



A Guide to Living with a Progressive Illness

Palliative Care Patient and Care Partner Toolkit

Adapted from Hospice Palliative Care Ontario

Table of Contents

| | |
|---|----|
| Diagnosis | 2 |
| What is Palliative Care?..... | 3 |
| Substitute Decision Makers..... | 4 |
| Advance Care Planning | 7 |
| The 6 Questions of Advance Care Planning | 8 |
| Caregiver / Care Partner Support and Education..... | 9 |
| First Nations: Caregiver / Care Partner Considerations..... | 23 |
| Progression of Disease | 26 |
| Navigating the System | 27 |
| Bluewater Palliative Care Clinic..... | 30 |
| References..... | 31 |

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.

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.

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:

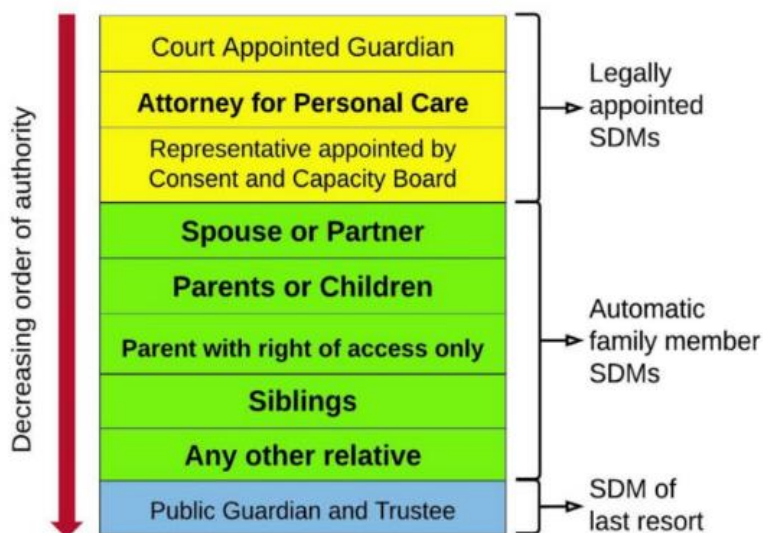
Email: CAO@ontario.ca

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).

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.

Substitute Decision Maker Hierarchy



Ontario's Health Care Consent Act, 1996

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](https://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](https://www.ontario.ca/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](https://www.ontario.ca/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.**

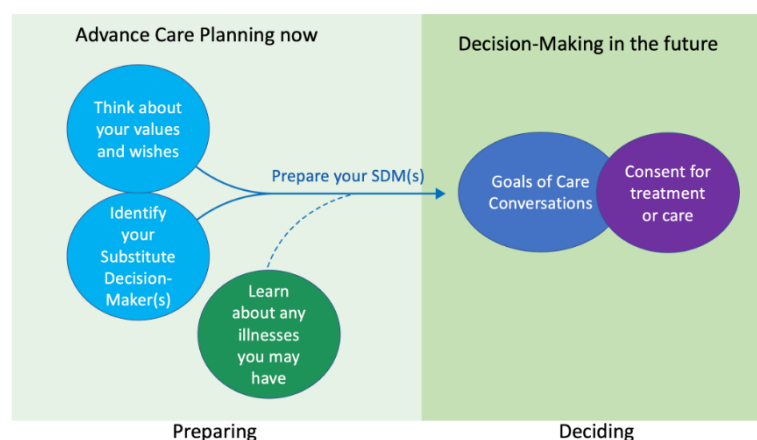
Things to Consider when Choosing a Substitute Decision Maker:

- 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
- Healthcare providers will provide information on your current condition and discuss treatment options with your SDM.
 - Your SDM's role is to determine the option that is best for you. They will think about your wishes and values and tell the healthcare team this as part of a goals of care conversation.
 - Since you will be incapable of participating at the time, it is important to share information on your values, and what is important to you during the ACP process.



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.

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.

Think about what values are important to you:

- Dignity
- Independence
- Wellness
- Clear-mindedness
- Family
- Hard work/dedication
- Strength
- Spirituality
- Not being a burden
- Relationships

Sharing these values with a Substitute Decision Maker will help them make decisions if you are unable.

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?
- What does having dignity mean to you?
- If spending time with family is important to you, what is it about spending time that means the most to you?



You can contact Advance Care Planning Ontario by:

Email: info@advancecareplanningontario.ca or **Tel:** 1-800-349-3111 ext. 231

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.



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.

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.

The below is a condensed version of full PDF's and video's in the use links below. Internet and computer access are available at Lambton County Libraries and Lambton Shared Services in Sarnia if you want further information, please visit these sites and access the internet provided to view full video and PDFs.

The Caregiver's Journey

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

<https://caregiversupport.hpco.ca/ocpfn/topic-2-the-palliative-approach-to-care/> (First Nations Caregiver Supports)

The 6 Stages of Care Giving:

Stage 1: Regardless of how you have become a caregiver, the first stage of Care giving is about sharing your fears, concerns, insecurities. Talk to your support people about the role you are taking on. You might gain new perspective that your relationships, responsibilities and hopes/dreams might be delayed during this time.

Stage 2: Your goal in the second stage is to learn as much as you can as fast as you can. You may notice/feel that a caregiving role may be much bigger than you first realized. Find out what supports and services are available to the person you are caring for and for yourself as well. If you are employed, explore how you will manage work and caregiving too. This is the time to start having Advance Care Conversations if you haven't had them already.

Stage 3: In this third stage, your calendar may be dominated by numerous appointments. You might feel like your worst fears are emerging and you don't know who to trust or what information to believe. You may also feel like no one understands what you are going through. Your first responsibility must be to care for yourself; doing everything you can to prevent caregiver burnout, illness, and injury. Your ability to continue caregiving and to have a healthy life after caregiving depends on caring for yourself now.

Stage 4: You are now involved in all aspects of caregiving for your family member or friend. You have come to the realization that you must sink or swim so you are swimming as hard and as fast as you can. You may be happy to help but you can't help but wondering "why me?" Over time, unless you take steps to prevent it, you will become exhausted physically, mentally and emotionally. Keep the lines of communication open, and don't be afraid to ask for help.

Stage 5: You are once again in transition. You may realize or imagine an end to your caregiving role either because the person is getting well and will soon be caring for themselves once again or because the person that you are caring for has little time left.

Stage 6: Your life changes once again and you must adapt to the new “normal”. If your loved one (friend or family member) has passed away, you might have questions about how to move forward. You may feel regret, guilt, sadness or relief and all those feelings are normal. Consider joining a support group, continue writing in your journal. Engage in relaxation and spiritual practices. Lighten your schedule to allow quiet times to be alone with your thoughts.

Care for the Caregiver and Handling your Emotions

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

<https://caregiversupport.hpco.ca/ocpfn/topic-3-understanding-how-being-a-caregiver-affects-you/> (First Nations Caregiver Supports)

Feeling a number of different emotions is normal and expected. You may at times feel overwhelming love for the person you are caring for and other times you may feel sad, angry, fearful or just exhausted.

Strategies for coping:

- Exercise or go for a walk
- Talk to friends, family or co-workers
- Step outside or just take a break and re-group
- Journal, draw or anything else that helps you relax

Key things to remember:

- Get a good night sleep
- Watch for signs of caregiver burnout (urge to run away, feeling scattered, irritable, angry, can't concentrate, losing weight, not sleeping)

***If you are experiencing burnout – call your doctor and schedule an appointment
YOU NEED TO TAKE CARE OF YOU TO CARE FOR OTHERS***

Keys to Managing Stress:

- Plan ahead so others can help you
- Remember both you and the person you are caring for are doing the best you both can to get through this situation, give each other grace, understand each other

What are Community and Residential Hospice Care?

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

Hospice palliative care is aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, advanced illness or are bereaved.

Hospices are able to provide a range of services including:

- Being “present” and listening to any needs or issues identified by the person or their loved ones
- Providing personal care and recognizing signs and symptoms of unmanaged pain
- Support the process of dying and providing care right until the end
- Providing bereavement support

Quality hospice palliative care neither hastens death nor prolongs life. The goal of hospice palliative care is to improve the quality of life for patients and their chosen care partners.

Look in the sections above or call the Age Friendly Community Navigator Line (519-336-3000) for services provided in Sarnia Lambton by the local St. Joseph’s Hospice.

What do People with a Progressive/Serious Illness Want?

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

<https://caregiversupport.hpco.ca/ocpfn/topic-4-honouring-the-priorities-of-the-person-you-are-caring-for/> (First Nations Caregiver Supports)

Be a Friend

A young woman named Courtney Strain died of brain cancer in June 2010 at the age of 25. In the months before she died, she said that when she was diagnosed with brain cancer she sometimes felt like an outcast. People didn’t know what to say to her, so they said nothing at all. So, with a friend’s help she wrote a simple guide called “What You Can Do When a Friend (Like Me) Faces the End of Life.” Here are some of the things she wanted people to know:

- **Hallmark doesn’t fix it all.** Write a letter or send an email... [Talk to me when] I’m strong enough to sit and laugh or cry with you.
- **Don’t pretend that everything is going to be OK.**
- **Don’t abandon me at my most vulnerable time.** Sit and pray with me. Don’t just pray for me.
- **Don’t treat me like a child — even a well-loved child.** Include me in decisions that affect our family or social group.
- **Instead of asking, “What can I do for you?”** Offer some concrete suggestions — like bringing a meal or treat, or running errands.
- **Respect my decisions about my health care** — my doctors, my medications and my treatments — and about my end-of-life plans.
- **Just because I’m dying doesn’t mean I’m any less capable of being your friend.** Dying isn’t my whole identity.

Why is a Loved One Acting that way?

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

Everyone deals with illness in different ways. Some people might distance themselves, others might become angry, frustrated and lash out at others and some might go into “fix-it” mode, a built-in

defense system takes over to “displace” the potentially threatening ideas, fears and feelings. The problem with displacing feelings is that they negatively affect a person’s ability to relate to others.

Communicating with the individual and sharing that you have similar feelings is a good way to break the ice. Let them know how they can help and to run towards their fears. Just outline to the person how they can help – give them tasks that will also help you.

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

Remember:

- Advance Care Planning conversations are NOT consent for future care.
- Wishes ARE NOT decisions.
- Advance Care Planning is a VOLUNTARY process.
- EVERYONE at any age should participate in Advance Care Planning.

See more in the Advance Care Planning Section above.

How to Make Tough Decisions

<https://caregiversupport.hpco.ca/ocp/topic-8-how-to-make-tough-decisions/>
<https://caregiversupport.hpco.ca/ocpfn/topic-6-how-to-make-tough-decisions/> (First Nations Caregiver Supports)

Strategy for Making Tough Decisions

1. **Ask yourself - is this your decision to make?** If the person you care for is mentally competent, it is not your decision to make.
2. **Recall the four priorities of someone living with a progressive/serious illness.**
 - To maintain a sense of dignity and privacy, as much as possible.
 - To maintain a sense of control, as much as possible.
 - To be treated with respect, sensitivity and an awareness of their feelings.
 - To avoid being a burden to their family and friends, as much as possible.
3. **Consider just one issue at a time.** Ask yourself, if the decision will impact the person’s sense of dignity, sense of control, feeling of being respected and desire not to be a burden, in a positive or negative way?
4. **Modify or change your “tough decision” based on those important priorities.** If the decision you make will destroy the person’s sense of dignity, remove all control from their life or make them feel as if their feelings don’t matter, then it isn’t the right decision to make. Are there alternatives? Take it one step at a time.

5. Time to decide. Once you feel that your solution is the best one considering the four priorities then it is time to make your decision.

6. Evaluate. Once the decision has been made and you have put an action in place, it is time to evaluate your “tough decision”.

- Are things better off than before, and if so, how?
- What improvement has this decision brought about?
- Have unexpected obstacles arisen? Or unexpected benefits?
- Should we give the plan more time to work? Or should we start working to change or replace it?
- Is it time to call for more help?

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/>

1. **Wash your Hands and Gather Equipment.**
2. For privacy, cover your loved one with a flannel sheet
3. Have one set of wash cloth and towel for face and body, and a second set for genital care
4. Have a basin of warm water, soap, a soap dish and moisturizer ready, along with clean pajamas or clothes, underwear and socks, (include an incontinence brief if required)
5. If changing the bedding, ensure you have clean sheets and remove blankets
6. Check the basin of water and ensure water is not too cold or too hot
7. Wet the washcloth; many people prefer no soap on their face
8. Wash the Person’s face first, making sure to carefully wash eyelids wiping from the inside corner outward, then wash the neck, and behind the ears and the back of the neck
9. Rinse the cloth out and dry well
10. Wash the arm and hand and between fingers, then rinse off the soap and dry well
11. Remove clothes/pajamas and uncover one side of the body first
12. Soap up the same washcloth used for the face and lay a towel under one arm of the person.
13. Wash the armpit area, it’s a good idea to place the person’s hand right in the basin of warm water
14. Wash the chest first, then the abdomen, back, each leg, and then feet
15. Rinse as many times as needed to get all the soap off
16. When drying, make sure the skin under women’s breasts is dry
17. You may want to use some moisturizer on the back, arm, leg, foot or other dry skin areas
18. Wash the armpit area, chest, abdomen, back, leg and foot on the opposite side of the body first covering up the washed side.
19. Using the second wash cloth, clean the genital area by folding the washcloth like a mitt and wipe the area with a small amount of soapy water
20. Rinse and dry thoroughly (do not use water after cleaning the genital areas)

21. Assist to put on clean pajamas or clothes
22. Dispose of the water and put the washcloths and towels in the laundry

Note: Vaseline is not to be used if a person wears oxygen. Powder should be avoided as it is a lung irritant and, if spilled, can cause slippery floors.

Home Safety, Fall Prevention & Assistive Devices

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

<https://caregiversupport.hpco.ca/ocpfn/topic-8-home-safety-fall-prevention-assistive-devices/> (First Nations Caregiver Supports)

Adapting Your Home - Simple changes to adapt your home without too much disruption.

- Remove throw rugs that can a tripping hazard.
- Use lights at the top and bottom of stairs and add a strip of contrasting coloured tape on the stair edge.
- Keep floors dry; wet or slippery floors are often a tripping hazard.
- Remove toys, papers, magazines, cables from the floor that could be tripped over.
- Create a special area near the person's bed and/or chair with special family pictures, mementoes, and where music can be played.
- Place a small table with a light on it near the bed and at the height of the bed for medications, snacks, iPad, a journal, a phone, etc.
- A small bell or even a baby monitor helps with letting you know that your loved one needs you.
- Consider installing grab bars in areas such as bathrooms.

Ask your visiting nurse or home care provider if there are other home aids or assistive devices that might of help. Many of these can be borrowed, rented or purchased.

How to Community Effectively with Family, Doctors, Volunteers and Helpers

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

<https://caregiversupport.hpco.ca/ocpfn/topic-5-your-community-care-team/> (First Nations Caregiver Supports)

Write down your most important questions or concerns in advance and take your list with you.

1. What is your most important question or concern?
2. Record the answers or take someone with you to help listen and record.
3. Be honest with your doctor / care professional about any other issues, concerns or complementary therapies so the doctor has a full understanding.
4. Be clear and tell the doctor / care professional briefly what is of concern.
5. If you have questions or don't understand, don't be afraid to ask for clarification.
6. If you / your loved one is receiving care in the home and you don't know the role of the home care worker coming in, ask them. There are different types of professionals you may see in your home and understanding each of their roles is important.

How to Communicate with Someone with a Progressive/Serious Illness

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

As someone's disease progresses think about the following as you communicate with them:

- Encourage hope – help your loved one maintain realistic hope
- Be honest – stay away from comments like “everything will be fine”
- Follow their lead – if they want to reminisce or talk about death, just listen and hear
- Do not force conversation, silence is ok
- Accept their feelings – don't argue if someone is in denial about their illness
- Respect that although they may not be responding, your loved one can hear you – the sense of hearing is the last to go
- Do not take anger and resentment personally – remember the saying that we take out frustration on those we love the most
- Be solution focused rather than problem focused – we can't change what has already happened, but we can change what happens next

Tips for communicating with someone who can't speak:

- Don't be afraid to talk. Share things from your life. Read to the person.
- Look them in the eyes and smile. Even ask them to blink once for yes or twice for no.
- Touch them. A gentle touch of the hand, a stroke of the hair, a kiss on the cheek or forehead can all be welcome gestures of affection.
- Make cue cards or picture cards to help you understand what they would like

How to Help with Physical Needs

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

<https://caregiversupport.hpco.ca/ocpfn/topic-10-how-to-help-with-physical-needs/> (First Nations Caregiver Supports)

How to Help with changes in Appetite?

It is perfectly fine if someone doesn't want to eat as long as they continue to drink fluids (sometimes there comes a point where even swallowing liquids becomes difficult)

- Try adding fruit / juice or milkshakes or smoothies
- Try serving water, tea or soft drinks to take a strange taste away
- Try new flavourings for food
- For someone who doesn't want meat try other foods high in protein (eggs, fish)
- Choose foods that are soft and easy to eat.
- Try serving smaller portions more often.
- Offer what your loved one feels like eating.

Breathing problems can be very frightening for caregivers. Anxiety can cause shortness of breath; shortness of breath can cause anxiety. Call the doctor when a sudden onset of breathing difficulties occurs.

How to help with Breathing Difficulties

- Try to make your loved one as comfortable as possible and minimize their feeling of distress
- If there are times where exertion is needed, take lots of breaks
- Help your loved one relax, stay close and stay calm
- Reposition and help your loved one sit up with their arms over a pillow or bed side table, elevate the head of the bed or place pillows behind them to raise the upper body
- Loosen clothing.
- A cold compress on the forehead or cheeks can help lessen the feeling of breathlessness.

When you see red, tender skin over pressure points or in skin folds, dry itchy skin, rashes, open weeping sores or tears in the skin then you know that skin is breaking down.

How to Help with Skin Difficulties

- Reposition every 1-2 hours
- Add a foam pad on top of their mattress (you can rent or purchase these)
- Put a pillow between the knees / ankles when they are laying on their side
- Gently massage hips, heels and tailbone with moisturizing lotion
- Keep linens dry and wrinkle free
- Give bed baths regularly
- Try using flannel towels as they are softer than terry cloth
- Report any skin changes to the care team

How to Help with Incontinence

- Use incontinence garments like Stayfree™, DryPlus™, Attends™, Poise™, will help keep sheets clean and dry.
- Change the garment often.
- Use a zinc oxide cream to help prevent sore skin.

Note: Be sure to wear gloves or wash your hands with warm soapy water each time you assist with incontinence garments

How to help with Constipation Difficulties:

Note that most of these suggestions are inappropriate in the final days of a person's life.

- Have them drink several glasses of water each day (this intake is unrealistic at end of life – people often only take ¼ cup per day in the final days of life)
- Gradually add more whole grains to their diet

- Offer hot drinks in the morning
- Encourage walking, exercising in bed
- Try to avoid chocolate, cheese and eggs
- Monitor bowel movements and let the care team know if your loved one is struggling with constipation

How to Help with Mouth Difficulties:

- Keep the mouth clean and moist
- Remove any dentures before cleaning the mouth
- Treat cracked dry lips
- Provide frequent sips of water as tolerated
- Provide oral care often (as often as every two hours) , after waking, after meals and at bedtime
- Use an alcohol free, gentle mouthwash

How to Deal with Confusion:

- Start with them and where they are at.
- Remind the person who you are frequently
- While talking to the person position yourself so that you are face to face turning off the background noise from the television or radio.
- Do not leave the person alone for prolonged periods of time.
- Keep the calendar and clock in view of the person so they can feel oriented.
- Be sure to keep the medication out of reach and bring it to the person yourself rather than having the person self-administer their own medication.
- Talk slowly and quietly using short statements.
 - Ask for help if:
 - Confusion occurs very suddenly or becomes worse.
 - The person becomes violent or agitated.
 - You or the person themselves are hurt physically because of the confusion.
 - You are tired and need relief.

How to Respond to Emotional and Spiritual Needs

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

<https://caregiversupport.hpco.ca/ocpfn/topic-11-how-to-respond-to-emotional-and-spiritual-needs/> (First Nations Caregiver Supports)

Spiritual Support

When faced with suffering, many people find that their spiritual well-being becomes more important to their quality of life. Sometimes there is a greater interest in spiritual or religious beliefs, sometimes people feel angry or “let down” by their god. This is not a time to impose your own spiritual belief. Follow the person’s lead. For example, the person you are caring for may appreciate praying with you.

Recognize that organized religion and spirituality are two different things. Spirituality includes a sense of connection to something bigger than us or a search for meaning in life. Of course, such questioning is part of the universal human experience. The connection between the spirit world and the mortal world is an important one for many Canadians. A person may never have gone to a church or synagogue or mosque and yet feel the need for a spiritual connection and association. Be supportive and non-judgmental. You may want to help the person that you are caring for engage with an elder or healer, a medicine man, a minister or priest, spiritual leader of a nearby synagogue or mosque or you may want to help them connect spiritually with the world around them.

Easing Emotional Suffering

Caregivers can support people who are suffering emotionally by providing a committed presence, by affirming the person's value and worth, by being compassionate and kind. Caregivers can support and reinforce dignity, hopefulness, and a sense of control or resilience by giving the person an opportunity to have their thoughts and wishes heard and acknowledged.

How to Respond to Cultural Needs

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

Cultural attitudes and beliefs can affect the way that people respond to pain, suffering and grief. Similarly, everyday routines such as eye contact, compliments, personal space, modesty and non-verbal communication can all be affected by a person's cultural orientation. It is important to respect those differences, to be sensitive to cultural values and beliefs, and to be non-judgmental about them. After all, every one of us belongs to a unique culture based on beliefs and practices.

A person's willingness to accept support from a caregiver may be influenced by cultural factors. In some cultures, the family is more important than the individual and health-related decisions are typically made as a family. Some health care professionals may need your help understanding this important cultural difference.

How a person thinks about time can also be different given the influence of culture. Some cultures are focused on the future and looking ahead while other cultures are more focused on the past or present. Sometimes such a time orientation can be a source of conflict between generations of the same family. It is important to talk about these different perspectives and come to a resolution for the support and well-being of the person being cared for.

A person's values, attitudes and beliefs may conflict with those of mainstream approaches to care. In some cultures, it is perfectly acceptable to seek and receive help with caregiving responsibilities from people outside the family; in others, it is not.

The Importance of Observation

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

You as a caregiver have the unique responsibility of being the eyes, ears, nose and touch of the person's physician. You can use your observation skills to gather subtle clues as to how your loved one is changing day to day.

Below is a list of signs/symptoms you may observe and should share with the care team. People who are suffering from a life-limiting illness or nearing end of life, may experience a few of these symptoms or many of these symptoms:

- Loss of appetite
- Thirst
- Jaundice (yellowish skin)
- Constipation (difficulty passing stool)
- Hiccups
- Loss of control of bladder and/or bowels
- Swelling
- Pain
- Weakness and Fatigue
- Fever
- Nausea/Vomiting
- Inability to Sleep
- Skin Irritation

Pain: How to Recognize It and How to Help

<https://caregiversupport.hpco.ca/ocp/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/> (First Nations Caregiver Supports)

How can a caregiver recognize pain?

It is very important that the caregiver observes very carefully. As people near end-of-life their ability to communicate lessens so observation is critical at that time.

Signs of Acute Pain:

- Moaning, grimacing, shielding, protecting or massaging the site of the pain

Signs of Chronic Pain:

- Harder to observe as the person may show few signs of distress other than looking exhausted or depressed

Questions to Ask:

- Are you experiencing pain?
- When did it start?
- Where do you feel it? In one place? All over?
- What does the pain feel like?
- Is the pain sharp or dull, constant or shooting?
- What makes it better? Worse?
- Do you feel nauseous or dizzy from the pain?

- On a scale from 1 to 10 with 10 being the worst pain you have experienced, how intense is the pain?
- What can I do to help?
- What medications are you taking for the pain?

How to be Present with a Dying Person

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

<https://caregiversupport.hpco.ca/ocpfn/topic-13-how-to-be-present-with-a-dying-person/> (First Nations Caregiver Supports)

- You can provide the greatest support by being “present”
- Be with the person physically and emotionally.
- Listen to their reactions and feelings and concerns in a non-judgmental way.
- Sit down so you are at eye level.
- Say the person’s name; hearing your own name is very grounding.
- Offer uninterrupted time for unhurried conversation.
- Be yourself. Be ordinary.
- Observe mood and behavior. Do not pit your anger against their peace or vice versa. If the person feels exuberant or joyful, feel exuberant or joyful yourself. Shed tears together. Laugh together.
- Make eye contact and physical contact: follow the person’s lead.
- Be specific about how you can help and what is going to happen. Don’t avoid talking about death.
- Be respectful; support a person’s dignity and sense of control.
- Think about how you and the person communicated before the illness, what worked and what may need help.
- Pay attention to what is being said, the tone of voice, the body language as well as the words themselves.
- Try different openings for conversation. “Tell me about...”
- Be attentive. Don’t let your mind wander. Stay “in the moment”.
- Do not let illness put a ban on laughter or smiles.

Signs of Approaching Death and What to Do

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

<https://caregiversupport.hpco.ca/ocpfn/topic-14-signs-of-approaching-death-and-what-to-do/> (First Nations Caregiver Supports)

- Physical Changes in the Last Hours of Life Each person’s experience will be different. Some people will have all of these physical changes and other people will only have a few. The person may:
- Sleep longer and sometimes have difficulty waking up eventually slipping into a coma

- Become confused or agitated
- Eat and drink less if at all and have no appetite or thirst
- Become unable to recognize familiar people or surroundings
- Become profoundly weak
- Have difficulty responding verbally
- May have difficulty swallowing or forget how to swallow
- Develop a fixed stare
- Breathe shallowly and irregularly even stopping breathing for several seconds at a time
- Make wet or moist breathing sounds or make a rattling gasp for air
- Have a weak or irregular pulse
- Have cool hands and feet and pale bluish or mottled skin (dark and light patches)
- Have less urine output and/or lose bladder control
- Have no bowel movement or have uncontrolled oozing of soft liquid or stool

Strategies to support your loved one in their last hours:

- Conversation – continue to speak to them
- Personal care – bathe as needed, reposition every 1-2 hours
- Pain management – continue to give pain medications
- Be present – encourage reminiscing, prayers, tears, hand holding
- Oral care – continue to lubricate lips and offer fluids if they are able to swallow
- Breathing care – raise the head of the bed, turn them on their side, if breathing sounds moist, reach out to the nurse or doctor as there are medications that can help with this
- Incontinence Care – place protective towels or pads under them and change as necessary (you can use adult incontinence briefs if required and change as necessary)

When to call for help:

Some situations that require assistance from health care professionals include:

- The person has pain or other symptoms that are difficult to manage or relieve.
- The person is unable to take prescribed medications.
- The person shows signs of distress, such as pain, breathing problems, or agitation.
- You are overwhelmed by the person's needs and condition.

Grief: The Stages and How to Cope

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

<https://caregiversupport.hpco.ca/ocpfn/topic-15-grief-the-stages-and-how-to-cope/> (First Nations Caregiver Supports)

There are many theories and views on the stages of grief. Regardless of which theory you find most applicable, it is important to remember that grieving takes place over an extended period of time and

there are different feelings that go with early, middle and later grief, although often people go back and forth between these stages.

Early Grief – When a Death Occurs

Panic and strong physical and emotional reactions are common:

- upset stomach
- low energy, weakness and restlessness
- crying, sobbing, wailing
- indifference, emptiness (“can’t feel anything”) outrage and helplessness
- confusion, forgetfulness and poor concentration
- denial and daydreaming
- continually thinking about the person who died and/or the death
- blaming God or life
- feeling a lack of meaning, direction
- wanting to join the person who died
- withdrawal from others
- unrealistic expectations
- poor judgement about relationships
- shortness of breath and heart racing

Middle Grief – Adjusting to Loss

- changes in appetite and sleep
- shortness of breath and racing or pounding heart
- upset stomach
- strong and conflicting emotions
- problems remembering
- problems with concentrating or understanding
- vivid dreams or nightmares
- feeling the presence of the person who died
- continued lack of meaning
- rushing into new relationships
- wanting company but unable to ask
- continued withdrawal and feeling alone
- feeling self-conscious

Later Grief – As Life Goes On (mending the Heart)

- Sleeping/eating are more settled
- Gut-wrenching emptiness begins to go away
- Emotions are not so strong
- Feeling of foggy subsides
- More peace; less guilt
- Concentration improves
- Fewer dreams and nightmares
- Reconnect with spiritual beliefs
- You may feel new purpose
- Acceptance of death as part of life
- More interested in daily life
- Able to reach out and meet others
- More energy for social events

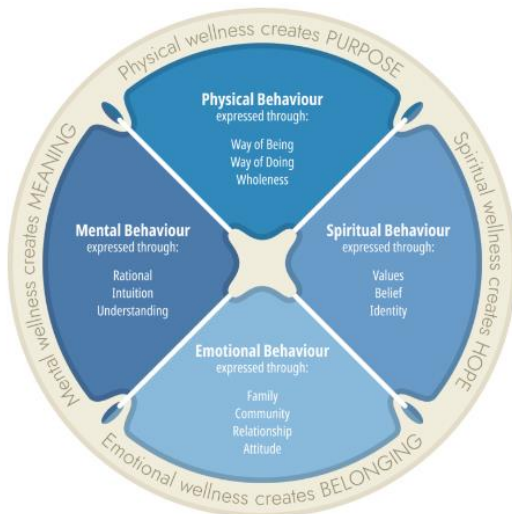
(Adapted from Victoria Hospice Bereavement Program pamphlet: Dealing with Grief)

First Nations: Caregiver / Care Partner Considerations

In addition to the information above, please see below considerations.

The Indigenous Wellness Framework is a great reminder that wellness is a balance of the spiritual, emotional, mental and physical, enriched when we find:

- **HOPE** for our future and the future of our families that is grounded in a sense of identity, unique values and a belief in spirit;
- A sense of **BELONGING** and connectedness within our families, our community and our culture;
- A sense of **MEANING** and an understanding of how our lives and the lives of our families and communities are part of Creation and a rich history; and
- **PURPOSE** in our daily lives, whether it is through education, employment, caregiving activities or cultural ways of being and doing.
- As you care for your loved one, remember the unique concepts of the Indigenous Worldview and let these guide you in your caregiver role.



Indigenous Wellness Framework

The IWF is a foundational framework that was developed by Elders and Knowledge Keepers who shared their understanding of what wellness is from an Indigenous point of view.

Spirit

Spirit is in all things. Our spirit, heart, mind and body work together as a whole.

Circle

The circle reminds us that everything is connected and part of a whole. Day is followed by night. Winter is followed by spring, then summer and fall, year after year.

If we look, we can see circular patterns in our own lives.

Harmony and Balance

The world is constantly changing, but it works towards harmony and balance. It's just like when people sing in harmony. The different individual voices blend together beautifully. We learn to balance when we ride a bicycle. We live in harmony and balance with our family, friends and neighbours when we respect each other's differences and care for one another.

All My Relations

We are connected to all things – people, plants, trees, animals and rocks. We are all related to one another and need to look after each other

Kindness/Caring/Respect

Kindness and caring are gifts from the Creator that our spirit carries into this world when we are born. Imagine that. We are naturally kind and caring. When we nurture this gift through our relationships, we learn about respect.

Earth Connection

We're all relatives because we're all part of Mother Earth.

Path of Life Continuum

Life is a journey. Babies learn to crawl and then to run. We grow up and figure out what our purpose is in life and how we can contribute to the life around us. We grow old. We're not alone on our journey because we're connected to our ancestors who came before us and to those who are not yet born.

Language

Our Indigenous languages are a sacred gift from the Creator. So, language is more than just a way of communicating.



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

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

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

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.agefriendlysarnialambton.ca/Services/Category/402460>

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. The Community Navigator Line (519-336-3000) is also available with live phone service to help Find Services in Sarnia Lambton such as:
 - Transportation
 - Food, Clothing & Housing
 - Mental Health & Addictions
 - 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

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.)

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

Call the number below to learn more about St. Joseph's Hospice Sarnia Lambton
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.
519-336-3000*

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

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

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.

Call the number below to learn more about HCCSS Palliative Care
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.

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

References

- Advance Care Planning Ontario (advancecareplanningontario.ca)
- Age-Friendly Sarnia Ontario (agefriendlysarnialambton.ca)
- Health Quality Ontario (hqontario.ca)
- Hospice Palliative Care Ontario (hpco.ca)
- Ontario Caregiver Association (ontariocaregiver.ca)
- Ontario Palliative Care Network (ontariopalliativecarenetwork.ca)
- Ontario.ca (ontario.ca)
- The Online Destination for Ontario Government Publications (publications.gov.on.ca)
- Vistas Healthcare - (vistas.com)
- Better Health - (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)
- Indigenous Wellness Framework
(https://www.google.com/search?q=indigenous+wellness+framework+ontario&rlz=1C5CHFA_e_nCA772CA772&oq=indi&gs_lcrp=EgZjaHJvbWUqCAgAEEUYJxg7MggIABBFGCcYOzIKCAEQABixAxiABDIGCAIQRRhAMgYIAxBFGDkyBggEEEUYPDIGCAUQRRg9MgYIBhBFGDwyBggHEEUYPNIBCDE4MzZqMGo3qAllsAIB&sourceid=chrome&ie=UTF-8)