



# A Guide to Living with a Progressive Illness

*Palliative Care Patient and  
Care Partner Toolkit*

# Palliative Care Patient and Care Partner Toolkit



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## Diagnosis

You, or someone you know has been diagnosed with a progressive illness...now what?

### *Things to consider:*

- Do you understand the illness you've been diagnosed with?
- Do you understand what the future may be like living with this illness?
- It is important to learn about your illness. Speaking with your healthcare provider can help you to better understand your illness. Consider creating an Advance Care Plan (ACP) if you have not already done so.

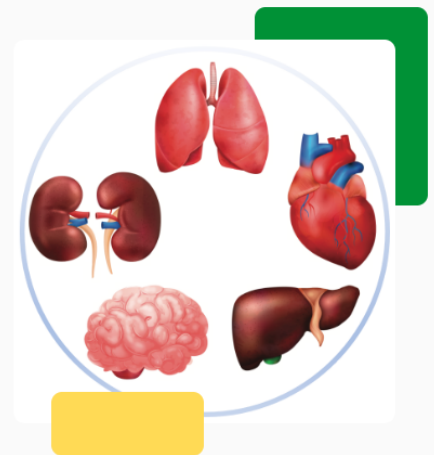
## LEARN ABOUT YOUR HEALTH CONDITIONS

Think about any illnesses you may have. If you are living with a chronic or serious illness, ACP includes learning about this illness and what you might expect to happen in the future.

Some examples of chronic or serious illnesses include:

- Heart problems (heart failure, valve problems, peripheral vascular disease)
- Nervous system problems (stroke, Parkinson's, movement disorders, ALS)
- Cancers
- Dementia
- Kidney problems
- Liver problems

Learning more about your illness can help you and your SDM prepare for the future.



### *Questions to ask your health care provider:*

- Will my illness get better or worse?
- How will my illness affect my life as it progresses?
- What impact will my illness have on other health conditions?
- What treatment options are available to me?
- What do my family/care-partner/friends need to know?

***Tip: write down questions as you think about them so that you can ask your healthcare provider when you have an appointment.***

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## What is Palliative Care?

Palliative care is a holistic approach that treats a person with serious illness of any age, and in any setting. It involves a range of care providers and includes the person's unpaid caregivers, such as family, friends or others in an individual's chosen support network.

If you have a progressive illness, palliative care can:

- help improve your quality of life
- reduce or relieve your symptoms
- help you make informed decisions
- provide grief support to you, your friends and your family (or chosen family)
- support you and your caregivers throughout your illness, from the time of diagnosis

This approach to care can involve management of symptoms such as:

- pain
- nausea
- anxiety
- depression
- difficulty breathing
- emotional, psychological, social and spiritual support
- grief support
- caregiver support

These services aim to make you and your caregivers feel as comfortable as possible. They can include personalized treatment plans that meet your needs and the needs of those who are caring for you.

For more information on palliative care click here: <https://www.canada.ca/en/health-canada/services/health-services-benefits/palliative-care.html>

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## Substitute Decision Makers

Capacity to make decisions may fluctuate throughout a person's healthcare journey. Deciding on a substitute decision maker early on is very important.

In Ontario, adults are presumed to be capable, depending on the type of decision being made. Capacity should be measured on a case-by-case basis. People with capacity also have the right to make decisions that others do not agree with, even where a decision made by a capable person with a mental health disability is thought by others not to be in his or her best interest.

Capacity assessors may be:

- doctors
- nurses
- psychologists
- social workers
- occupational therapists

All capacity assessors have training and expertise in conducting assessments, but some may have specific skills and experiences working with people who have certain types of disabilities, such as:

- dementia
- mental illness
- brain injuries
- intellectual disabilities

**You can contact the Capacity Assessment Office by:**

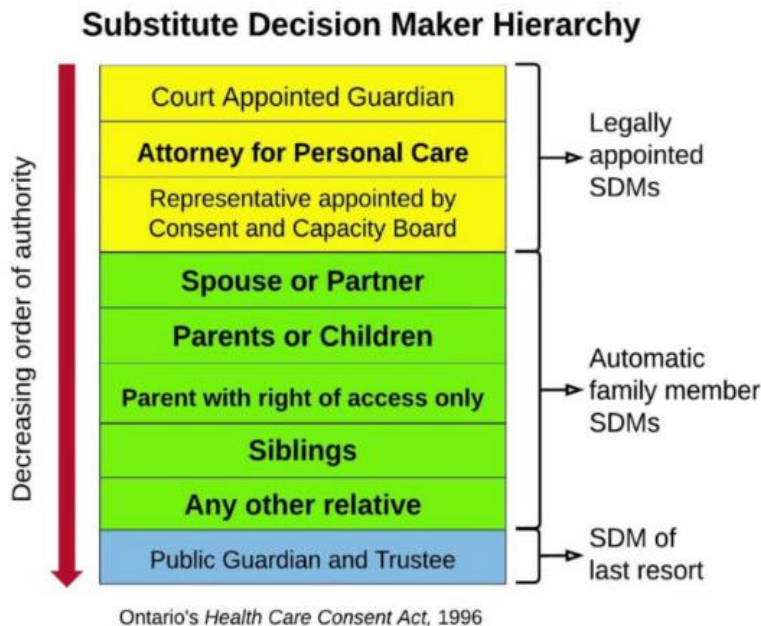
**Email:** [CAO@ontario.ca](mailto:CAO@ontario.ca)

**Tel:** [416-327-6766](tel:416-327-6766) or [Toll-free: 1-800-366-0335](tel:1-800-366-0335)

A person who makes decisions for another person that has been found mentally incapable is called a "Substitute Decision Maker." In Ontario, everyone has a Substitute Decision Maker, and the Health Care Consent Act tells healthcare providers who this would be (For most people it is your closest living relative unless you have a Court Appointed Guardian, or you have appointed an Attorney for Personal Care). [Substitute Decision Makers \(advancecareplanningontario.ca\)](http://advancecareplanningontario.ca)

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A person's wishes about their future and healthcare may change. It is important to review your wishes regularly and communicate with your substitute decision maker. Especially if your health changes or there is a major change in your life.



**Court Appointed Guardian (of the person):** A guardian of the person, is someone appointed by the court to make personal care decisions on behalf of a mentally incapable adult. This usually happens when the person doesn't have a power of attorney for personal care or if their attorney is not able or willing to fulfill their duties. [Guardianship | ontario.ca](http://www.ontario.ca/guardianship)

**Attorney for Personal Care:** A power of attorney is a legal document that gives someone you trust the right to make health care decisions for you should you be mentally incapable. This trusted person does not have to be a lawyer to be your attorney. You can make a power of attorney document yourself for free or have a lawyer do it. Consider consulting a lawyer as they can provide additional things to consider when appointing an Attorney for Personal Care. [Make a power of attorney | Ontario.ca](http://www.ontario.ca/make-a-power-of-attorney)

**Office of the Public Guardian and Trustee:** The Office of the Public Guardian and Trustee acts as Substitute Decision Maker of last resort to make substitute treatment or long-term care admission decisions for incapable individuals. [Office of the Public Guardian and Trustee | ontario.ca](http://www.ontario.ca/office-of-the-public-guardian-and-trustee)

If you suspect that a person may be incapable and at risk of harm, abuse or neglect, call the **OPGT's Investigations line at 416-327-6348 or Toll Free 1-844-640-3615.**

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## Things to Consider when Choosing a Substitute Decision Maker:

- Can I talk with this person(s) about my wishes, values and beliefs?
- Do I trust this person(s) to make decisions that reflect my wishes even if they disagree with them?
- Can they make decisions under stress?
- Can they communicate clearly with my health team in a stressful manner? It's not always possible to know what kind of future health problems you may have.

## Key Responsibilities of your Substitute Decision Maker:

- Willing to be your Substitute Decision Maker and make decisions on your behalf if you are not capable of making the decision yourself
- Available when decisions need to be made
- Over 16 years of age
- Capable of providing consent
- Not prohibited by court order or a separation agreement

## Remember:

Your Substitute Decision Maker can only make your healthcare decisions when you are **NOT** mentally capable of making healthcare decisions on your own, for example:

- During surgery if you are unconscious
- Cases of advanced dementia
- During a temporary time of incapacity
- Alcohol or drug intoxication
- Medication side effects
- Infection causing confusion

If you recover, and become mentally capable again, you will make your own healthcare decisions.

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## Advance Care Planning

Advance Care Planning is a process of planning for future healthcare decisions. Should you become mentally incapable, it is important to prepare for who will step in to make healthcare decisions for you. This person(s) will be identified as your Substitute Decision Maker(s).

As long as you are mentally capable, you will continue to make your own healthcare decisions, however, sometimes people cannot make their own decisions because they are too sick or unconscious (not awake). This could be during surgery, from an accident or due to an illness. If you recover, and become mentally capable again, you will make your own healthcare decisions.

Think about what is important to you

Complete a values exercise to help you determine what is important to you and share it with someone you trust that will uphold your wishes.

[Thinking about values \(advancecareplanningontario.ca\)](http://advancecareplanningontario.ca)

*Questions to Consider:*

- What gives your life meaning?
- What brings quality to your life?
- What worries or fears do you have about your future and your health?
- Think about previous healthcare choices you've made and what factors did you consider then?
- Think about past medical care a family member or friend may have received during an illness or at the end of life – what stuck out in your mind? Was there something that could have been done differently?



*Here's a link for more information*

<https://advancecareplanningontario.ca/acp/what-is-the-acp-process/thinking-about-whats-important-to-you>

**You can contact Advance Care Planning Ontario by:**

**Email:** [info@advancecareplanningontario.ca](mailto:info@advancecareplanningontario.ca)

**Tel:** [1-800-349-3111](tel:1-800-349-3111) ext. 231



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## The 6 Questions of Advance Care Planning

1. What do I understand about my health or illness? What have I been told about my illnesses?
2. What information would I like to find out?
3. What do I value most? What brings quality or meaning to my life?
4. What concerns or worries do I have about how my health may change in the future?
5. What might I trade for the chance of gaining more of what I value or what's important to me (i.e. more time with family)?
6. If I was near the end of my life, what would make this time the most meaningful?

### Maintaining Your Quality of Life

While you receive end of life and palliative care it may be important to try to continue your life as normally as you can. Simple things such as following a routine, connecting with family, eating well and being physically active where possible will help you feel more positive, enjoy each day and keep doing the things you enjoy for longer.

Palliative care is more than just medical treatment and relief from pain or discomfort. If a physician recommends palliative care to you or a loved one, this does not mean they have “given up.” It is care that aims to enhance your overall sense of wellbeing. With this in mind, it is important to look after yourself, stay connected with the people around you, and do things that provide meaning to your life. You can do some of these things on your own, but for others you may need the help of your family and friends, your doctor, the palliative care team and other healthcare professionals.

Learn more here:

<https://advancecareplanningontario.ca/acp/what-is-the-acp-process/six-questions>



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*Keeping a journal with your questions and thoughts and bringing this to your medical appointments can be helpful so you can remember your routines, symptoms, questions and thoughts to share with your health care provider.*

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## Caregiver / Care Partner Support and Education

Being a caregiver / care partner can be both a rewarding and challenging experience. There is support and education available to all regardless of whether you are new to being a caregiver / care partner or you're well into your caregiving journey. Caring for yourself is a key part of caring for others. Topics covered include:

### Topics Covered Include

#### **The Caregiver's Journey**

<https://caregiversupport.hpco.ca/ocp/topic-2-the-caregivers-journey/>

#### **Care for the Caregiver and Handling your Emotions**

<https://caregiversupport.hpco.ca/ocp/topic-3-care-for-the-caregiver-and-handling-your-emotions/>

#### **What are Community and Residential Hospice Care?**

<https://caregiversupport.hpco.ca/ocp/topic-4-what-are-community-and-residential-hospice-care/>

#### **What do People with a Life Limiting Illness Want?**

<https://caregiversupport.hpco.ca/ocp/topic-5-what-do-people-with-a-life-limiting-illness-want/>

#### **Why is a Family Member Acting that way?**

<https://caregiversupport.hpco.ca/ocp/topic-6-why-is-a-family-member-acting-that-way/>

#### **What are Advance Care Planning, Goal of Care Discussions and Health Care?**

<https://caregiversupport.hpco.ca/ocp/what-are-advance-care-planning-goals-of-care-discussions-and-health-care-consent/>

#### **How to make Tough Decisions**

<https://caregiversupport.hpco.ca/ocp/topic-8-how-to-make-tough-decisions/>

#### **How to Give a Bed Bath and Attend to Personal Hygiene**

<https://caregiversupport.hpco.ca/ocp/topic-9-how-to-give-a-bed-bath-and-attend-to-personal-hygiene/>

#### **Home Safety, fall Prevention, Assistive Devices**

<https://caregiversupport.hpco.ca/ocp/topic-10-home-safety-fall-prevention-assistive-devices/>

#### **How to Communicate Effectively with Family, Doctors, Volunteers and Helpers**

<https://caregiversupport.hpco.ca/ocp/topic-11-how-to-communicate-effectively-with-family-doctors-volunteers-and-helpers/>

#### **How to Communicate with Someone with a Life Limiting Illness**

<https://caregiversupport.hpco.ca/ocp/topic-12-how-to-communicate-with-someone-with-a-life-limiting-illness/>

#### **How to Help with Physical Needs**

<https://caregiversupport.hpco.ca/ocp/topic-13-how-to-help-with-physical-needs/>

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## How to Respond to Emotional and Spiritual Needs

<https://caregiversupport.hpco.ca/ocp/topic-14-how-to-respond-to-emotional-and-spiritual-needs/>

## How to Respond to Cultural Needs

<https://caregiversupport.hpco.ca/ocp/topic-15-how-to-respond-to-cultural-needs/>

## The Importance of Observation

<https://caregiversupport.hpco.ca/ocp/topic-16-the-importance-of-observation/>

## Pain: How to Recognize it and How to help

<https://caregiversupport.hpco.ca/ocp/pain-how-to-recognize-it-and-how-to-help/>

## How to be Present with a dying person

<https://caregiversupport.hpco.ca/ocp/topic-18-how-to-be-present-with-a-dying-person/>

## Signs of Approaching Death and What to do

<https://caregiversupport.hpco.ca/ocp/signs-of-approaching-death-and-what-to-do/>

## Grief: The Stages and How to Cope

<https://caregiversupport.hpco.ca/ocp/topic-20-grief-the-stages-and-how-to-cope/>

## First Nations Caregiver Supports

Topics Covered in this Indigenous Support kit include:

### The Palliative Approach To Care

<https://caregiversupport.hpco.ca/ocpfn/topic-2-the-palliative-approach-to-care/>

### Understanding how being a Caregiver Affects you

<https://caregiversupport.hpco.ca/ocpfn/topic-3-understanding-how-being-a-caregiver-affects-you/>

### Honoring the Priorities of the Person you are caring for

<https://caregiversupport.hpco.ca/ocpfn/topic-4-honouring-the-priorities-of-the-person-you-are-caring-for/>

### Your Community Care Team

<https://caregiversupport.hpco.ca/ocpfn/topic-5-your-community-care-team/>

### How to Make Tough Decisions

<https://caregiversupport.hpco.ca/ocpfn/topic-6-how-to-make-tough-decisions/>

### What are Advance Care Planning and Healthcare Consent?

<https://caregiversupport.hpco.ca/ocpfn/what-are-advance-care-planning-goals-of-care-discussions-and-health-care-consent/>

### Home Safety, Fall Prevention, Assistive Devices

<https://caregiversupport.hpco.ca/ocpfn/topic-8-home-safety-fall-prevention-assistive-devices/>

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## How to help with physical needs

<https://caregiversupport.hpco.ca/ocpfn/topic-10-how-to-help-with-physical-needs/>

## How to Respond to Emotional and Spiritual Needs

<https://caregiversupport.hpco.ca/ocpfn/topic-11-how-to-respond-to-emotional-and-spiritual-needs/>

## Pain: How to Recognize it and How to Help?

<https://caregiversupport.hpco.ca/ocpfn/topic-12-pain-how-to-recognize-it-and-how-to-help/>

## How to Be Present with a Dying Person

<https://caregiversupport.hpco.ca/ocpfn/topic-13-how-to-be-present-with-a-dying-person/>

## Signs of Approaching Death and What to Do

<https://caregiversupport.hpco.ca/ocpfn/topic-14-signs-of-approaching-death-and-what-to-do/>

## Grief: The Stages and How to Cope

<https://caregiversupport.hpco.ca/ocpfn/topic-15-grief-the-stages-and-how-to-cope/>

Other Caregiver Supports are also **available** including a 24/7 helpline, Peer Support, Webinars, Caregiver Coaching, Online Learning Library, Toolkits for Caregivers:

<https://ontariocaregiver.ca/for-caregivers/>

**Caregivers 24/7 Helpline:** 1-833-416-2273

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## Progression of Disease

Being prepared to care for a loved one nearing the end of life can be challenging, there are resources available.

- Understanding the different services available and which agencies provide your main sources of support is critical to ensuring you or your loved one receives the best care. (Please refer to the [Navigating the System](#) section below).
  - [https://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home/Support/Resources/Books+Links+and+More/Caregiver+and+caregiving/Books/A+Caregiver+s+Guide+A+Handbook+About+End\\_of\\_Life+Care.aspx](https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Resources/Books+Links+and+More/Caregiver+and+caregiving/Books/A+Caregiver+s+Guide+A+Handbook+About+End_of_Life+Care.aspx)

It is Important to understand that disease progresses in stages and that these stages may flow into one another, with some stages advancing quicker than others.

- Advocacy is important throughout all stages
- Each stage may bring unique physical, mental, emotional and spiritual challenges
- Ask for reevaluation of supports to keep up with changing needs
- The care team will adjust treatment plans as needed

Providing care or being cared for in your home brings additional considerations:

Your caregivers will support you with care, including personal hygiene (toileting, managing incontinence), giving medications and other possible caregiving duties.

Understanding that care plans may not always work out as planned – service providers such as personal support workers may be scheduled at specific times but may be late or unable to attend due to unforeseen circumstances. While this is challenging, it is a reality of care at home.

Be your own advocate – or advocate for the person you are caring for – you are there to advocate for the best possible care for yourself / the person with the progressive illness.

Some homemaking services (housekeeping, laundry, outdoor maintenance, food services) have additional costs. Links to many of these services can be found below:

- <https://www.agefriendlyarnialambton.ca/Services/Category/402460>

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## Navigating the System

- There are many supports and services to assist in your healthcare journey after diagnosis of a life limiting illness.
- Sarnia-Lambton's Age Friendly Website (<https://www.agefriendlyarnialambton.ca/>) is a one-stop shop for community supports and health services for any age and stage and is available to residents of Sarnia and Lambton County. Find Services in Sarnia Lambton such as:
  - Transportation
  - Food, Clothing & Housing
  - Mental Health & Additions
  - Help at Home
  - Family and Caregiver Supports
  - Health Care
  - Social Participation & Active Living
  - Equity, Diversity & Inclusion
  - Indigenous Supports
  - Financial & Legal
  - Employment & Volunteering
  - 24/7 Supports

Some specific services are of note as an illness progresses, including Home and Community Care, St. Joseph's Hospice, Age Friendly – End of Life Care



Click the link below to learn more about Age-Friendly or you can watch a YouTube tutorial on how to use the website click here:

<https://www.youtube.com/watch?v=jKtyH8Mie3Y>

<https://www.agefriendlyarnialambton.ca/Services/Category/402466>

## Talk to a Community Navigator

Please note: If this is an emergency, call 9-1-1 or go to the Emergency Department.

### What is a Community Navigator?

Community Navigators are here to find the resources and supports available to help people play an active role in accessing the many programs, supports and services throughout Lambton County. Their role is to actively listen to you and suggest local sources of help and support tailored to your needs.

Call 519-336-3000  
to Connect to a Community Navigator  
(Available 7 days a week from 9:00 a.m. - 10 p.m.)

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## St. Joseph's Hospice

St. Joseph's Hospice Sarnia Lambton offers residential care and community-based programming. Services include grief support, palliative and end of life care, provided in partnership with an individual's circle of care in Lambton County.

**St. Joseph's Hospice also provides Living Life Well (Illness and Caregiver Support) programming, which offers a variety of services to educate and support individuals with a progressive illness and their caregivers, while enabling them to live at the end-of-life with dignity, self-determination and a sense of community. The first step to accessing care at St. Joseph's Hospice is to call Home Care Community Support Services Southwest at (519) 473-2222.**

Additional programs include:

- Adult Bereavement Support Groups
- Caregiver Support Groups
- Caring Hearts Children's Program
- Parents of Grieving Children Support Groups
- Complementary Therapies
- Day Hospice
- Virtual & Telephone Counselling
- Public Education Hospice Volunteer Visiting Program
- Bereaved Drop In

Click the link below to learn more about St. Joseph's Hospice Sarnia Lambton

<https://www.stjosephshospice.ca/>

or call 519-337-0537



*If you don't have access to the Internet, or you are having difficulty finding what you need, you can always call the Community Navigator phone line.*

*Alternatively, you can visit your local library (in Sarnia, Lambton County) and a library services member can assist you in accessing the Age Friendly Website.*

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## Home and Community Care Support Services (HCCSS)

HCCSS coordinates in-home and community-based care services to patients, their families and caregivers. HCCSS assist to:

- Remain safely at home with support of health and other care professionals
- Return home from hospital and recover at home
- Find a family doctor or nurse practitioner
- Find community services that support healthy, independent living
- Transition to long term care or supportive housing
- Die with dignity in the setting of their choice

Click the link below to learn more about Home and Community Care Support Services  
<https://www.healthcareathome.ca/>

### HCCSS Palliative Care

Palliative Care Nurse Practitioners connect, support and care for patients who have a progressive illness. Nurses help people and families understand their options and provide support. They work closely with your existing supports and professional services and bring in additional services as needed.

Click on the link below to learn more about HCCSS Palliative Care  
<https://www.healthcareathome.ca/home-care/palliative-care/>  
or call **312-2222** (no area code required)

### eShift

Home and Community Care Support Services offers an innovative E-Shift program. The program has been designed to support caregivers who are caring for patients in the home with 24/7 needs when those patients are at end-of-life.

The E-Shift model places specially trained personal support workers (PSWs) in the home to provide overnight care for patients, with the support of a registered nurse working from a remote office location. Using a smartphone, the nurse can review clinical observations and assessments completed by the PSW at the bedside and provide care direction.



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How to access E-Shift: If you or a loved one are a caregiver providing care 24/7 and require additional support, you may qualify for E-Shift. **To make a referral, simply contact your Care Coordinator at 1-888-447-4468**

## Bluewater Palliative Care Clinic

The Bluewater Palliative Care Clinic is an outpatient palliative care clinic with physicians specialized in providing palliative services and patient care. The clinic provides support for patients navigating the healthcare system, and support for pain and symptom management, with a focus on quality of life.

Palliative physicians see patients in multiple locations including; the clinic, home visits, long-term care and nursing home settings. The team helps support patient transitions between care locations as needed, including transitions between hospital, home, long-term care and hospice. The team works collaboratively with the St. Joseph's Hospice and Home and Community Care Support Services, ensuring that the patient has comprehensive supports and collaborates in adjusting care plans as needed.

**How to Access:** To access the Bluewater Palliative Care Clinic a referral may be made from a primary care/ specialist or a Home and Community Care nurse practitioner.

**Phone:** 519-337-3848

**Fax:** 519-491-5803

**Address:** 4-460 Christina Street North, Sarnia, On N7T 5W4

**Hours:** Mon-Fri 8:30-4:30pm, except holidays

# Palliative Care Patient and Care Partner Toolkit



## References

- Advance Care Planning Ontario ([advancecareplanningontario.ca](http://advancecareplanningontario.ca))
- Age-Friendly Sarnia Ontario ([agefriendlysarnialambton.ca](http://agefriendlysarnialambton.ca))
- Health Quality Ontario ([hqontario.ca](http://hqontario.ca))
- Hospice Palliative Care Ontario ([hpcoco.ca](http://hpcoco.ca))
- Ontario Caregiver Association ([ontariocaregiver.ca](http://ontariocaregiver.ca))
- Ontario Palliative Care Network ([ontariopalliativecarenetwork.ca](http://ontariopalliativecarenetwork.ca))
- Ontario.ca ([ontario.ca](http://ontario.ca))
- The Online Destination for Ontario Government Publications ([publications.gov.on.ca](http://publications.gov.on.ca))
- Vistas Healthcare - ([vistas.com](http://vistas.com))
- Better Health - ([betterhealth.vic.gov.au/health/servicesandsupport/Maintaining-quality-of-life-during-a-life-limiting-illness](http://betterhealth.vic.gov.au/health/servicesandsupport/Maintaining-quality-of-life-during-a-life-limiting-illness))
- Government of Canada ([canada.ca/en/health-canada/services/health-services-benefits/palliative-care.html](http://canada.ca/en/health-canada/services/health-services-benefits/palliative-care.html))

## Glossary of Common Palliative Care Terms

- *Palliative Performance Scale (PPS)*
  - <https://victoriahospice.org/wp-content/uploads/2019/12/PPSv2-English-Sample.pdf>
- *Canadian Virtual Hospice*
  - [Canadian Virtual Hospice](#)
- *Key Palliative Care Concepts and Terms*
  - [Key Palliative Care Concepts and Terms \(ontariopalliativecarenetwork.ca\)](#)