co-design,’ caregivers and healthcare providers worked together to develop a number of tools and resources to make the caregiving journey a little easier. The following provides an overview of each of these resources – all of which can be found on our website www.caregivershuronperth.ca

Caregiver Website: Designed to help caregivers and healthcare providers across Huron and Perth counties find local services, programs, and resources. Not sure where to begin? On the home page of the website, you’ll find a ‘How to Use the Website’ video which walks you through how to access all of these resources. Make sure you read the Caregiver Tips and A Caregivers Perspective to take full advantage of the site: www.caregivershuronperth.ca.

Time to Talk Pamphlet: This pamphlet provides caregivers with simple and easy-to-read information that caregivers might find helpful including:

- What it means to be a caregiver
- Impacts of caregiving
- Recognizing caregiver burnout
- A list of caregiver resources in Huron and Perth

Caregiver ID: Created to empower caregivers, this card can be used two ways. Using the front of the card, this card can be worn within healthcare settings to visually identify caregivers helping to encourage their participation and role as a member of the healthcare team. The back of the caregiver ID also offers a list of quick reference questions that caregivers can ask when sharing or receiving information with or from a healthcare team member.

Healthcare Journey Binder: Created by caregivers and healthcare providers to help improve the overall healthcare experience for people with an illness, disease, or medical condition. It can be used by anyone, including caregivers, to manage important healthcare information by:

- Having a place where documents and information can be kept in one place
- Making it easy to organize and find health information
- Allowing you to easily share any information with the healthcare team
- Helping to give you a sense of control

Caregiver Education Video Series: Using the same sections presented in this guide, a caregiver video series has also been developed to help summarize the main section messages. These videos can be found on www.caregivershuronperth.ca under the education and resources tab.

Additional Huron Perth Resources

There are a number of additional educational opportunities available for caregivers online and in-person. Please explore the list below if you are interested in learning more. Many of these resources can also be found under the Quick Links section of www.caregivershuronperth.ca.

Powerful Tools for Caregivers

www.swsselfmanagement.ca

A free six-week workshop to help caregivers care for themselves. Locally, these workshops are offered by South West Self Management. Go online or call 1-855-463-5692 for more information and registration.

Alzheimer Society

www.alzheimer.ca

The Alzheimer Society of Perth County and the Alzheimer Society of Huron County offer education programs and support for people living with Alzheimer's disease and other dementias, caregivers, healthcare professionals and community groups. Contact the Perth County office at 1-888-797-1882 or the Huron County office at 1-800-561-5012 for more information.

Additional Online Resources

The Change Foundation

www.changefoundation.ca

An independent healthcare think tank committed to improving the caregiver experience within Ontario's healthcare system, including through the Changing CARE projects and work with young carers. Click on Family Caregivers to access a variety of reports, videos and resources for caregivers and healthcare providers.

Bounce Back

www.bouncebackontario.ca

A free skill-building program for youth and adults to help manage symptoms of depression and anxiety through telephone coaching, workbooks and videos. A referral is needed for the program through your primary care provider or by self-referral.

Canadian Caregiver Network

www.thecaregivernetwork.ca

An online social community where you can connect with other caregivers and find a variety of resources including articles and videos.

Caregiver Exchange

www.caregiverexchange.ca

A website that provides practical tips and insights for family caregivers as well as access to an up-to-date, comprehensive listing of services across Ontario. It also features video interviews with experienced caregivers and a listing of local events.

Caregivers Alberta

www.caregiversalberta.ca

As an organization of caregivers for caregivers, they understand how hard providing care can be. Click on FOR CAREGIVERS and look under the resources section for printables and helpful links.

Caregivers Nova Scotia

www.caregiversns.org

Caregivers Nova Scotia provides programs, services and strong advocacy for caregivers. On their website you will find The Caregiver's Handbook (2018) available for free download.

Enhancing Care for Ontario Dementia Care Partners

www.dementiacarers.ca

The Reitman Centre, part of Sinai Health System and Alzheimer Societies across Ontario are providing in-person and online programs for people caring for family members or friends living with dementia. Go online or contact the Alzheimer Society of Perth County (1-888-797-1882) or the Alzheimer Society of Huron County (1-800-561-5012) for more information.

Family Caregivers of British Columbia

www.familycaregiversbc.ca

Family Caregivers of British Columbia is a registered non-profit dedicated 100% to supporting family caregivers. Click on FIND RESOURCES for Family Caregivers to view available resources including tips and webinars.

RGPs of Ontario

www.rgps.on.ca/caregiving-strategies

Caregiving Strategies: Providing Care and Support for a Senior Living Frailty includes new resources designed by caregivers and healthcare experts. Improve your skills, knowledge and confidence as a family member or friend caregiver through a free online course, handbook and resources.

Ontario Caregiver Helpline: 1-833-416-2273 (CARE)

www.ontariocaregiver.ca

Telephone assistance is available 24/7 and a Live Chat on their website is available from 7am – 9pm (Mon – Fri).

The Ontario Caregiver Helpline provides caregivers with a one-stop resource for information and support. Whether you are looking for respite care in your area, a support group, information about financial supports available to caregivers, as well as help navigating the health and social service systems, the helpline is here to connect you to the resources you need.

The Helpline is answered by professional Community Resource Specialists in English and French. Helpline representatives have been trained by caregivers to understand the unique needs of caregivers. They provide information, assessment and referral to connect people to community services based on their individual needs and preferences while considering the eligibility criteria of Ontario's community programs and services.

***Please note that the above links and information were accurate as of March 2020, but may have been updated following printing of this guide.*

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Project Partners Include:

Caregivers in Huron Perth
Huron Perth Healthcare Alliance
Alzheimer Society of Perth County
North Perth Family Health Team
ONE CARE Home and Community Support Services
South West Local Health Integration Network
STAR Family Health Team

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Thank you!

My Caregiver Plan



Ideally you should complete this plan before a crisis and return to it regularly to see if you need to make any changes. Make a copy of this plan and keep copies in areas that you could grab it quickly. You can also share this plan with family, friends, or neighbours.

Important Phone Numbers:

(Family, friends, doctor, community agency, care coordinator etc.)

Who: _____	Phone Number(s): #1 _____	#2 _____
Who: _____	Phone Number(s): #1 _____	#2 _____
Who: _____	Phone Number(s): #1 _____	#2 _____
Who: _____	Phone Number(s): #1 _____	#2 _____

Things to Remember to Do in A Crisis:

e.g. Call neighbour to watch children/pets

Other Helpful Numbers:

Huron Perth Helpline and Crisis Response Team: 1.888.829.7284

Telehealth Ontario: 1.888.797.0000

TIP: Pack a 'grab bag' of the things you think would be important to bring with you ahead of time!

Items I Might Need to Bring with Me:

Caregiver Items (Clothes, phone charger, book, personal items etc.):

Care Recipient Items (Health information, list of medications, legal documents, clothes, personal items etc.):

Quick Tips for Making a Decision in a Crisis Situation

Ask:

- How long do I have to make the decision?
- Can you tell me what this isn't?
- What happens if we do nothing?
- What are our other options?
- Are there any questions that I should be asking that I haven't?

Remember: The only way the health team will know if you don't understand something is if you say that you don't understand.

Other Tips:

- If possible, have someone come with you that can help you ‘co-pilot’ the situation. They could help to take notes, do research for you, make phone calls, or anything else you might need.
- Find out what needs to be done after the crisis. For instance, did anything about the care recipients care change such as medications or treatments. Do you have any follow-up appointments?
- Don’t be afraid to let the healthcare team know what you are and aren’t comfortable doing. If you don’t think you can do something the team is recommending, let them know.

Advocating for Yourself or the Care Receiver

*****Remember to use the SBAR acronym to help guide advocating for yourself or the person you are caring for***

Situation: Describe the situation

Background: Provide any additional details that would be helpful for the health team

Assessment: What do you think about this situation? How do you feel?

Request: What do you want? What are you asking for?

Additional Notes:
