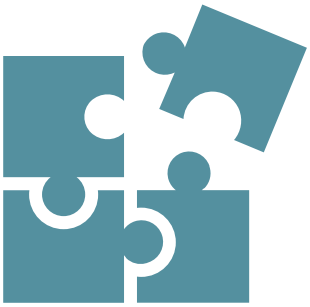
Couchiching
Ontario Health Team

# Palliative Pieces

## QUICK READS AND REFERENCES FOR THE COUCHICHING ONTARIO HEALTH TEAM SERVICE AREA



COHT IMPLEMENTATION OF

THE ONTARIO PALLIATIVE CARE NETWORK

MODEL OF CARE:

ADULTS RECEIVING PALLIATIVE CARE IN THE COMMUNITY

# Introduction

Palliative Pieces is a general education guide compiled for a broad audience to support the implementation of the Ontario Palliative Care Network Models of Care in the Couchiching Ontario Health Team service area. The Palliative Care Clinical Coach Nancy Merrow is a retired family physician with palliative focused training and experience. Artificial Intelligence assistance was used for research and reference sourcing. Resources are current, authoritative, Canadian and Ontario specific where possible. All text was reviewed by currently practicing physicians and health care professionals for relevance, and all links were live as of Oct 2026.

The booklet was designed to be used as a self-study guide to lead the reader to areas of clinical curiosity or cased based team discussions. Chapters could be excerpted for small group learning, rounds topics or community education.

Palliative Pieces is an overview of how to think about and plan a palliative approach for anyone with a progressive life limiting condition. Many more comprehensive clinical sources are listed in the chapter about more education and training, where readers can learn about discipline specific prescribing, treatments and interventions within your scope of practice.

I hope you find some inspiration and insight from this overview of the palliative approach, and that it helps to enrich your care and experience.

*Nancy*

*Nancy Merrow, MD, CCFP(PC), FCFP*
Palliative Care Clinical Coach

# Palliative Pieces

## COHT IMPLEMENTATION OF THE MODEL OF CARE

## ADULTS RECEIVING PALLIATIVE CARE IN THE COMMUNITY

## QUICK READS AND REFERENCES

## TABLE OF CONTENTS



*Palliative Pieces was compiled from publicly available sources using AI assistance for research and references. It is a general education guide and not a substitute for formal accredited training and published clinical guidance.*

Palliative Pieces

# Palliative Care - It's Not Just About Dying

For many patients - and some health care providers - the words palliative care still signal that death is imminent or that active treatment is stopping. That perception can make us reluctant to introduce a palliative approach until very late in an illness. **But palliative care is much broader than end-of-life care.**

## What is a palliative approach?

Palliative care focuses on relieving suffering and improving quality of life for people living with serious illness and for their families and care partners. It considers the whole person: physical symptoms as well as psychological, social, spiritual and practical needs.

**Importantly, a palliative approach does not require stopping disease-directed treatment.**

A patient with heart failure can receive optimal cardiac therapy and a palliative approach. A patient with COPD can continue active treatment of exacerbations while also receiving help with breathlessness, advance care planning and support for caregivers. A person with cancer can receive chemotherapy or radiation while palliative needs are addressed at the same time.
The balance between disease-directed treatment and comfort-focused care may change as illness progresses, but these are not necessarily either/or choices. Resistance to “giving up” is a barrier to holistic person centered care planning in progressive life limiting illness.

## Palliative care can begin early

Current palliative-care models emphasize identifying and addressing palliative needs earlier in the illness trajectory rather than waiting until a patient is clearly approaching the last weeks or days of life.

Ontario Health's Palliative Care Quality Standard states that people with serious illness should have their palliative care needs identified early through comprehensive and holistic assessment.

Earlier integration gives patients and families time to:

- manage pain and other distressing symptoms;
- understand the illness and what may lie ahead;
- discuss their goals, values and priorities;
- make informed decisions as circumstances change;
- plan for future care; and
- access psychosocial, spiritual and caregiver support.

## Palliative care is everyone's work

A palliative approach is not synonymous with referral to a palliative-care specialist.

Many core elements of palliative care can and should be provided by clinicians who already care for the patient. Ontario's current Model of Care emphasizes strengthening palliative-care competencies among generalist and non-palliative-care-specialist providers, while using specialist palliative-care expertise for patients whose needs require it.

**Think of palliative care as an added focus of care, not an abrupt change in management.**

## Try this in practice

**When caring for someone with a serious, progressive illness, ask yourself: "Does this person have unmet needs that a palliative approach could help address - now?**

The trigger does not have to be an estimate that the person has only weeks or months to live. Increasing symptom burden, functional decline, repeated hospitalizations, growing caregiver needs or uncertainty about goals of care may all be reasons to consider palliative needs.

## Words that work

Instead of: "I think it's time to consider palliative care."

*Try: "Along with treating your illness, I want to make sure we're paying attention to your symptoms, what is most important to you, and what you and your family may need as things change."*

In the next cha, we will be sharing tools and tips to support learning and practice. If you would like to pursue further education please visit *Pallium Canada* and the *North Simcoe Muskoka Hospice Palliative Care Network* (NSM HPCN) for courses and resources.

## This Piece

**Palliative care is not about giving up treatment. It is about adding another dimension to good care - relieving suffering, supporting quality of life, and helping care remain aligned with what matters to the patient throughout serious illness.**

# References and further reading


1. Ontario Health. Palliative Care: Care for Adults With a Serious Illness - Quality Standard. Updated 2024.
2. Ontario Health. Model of Care: Adults Receiving Palliative Care in Hospital Settings. Updated September 9, 2025.
3. Ontario Health. Palliative Care Health Services Delivery Framework / Models of Care. Updated June 4, 2026.
4. Ontario Health. Palliative Care Competency Framework. Updated June 4, 2026.
5. Ontario Health. Earlier Identification Tools for Palliative Care. Updated June 4, 2026.
6. World Health Organization. Palliative Care. WHO; 2020.

Palliative Pieces

# Early Identification & Introducing the Palliative Approach

## Would You be Surprised?

One of the challenges in providing a palliative approach is knowing when to begin.
For people living with heart failure, COPD, frailty, dementia, renal disease or multiple chronic illnesses, decline may be difficult to recognize. Repeated exacerbations, hospitalizations and partial recoveries can obscure the fact that the overall trajectory has changed.
Rather than waiting until a patient is clearly approaching the end of life, clinicians can look systematically for signs that palliative needs may be emerging.

## The Gold Standards Framework

The Gold Standards Framework (GSF) was developed in the United Kingdom to support proactive, coordinated care for people approaching the later stages of life. Its Proactive Identification Guidance (GSF-PIG) helps clinicians recognize deterioration and identify people who may benefit from further assessment and proactive care planning.
Ontario Health's current Palliative Care Toolkit uses the GSF three-step model to organize best-practice tools:
1. Identify - Who may benefit from palliative care earlier in the illness trajectory?
2. Assess - What are the person's current and future needs and preferences?
3. Plan and manage - How can care be coordinated to address the needs identified?

**Identification is the beginning of a process - not a prognosis and not a decision to stop treatment.**

## Start with the Surprise Question

**A simple prompt can help clinicians reconsider a patient's trajectory: "Would you be surprised if this patient were to die in the next 12 months?"**
If the answer is "No, I would not be surprised," look more closely. The Surprise Question should not be used alone to predict exactly when someone will die. Within an identification framework, it is a prompt to consider whether changing health and function warrant a more comprehensive assessment.

## Look for general indicators of decline

The GSF-PIG combines clinical judgement with general and disease-specific indicators. Patterns that should prompt closer assessment may include:
declining functional or performance status;
increasing frailty or dependence in activities of daily living;
unplanned or repeated hospital admissions;
progressive weight loss or nutritional decline;
persistent symptoms despite optimal treatment;
decreasing response to treatment;
increasing caregiver needs or caregiver distress; and
a patient preference to focus more on quality of life or reduce treatment burden.

**No single indicator establishes prognosis. It is the pattern of changing needs and progressive decline that should trigger closer assessment.**

## Identification is not the same as referral

Identifying someone who may benefit from a palliative approach does not automatically mean referral to specialist palliative care. It means asking whether symptoms are controlled, whether the patient understands the illness, what matters most now, whether decisions should occur before the next crisis, what support the family or care partner needs, and what can be anticipated and planned.
**Many of these needs can be addressed by the patient's existing care team, with specialist palliative care added when needs require additional expertise.**

## Try this in practice

Think of a patient with repeated unplanned hospital visits, noticeable functional decline, increasing symptom burden or growing dependence on family or caregivers.
**Ask: "Would I be surprised if this person died within the next year?"**
**Then ask: "Regardless of prognosis, does this person have unmet palliative needs that we should be addressing now?"**

## Words that work

Instead of labelling someone as "palliative," begin with what you are observing:
*"You've been through several changes in your health recently. I'd like to talk about how things are going overall, what is most important to you, and what we can do now to help you stay as well and comfortable as possible."*

## This Piece

**Don't wait for certainty about prognosis. Look for the pattern. Earlier identification creates an opportunity to assess symptoms, understand what matters to the patient, anticipate future needs and plan care before the next crisis.**

## Earlier identification tools - live links

Ontario Health - Earlier Identification Tools
Ontario Health - Toolkit: Step 1 Identification
Ontario Health - Palliative Care Toolkit (Identify - Assess - Plan and Manage)
Ontario Health - Tools to Support Earlier Identification for Palliative Care (PDF)
Gold Standards Framework - Proactive Identification Guidance (GSF-PIG)

## References

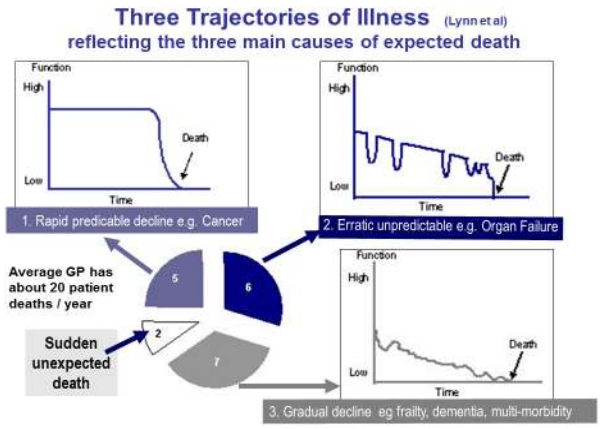
1. Ontario Health. Earlier Identification Tools. Updated June 4, 2026.
2. Ontario Health. Palliative Care Toolkit: Step 1 - Identification. Updated June 4, 2026.
3. Ontario Health. Palliative Care Toolkit. Updated June 4, 2026.
4. Gold Standards Framework Centre. Proactive Identification Guidance (PIG), 7th edition. 2022.
5. Ontario Health. Palliative Care: Care for Adults With a Serious Illness - Quality Standard. Published 2024; webpage updated June 26, 2026.

# The Gold Standards Framework
## Proactive Identification Guidance (PIG)

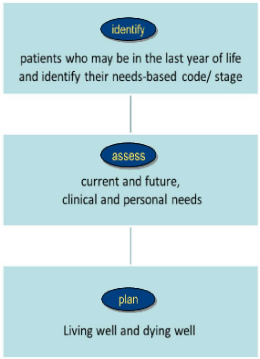
**The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life, leading to improved proactive person-centred care.**

**GSF PIG 7th Edition June 2022 Keri Thomas, Max Watson (HUK), Julie Armstrong Wilson and the GSF team**
**For details see** http://www.goldstandardsframework.org.uk, https://www.goldstandardsframework.org.uk/PIG, https://www.gsfinternational.org.uk/pig-tool

**Proactive Identification Guidance – identifying patients' decline earlier, enabling more proactive care.**
This updated 7th edition of the GSF Proactive Identification Guidance or PIG (previously known as the GSF Prognostic Indicator Guidance), aims to enable the earlier identification of people who may need additional supportive care as they near the end of their life (see GMC and NICE definition of end of life care), to include final year of life as well as final days. This includes people with any condition, in any setting, given by any care provider (not just those needing specialist palliative care), following any trajectory of decline for expected deaths (see below). Additional contributing factors when considering prediction of likely needs include underlying co-morbidities, current mental health and social care provision etc.




**Why is it important to identify patients early?**
Earlier identification of people who may be in their final stage of life leads to more proactive person-centred care as recommended in the NHSE Long term Plan (2019) and NICE guidance (2021). Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer crisis hospital admissions and care tailored to peoples' wishes, with better outcomes enabling more people to live and die where they choose. Once identified, people are included on a register and where available the locality/electronic register, triggering specific active supportive care, as used in all GSF programmes and in GSF cross boundary care sites.




**The 3 key steps of GSF** – Early proactive identification of patients is the crucial first step of GSF, used by many thousands of doctors and nurses in the community and hospitals.

For more information on GSF, how it is used in practice to help **identify** patients early, **assess** needs and wishes through advance care planning discussions and **plan** care tailored to patient choices

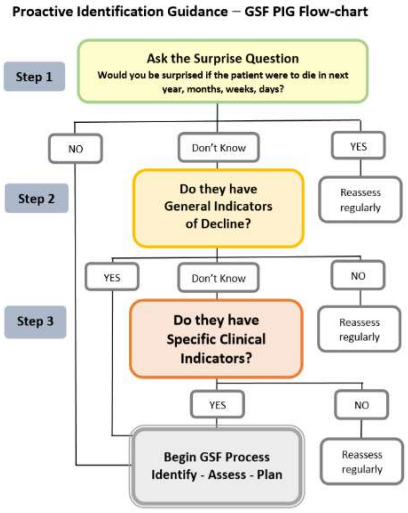
**Definition of End of Life Care General Medical Council**
**GMC -** https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life
**NHS -** https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/
The GMC definition of End of Life Care, used by the NHS, NICE and others is **'**People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic events.'

**NICE Guidance in End of life care 2021 Identification**
https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-Identification
'Statement 1 Adults who are likely to be approaching the end of their life are identified using locally developed systems.'
**NICE Service Delivery 2019** https://www.nice.org.uk/guidance/ng142
Services should develop systems to identify adults who are likely to be approaching the end of their life e.g., using tools such as GSF proactive identification guidance (PIG).

**SARS COVID 19** infections can cause rapid decline, emphasising the importance of early advance care planning and screening. Contributing factors include age, multi-morbidity, BAME and social status, etc. Pulse oximetry SpO2 of 92% or under triggers immediate treatment - more information see NHS guidance or https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(20)30193-0/fulltext.

**GSF Proactive Identification Guidance Flow-chart**




**For information on the development of the GSF PIG, its use in practice, evidence base, applications and when referencing it, please refer to** https://www.goldstandardsframework.org.uk/PIG; https://www.gsfinternational.org.uk/pig-tool **or contact** info@gsfcentre.co.uk

## STEP 1: The Surprise Question

**For patients with advanced disease or progressive life limiting conditions, would you be surprised if the patient were to die in the next year, months, weeks, days?**

The answer to this question should be an intuitive one, pulling together a range of clinical, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

This includes proactive planning of care and treatments and offering advance care planning and DNACPR discussions as early as possible.

## STEP 2: General indicators of decline and increasing needs

- General physical decline, increasing dependence and need for support
- Repeated unplanned hospital admissions or acute crises at home
- Advanced disease - unstable, deteriorating, complex symptom burden
- Presence of significant multi-morbidities
- Decreasing activity – functional performance status declining (e.g., Barthel or Karnofsky Performance score, Rockwood) limited self-care, in bed or chair 50% of day and increasing dependence in activities of daily living
- Decreasing response to treatments, decreasing reversibility
- Patient choice for no further active treatment, focus on quality of life
- Progressive weight loss (>10%) in past six months
- Sentinel Event e.g., serious fall, carer distress, bereavement, transfer to nursing home, etc
- Serum albumin <25g/l
- Considered eligible for DS1500 payment

## STEP 3: Specific Indicators related to single/multiple organ failure

### 1. CANCER

- Deteriorating performance status and functional ability due to metastatic cancer, multi-morbidities or not amenable to treatment – if spending more than 50% of time in bed/lying down, prognosis estimated in months
- Persistent symptoms despite optimal palliative oncology. More specific prognostic predictors for cancer are available, e.g., PPS, IPOS, ECOG.

### 2. ORGAN FAILURE

**HEART DISEASE**

- Advanced heart failure - CHF NYHA Stage 3 or 4 with symptoms despite optimal HF therapy – shortness of breath at rest/on minimal exertion
- Repeated admissions with heart failure – 3 admissions in 6 months or a single admission aged over 75 (50% 1yr mortality)
- Heart failure patients with reduced ejection fraction (HFrEF) have a poorer prognosis than those with preserved ejection fraction (HFpEF)
- Severe untreatable coronary artery or peripheral vascular disease
- Difficult ongoing symptoms despite optimal tolerated therapy
- Unpredictability but other indicators include age, low EF, ischaemic heart disease/arrythmias multi-morbidities including diabetes, obesity depression, hyponatraemia, high BP, declining renal function, anaemia
- See NICE Guidance https://cks.nice.org.uk/topics/heart-failure-chronic

**CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)**

- Severe disease (e.g., FEV1 <30% predicted), persistent symptoms e.g., breathlessness despite optimal therapy, causing distress
- Recurrent hospital admissions (at least 3 in last year due to COPD)
- Hypoxia/fulfilling long term oxygen therapy criteria (PaO2<7.3kPa)
- Too unwell for surgery or pulmonary rehabilitation
- MRC grade 4/5 – shortness of breath after 100 metres on level surface
- Required ITU/NIV during admission or ventilation contraindicated
- Other factors e.g., right heart failure, anorexia, cachexia, >6 weeks steroids in preceding 6 months, despite specialist review/treatment optimisation, requires palliative medication for breathlessness.

**KIDNEY DISEASE**

- Stage 4/5 Chronic Kidney Disease (CKD) deteriorating eGFR<30ml/min
- Repeated unplanned admissions (more than 3/year)
- Patients with poor tolerance of dialysis with change of modality
- Patients choosing the 'no dialysis' option (conservative management), dialysis withdrawal or not opting for dialysis if transplant has failed
- Difficult physical or psychological symptoms that have not responded to specific treatments
- Symptomatic Renal Failure in patients who have chosen not to dialyse or complicating other life limiting conditions – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload

**LIVER DISEASE**

- Advanced cirrhosis - see the Child-Turcotte-Pugh (CTP) score for chronic liver disease and cirrhosis mortality - See CTP calculator https://www.hepatitisc.uw.edu/page/clinical-calculators/ctp
- Hepatocellular carcinoma
- Liver transplant is considered potentially difficult or not amenable to treatment of underlying condition
- Other adverse factors including malnutrition, bacterial infection, raised INR, hyponatraemia

**GENERAL NEUROLOGICAL DISEASES**

- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- No longer able to communicate basic needs
- Symptoms which are complex and too difficult to control
- Increased hospital admissions not returning to previous baseline Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communication and progressive dysphasia
- Mobility problems and falls increasing
- Reduced independence, needs ADL help, similar to frailty below
- Deteriorating cognition/psychiatric signs (depression, anxiety, hallucinations, psychosis)

**PARKINSONS DISEASE** including the above, and more specifically -

- Drug treatment less effective or increasingly complex drug regime, less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls

**MOTOR NEURONE DISEASE** including the above, and specifically -

- Episodes of aspiration pneumonia
- Low vital capacity (below 70% predicted), or initiation of NIV

**STROKE**

- Predicting the prognosis after acute stroke can be challenging, yet 1:20 die within 72 hours. Care should include symptomatic comfort and not to impose burdensome restrictions
- Persistent paralysis after stroke with significent loss of function, medical complications, lack of improvement or ongoing disability
- Persistent vegetative, minimal conscious state or dense paralysis Cognitive impairment/Post-stroke dementia

### 3. FRAILTY, DEMENTIA and MULTI-MORBIDITIES

- For older people with complexity and multiple comorbidities, with frequent fluctuations in health needs and deterioration
- Electronic Frailty Index (0.24 or more) or Rockwood Score/ CFS 7 or above
- Comprehensive Geriatric Assessment (CGA) includes cumulative multiple morbidities, weakness, weight loss, fatigue, advancing frailty e.g., male over 85, health problems, reduced activity and need to stay at home, needs regular help, uses stick/walker regularly

**DEMENTIA**

Identification of moderate/severe stage dementia using a validated tool or Comprehensive Geriatric Assessment (CGA) of frailty, Clinical Frailty Scale (CFS), Functional Assessment Staging, Electronic Frailty Index (EFI) or Rockwood scale, identifying decline in dementia or frailty. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to recognise family members or consistently unable to have meaningful conversations
- Completely dependent on others for care or unable to do ADL
- Recurrent episodes of delirium
- Aspiration pneumonia
- Urinary and faecal incontinence, and Barthel score <3

Plus: Weight loss, urinary tract Infection, skin failure or stage 3 or 4 pressures ulcers, recurrent fever, reduced oral intake

**MULTI-MORBIDITIES**

- Increasingly relevant in ageing population needing complex care
- 2 or more long term conditions including physical, mental, learning disability, frailty, sensory impairment, alcohol misuse
- Consider multi-morbidity approach if have frailty, physical + mental conditions, not managing ADL or treatments, using multiple services, frequent falls or crisis admissions
- See NICE Guidance - https://www.nice.org.uk/guidance/ng56
  BGS - https://www.bgs.org.uk/topics/multimorbidity

# Words That Work

## Starting the Conversation About Serious Illness

We know these conversations matter. We also know they can be difficult to start.
Clinicians may worry about taking away hope, frightening a patient, saying the wrong thing - or simply not knowing how to begin.
An effective serious illness conversation does not require perfect words. It requires curiosity, honesty, empathy and a willingness to listen. Having a few words that work can make getting started much easier.

### Don't start with a label

For some patients, the word palliative is immediately associated with dying, stopping treatment or hospice. Begin instead with the patient's experience.

**"You've been through quite a lot with your health recently. I'd like to talk about how things are going overall and what is most important to you as we plan your care."**

### Ask permission and invite those who matter to the person

A simple invitation gives the patient some control over a conversation that may feel threatening.

### Start with what they know

Before providing more information, find out what the patient already understands.

**"Tell me what you understand about where things are with your illness right now."**

**"What have the doctors told you about what to expect?"**

**"How have things been changing from your point of view?"**

Listening first helps identify misunderstandings, information gaps and what the patient may already suspect.

### Find out how much they want to know

**"Some people want to know as much as possible about what might happen in the future. Other people prefer to focus on what is happening now. What feels right for you?"**

This allows information to be tailored to the individual rather than assuming everyone wants the same level of prognostic detail.

### When the future is uncertain

Clinical uncertainty does not mean we cannot talk about the future.

**"I can't predict exactly what will happen, but I can tell you what I'm concerned about and what we should prepare for."**

**"I'm hoping that things remain stable, and I'm also worried that your illness may continue to progress."**

**Hope and preparation can exist in the same conversation.**

### Ask what matters

Once there is a shared understanding of the illness, move from "What's the matter?" to "What matters?"

**"What is most important to you if your health gets worse?"**

**"What are you hoping for?"**

**"What are you most worried about?"**

**"What abilities or activities are so important to you that you can't imagine living without them?"**
**"What gives you strength when things are difficult?"**
These answers can guide future treatment decisions more effectively than asking about individual interventions in isolation. using the backspace adn then enter produced the same gap

## Respond to emotion before giving more information

A patient may respond with fear, sadness, anger or silence. Rather than immediately adding facts or reassurance, acknowledge what you are hearing.

**"I can see this is difficult to hear."**
**"It sounds like you're worried about what this means for your family."**
**"I wish things were different."**

Then pause. Silence may mean the patient is processing something important.

## You don't have to do everything in one conversation

Serious illness conversations are a process, not an event. The first conversation may establish understanding and identify what matters most. Future conversations can explore prognosis, treatment options, goals of care and planning in greater depth.
Ontario Health recommends that discussions about a person's wishes, values, beliefs and goals for current and future care be ongoing and revisited regularly.

## Try this in practice

Choose one opening phrase that feels natural and use it this week.
**"You've been through quite a lot recently. I'd like to step back and talk about how things are going overall. Would that be okay?"**
Then ask:
**"What is your understanding of where things are with your illness?"**
And listen. You don't need to have the whole conversation at once.

## This Piece

**Don't wait for the perfect words.**
Start with permission.
Ask what the patient understands.
Include those that matter to the person.
Listen before you explain.
Explore what matters.
Respond to emotion.
Keep the conversation going.

## Recommended Training:

**Canadian Serious Illness Conversations -free 2 hr self-study followed by 2 hr facilitated session**

Palliative Pieces

# Do Not Resuscitate Orders (DNR) and Goals of Care

What a resuscitation decision does — and does not mean

## A common clinical short circuit

A patient has a DNR/no-CPR order and develops pneumonia. Do we treat it? The DNR order alone does not answer that question. A decision about cardiopulmonary resuscitation addresses what will happen if cardiac or respiratory arrest occurs; it should not be used as a shorthand for the rest of the patient's treatment plan.

## Separate three different conversations

**GOALS OF CARE**: What outcomes matter to the patient, given the illness and realistic treatment options? The Goals of Care are not static and must be re-discussed and updated when the patient transitions between care settings and when their condition is changing.

**CONSENT TO TREATMENT**: Does the capable patient, or substitute decision-maker when required, consent to a specific treatment or plan of treatment?

**RESUSCITATION PLANNING**: Are resuscitative measures such as chest compressions, ventilation, intubation or defibrillation clinically appropriate if arrest occurs?

Goals-of-care discussions help inform later decisions but do not themselves constitute consent to treatment. CPSO similarly distinguishes goals-of-care discussions from decisions about specific treatments and resuscitative measures.

## DNR does not automatically rule out treatment

Depending on the clinical situation, goals and consent, a person with a no-CPR order may still receive investigations, antibiotics, IV or subcutaneous fluids, oxygen when indicated, transfusion, hospitalization, symptom treatment or other appropriate interventions. Each proposed treatment needs to be considered on its own merits.

**Do not infer the entire plan of care from the code-status box.**

## Words that work

**"If your heart or breathing were to stop, we would not attempt CPR. That does not mean we stop caring for you. We will continue to assess and treat problems in ways that fit your goals and the treatments that can realistically help."**

**"Let's talk separately about which treatments would make sense if your condition worsens."**

CPSO's current Decision-Making for End-of-Life Care policy notes that Ontario case law distinguishes withholding CPR from withdrawing life-sustaining treatment. Consent is required before withdrawing life-sustaining treatment. The writing of a DNR order and withholding CPR do not fall within the definition of treatment under the Health Care Consent Act; physicians provide resuscitative measures in accordance with the standard of care.

This is an area where precise language and documentation matter. Follow applicable organizational policy and professional standards.

## This Piece

**DNR means no CPR in the event of cardiac arrest. It does not mean "do not assess," "do not treat," or "do not care." People who resist a DNR order are often afraid that it will reduce the level of clinical judgement and intervention applied to evolving symptoms and circumstances.**

## Useful links

CPSO — Decision-Making for End-of-Life Care
Ontario Health — Palliative Care Quality Standard

## References

1. College of Physicians and Surgeons of Ontario. Decision-Making for End-of-Life Care. Current policy, accessed August 2026.
2. Ontario Health. Palliative Care: Care for Adults With a Serious Illness — Quality Standard. 2024; last updated June 26, 2026.
3. Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A.

# Prognosis in Palliative Care

## Why Prognosis Matters

Patients and families often want to know what to expect. “How much time do I have?” is one of the most difficult questions clinicians face. Yet avoiding the question can leave patients and families without the information they need to make decisions, prepare for what is coming, and focus on what matters most.

**Prognostication is not about predicting an exact date.** It is about using the best available clinical information to help patients and families anticipate the future and plan for it.

## Start With the Trajectory

Before estimating survival, consider the patient's overall illness trajectory. Ask:

Is function declining?

Is the patient spending more time in bed or a chair?

Is oral intake decreasing?

Is the patient increasingly dependent for personal care?

Have there been repeated hospitalizations or ED visits?

Is recovery after each illness or hospitalization becoming less complete?

Are symptoms becoming more difficult to control?

Is there evidence of progressive frailty?

**Often, the pattern of change over time is more informative than any single laboratory value or diagnosis.**

## Use Function as a Vital Sign

The Palliative Performance Scale (PPS) provides a structured way to describe functional status. It considers five domains:

Ambulation

Activity and evidence of disease

Self-care

Intake

Level of consciousness

A falling PPS can be an important signal of disease progression and can support—but should not replace—clinical judgment. Trend the PPS over time whenever possible.

## PPS in Practice: Watch the Direction of Travel

Consider a patient with advanced illness whose PPS changes over several weeks:

**PPS 60% —** The patient is still walking but has reduced activity, needs occasional assistance and has reduced intake.

**PPS 40% —** The patient is now mainly in bed, unable to carry out most activities, requires considerable assistance with personal care and has further reduction in intake.

**PPS 30% —** The patient is essentially bedbound, requires total care and has significantly reduced intake.

**The important prognostic information is not simply that the patient's PPS is 30%.** It is that the patient has declined from **60% → 40% → 30%** over a relatively short period of time.

That trajectory should prompt the clinical team to ask:

Is this decline reversible, or does it represent progression of the underlying illness?

Has the patient and family been told that time may be getting shorter?

Are goals of care clear?

Are medications and investigations still appropriate?

Are symptoms anticipated and medications available?
Are adequate home and caregiver supports in place?
Should hospice or additional specialist palliative-care support be considered?

**Remember: PPS is not a countdown clock.** Two patients with the same PPS may have very different prognoses depending on diagnosis, complications, illness trajectory and rate of decline. Use the PPS to identify the direction and pace of change, then combine it with clinical judgment and other prognostic information.

## Think in Ranges, Not Dates

Prognostic estimates are inherently uncertain. Rather than "You have three months," consider communicating in broader ranges:
Days to weeks
Weeks to months
Months to a year or more
When uncertainty is significant, name it**: "I can't tell you exactly how much time you have. Based on the changes we're seeing, I am worried that time may be getting shorter."**

## Ask Before You Tell

Not every patient wants the same amount of prognostic information.
Try: "**Would it be helpful if I shared what I think may be ahead?" or "Some people want quite specific information about time, while others prefer a more general picture. What would be most helpful for you?"**

## Use "Hope for the Best, Prepare for the Rest"

Hope and preparation can coexist. For example: **"I hope that you have many months ahead. I'm also worried that things are changing more quickly, and I think we should prepare in case time is shorter."**

## Watch for Signs That Prognosis Is Shortening

No single finding determines prognosis, but concern should increase when several changes occur together:
Rapidly declining PPS
Increasing time in bed
Reduced oral intake
Progressive weakness
Increasing dependence for care
Recurrent infections or hospitalizations
Worsening cognition or delirium
Increasing symptom burden
Disease progression despite treatment

## Prognosis Should Change the Plan

A prognostic estimate is useful only if it helps guide care. When prognosis appears to be shortening, consider:
Are the patient's goals of care clear?
Does the patient understand what may be ahead?
Has substitute decision-making been discussed?
Are medications still providing meaningful benefit?
Are investigations and treatments consistent with the patient's goals?
Are symptoms anticipated and medications available?
Are home-care and palliative-care supports adequate?
Does the caregiver understand what to expect?

Is hospice appropriate?
Is there a plan for what to do during a crisis?
**Recognizing a changing prognosis should trigger planning—not simply documentation.**

## This Piece

**Prognosis is not a date on the calendar.**
It is an evolving clinical assessment based on disease trajectory, function, symptoms and the rate of change.

Use tools such as the Palliative Performance Scale to strengthen clinical judgment, communicate uncertainty openly, and translate prognosis into a plan.
**The goal is not to predict the future perfectly. It is to help patients and families prepare for it.**

## Useful Tools

**Palliative Performance Scale (PPS) —** A functional assessment tool widely used in palliative care to describe performance status and support prognostication.
**Palliative Prognostic Index (PPI) —** Combines PPS with clinical features including oral intake, edema, dyspnea at rest and delirium to help estimate prognosis in patients with advanced illness.
Prognostic tools should support rather than replace clinical judgment and should be interpreted in the context of the individual patient.

## References and Resources

Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative Performance Scale (PPS): a new tool. Journal of Palliative Care. 1996;12(1):5–11.
Pallium Canada. LEAP: Learning Essential Approaches to Palliative Care.
Morita T, Tsunoda J, Inoue S, Chihara S. The Palliative Prognostic Index: a scoring system for survival prediction of terminally ill cancer patients. Supportive Care in Cancer. 1999;7:128–133.
Lau F, Downing M, Lesperance M, Shaw J, Kuziemsky C. Use of Palliative Performance Scale in end-of-life prognostication. Journal of Palliative Medicine. 2006;9(5):1066–1075.

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**Palliative Performance Scale (PPSv2)**
*version 2*

| PPS Level | Ambulation | Activity & Evidence of Disease | Self-Care | Intake | Conscious Level |
|---|---|---|---|---|---|
| 100% | Full | Normal activity & work<br>No evidence of disease | Full | Normal | Full |
| 90% | Full | Normal activity & work<br>Some evidence of disease | Full | Normal | Full |
| 80% | Full | Normal activity *with* Effort<br>Some evidence of disease | Full | Normal or reduced | Full |
| 70% | Reduced | Unable Normal Job/Work<br>Significant disease | Full | Normal or reduced | Full |
| 60% | Reduced | Unable hobby/house work<br>Significant disease | Occasional assistance necessary | Normal or reduced | Full<br>or Confusion |
| 50% | Mainly Sit/Lie | Unable to do any work<br>Extensive disease | Considerable assistance required | Normal or reduced | Full<br>or Confusion |
| 40% | Mainly in Bed | Unable to do most activity<br>Extensive disease | Mainly assistance | Normal or reduced | Full or Drowsy<br>+/- Confusion |
| 30% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Normal or reduced | Full or Drowsy<br>+/- Confusion |
| 20% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Minimal to sips | Full or Drowsy<br>+/- Confusion |
| 10% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Mouth care only | Drowsy or Coma<br>+/- Confusion |
| 0% | Death | - | - | - | - |

| PPS & Symptoms | Partial Score |
|---|---|
| **PPS** | |
| 10-20 | 4 |
| 30-50 | 2.5 |
| > 60 | 0 |
| **Oral Intake** | |
| Mouthfuls or less | 2.5 |
| Reduced, more than mouthfuls | 1 |
| Normal | 0 |
| **Edema** | |
| Present | 1 |
| Absent | 0 |
| **Dyspnea at Rest** | |
| Present | 3.5 |
| Absent | 0 |
| **Delirium** | |
| Present | 4 |
| Absent | 0 |

# Palliative Prognostic Index*

PPI >6 = Survival < 3 weeks
PPI >4 = Survival < 6 weeks
PPI ≤4 = Survival > 6 weeks

*Validated in patients with advanced cancer- use caution in other diseases. Always apply clinical judgement.

Palliative Pieces

# Pain: More Than a Number

*Assess the mechanism, impact and response — not just the score*

## Start with the person's experience

A 0–10 score is useful, but it is not a complete pain assessment. In palliative care, ask what the pain feels like, where it is, when it occurs, what worsens or relieves it, how it affects function and sleep, and what level of relief would be meaningful to the patient. Learn methods of assessing pain in non-verbal patients.

## Think mechanism

Nociceptive pain may be somatic or visceral.

Neuropathic pain may be burning, shooting, electric or associated with altered sensation.

Many patients have mixed pain mechanisms.

Incident pain may be predictable with movement, care or procedures.

Identifying the likely mechanism helps guide treatment and avoids simply escalating one medication when a different approach may be needed.

## The concept of Total Pain

Pain is influenced by physical disease as well as psychological, social and spiritual distress. Ask about fear, sleep, mood, caregiver stress and practical concerns. This does not make the pain "psychological"; it recognizes that suffering is multidimensional. The total burden of pain requires a holistic approach. Consult skilled team members to provide psychosocial support and interventions.

## Use multimodal treatment

Depending on the cause and goals, management may include disease-directed treatment, non-opioid analgesics, opioids, adjuvant medications, positioning, mobility or rehabilitation strategies, heat/cold when appropriate, psychological approaches and interventional procedures. Reassess both benefit and adverse effects.

## Opioids: use deliberately

Opioids remain essential medications for moderate-to-severe pain in many people with advanced illness. Safe prescribing includes careful assessment, selection of drug and route, attention to renal/hepatic function and frailty, bowel management, education, reassessment and safe storage/disposal. Watch for signs of opioid toxicity. Chronic non-cancer pain opioid guidelines should not be applied uncritically to end-of-life pain. Treating pain in people with substance use disorder is complex and may require consultation with allied health and specialist services.

## Words that work

**"Tell me what the pain stops you from doing."**
**"What would better pain control allow you to do that matters to you?"**
**"Let's work out what kind of pain this is so we can choose the treatment most likely to help."**

## This Piece

**Good pain management starts with diagnosis and goals, not just a number. Assess the mechanism, the impact and the whole person — then treat and reassess. Engage team members and use guidelines to support decision making.**

## Useful links

BC Centre for Palliative Care — Symptom Management Guidelines
Ontario Health — Plan and Manage Toolkit
Canadian Virtual Hospice — Common Concerns About Opioids

## References

1. Pallium Palliative Handbook
2. Ontario Health. Palliative Care Toolkit: Step 3 — Plan and Manage. Updated June 4, 2026.
3. BC Centre for Palliative Care. Inter-professional Palliative Symptom Management Guidelines: Pain. Guideline collection updated 2025; accessed August 2026.
4. Canadian Virtual Hospice. Common Concerns About Opioids in Palliative Care. Content reviewed January 2023.
5. Canadian Virtual Hospice. Principles of Opioid Management. Clinical practice resource.
6. Ontario Health. Palliative Care Competency Framework. Updated June 4, 2026.

Palliative Pieces

# Breathlessness: When Oxygen Isn't the Answer

*A practical palliative approach to dyspnea*

## Dyspnea is more than an oxygen number

Breathlessness is the patient's subjective experience of difficult or uncomfortable breathing. Oxygen saturation can help identify hypoxemia, but the intensity of dyspnea and the saturation reading do not always move together. Treat the person, not just the number.

## First: assess and treat reversible contributors

Clarify onset, severity, triggers and impact.

Look for potentially reversible causes that fit the goals of care — for example infection, bronchospasm, pulmonary edema, pleural effusion, anemia, pulmonary embolism or anxiety.

Review current medications, functional status and the patient's goals.

In advanced illness, treating the underlying cause and relieving the sensation of breathlessness often happen at the same time.

## Simple measures can help

Position upright or forward if comfortable.

Reduce exertion and pace activities.

Use cool airflow or a fan directed toward the face when acceptable.

Create a calm environment and coach slow, comfortable breathing.

Address fear and anxiety without assuming anxiety is the sole cause.

## Where do opioids fit?

Systemic opioids are an established option for refractory dyspnea in advanced life-limiting illness. Choice of opioid, dose, route and titration should reflect prior opioid exposure, renal and hepatic function, frailty and the clinical setting. Clinicians unfamiliar with palliative opioid prescribing should use a current palliative guideline or seek specialist/pharmacy support.

**The goal is relief of breathlessness, with careful assessment and reassessment.**

## And oxygen?

Oxygen is appropriate when there is clinically important hypoxemia or another clear indication. For a patient who is not hypoxemic, oxygen may not improve the subjective sensation of dyspnea more than room air. A fan or airflow may be more practical and less burdensome. Individualize decisions to the patient's response and goals.

## Words that work

**"Your oxygen level is only one part of what you're feeling. Let's treat the breathlessness itself and also look for anything reversible that may be making it worse."**

## This Piece

**Breathlessness is a symptom, not a saturation number. Assess the cause, use simple non-drug measures, consider opioids for refractory dyspnea, and reserve oxygen for patients likely to benefit.**

## Useful links

Ontario Health — Palliative Care Toolkit: Plan and Manage
BC Centre for Palliative Care — Symptom Management Guidelines

Canadian Virtual Hospice — Shortness of Breath

## References

1. Ontario Health. Palliative Care Toolkit: Step 3 — Plan and Manage. Updated June 4, 2026.
2. BC Centre for Palliative Care. Inter-professional Palliative Symptom Management Guidelines: Dyspnea. Current guideline collection, accessed August 2026.
3. Canadian Virtual Hospice. Shortness of Breath. Current online clinical/patient resource, accessed August 2026.
4. Ontario Health. Palliative Care Competency Framework. Updated June 4, 2026.

Palliative Pieces

# Delirium: Don't Miss It

*A sudden change in attention or thinking is a clinical signal*

## Delirium is common — and often missed

Delirium is an acute disturbance of attention and awareness with a fluctuating course. It may be hyperactive, hypoactive or mixed. Hypoactive delirium — quiet withdrawal, drowsiness or reduced interaction — is particularly easy to mistake for depression, fatigue or simply "decline."

## Look for a change from baseline

New inattention or difficulty following conversation.

Fluctuating alertness or cognition.

Disorganized thinking or altered perception.

New agitation, restlessness or hallucinations.

New drowsiness, withdrawal or reduced responsiveness.

Use a validated delirium assessment approach appropriate to your setting, alongside clinical assessment.

## Search for reversible contributors — when appropriate

Potential contributors include medications, infection, dehydration, urinary retention, constipation, metabolic disturbance, organ failure, pain, hypoxia and environmental change. The extent of investigation should reflect prognosis, goals of care and whether identifying the cause is likely to change management.

## Start with safety and non-drug measures

Provide a calm, familiar environment.

Use glasses and hearing aids when helpful.

Orient gently; avoid arguing about misperceptions.

Reduce unnecessary stimulation at night and support normal sleep-wake cues.

Address pain, bladder/bowel problems and other sources of distress.

Explain delirium to family members, who may find the sudden change frightening.

## Medication is not the whole answer

Medication may be considered when delirium is causing significant distress or creating safety concerns, but treatment should be individualized. Evidence for antipsychotics in palliative delirium is nuanced, and routine use for all delirium is not appropriate. Seek current guidance when symptoms are severe, persistent or difficult to manage.

## Words that work with families

**"This sudden change in attention and thinking is called delirium. It is caused by changes in how the brain is functioning during illness. Sometimes we can find and treat a contributing cause; sometimes, especially very near the end of life, our focus is on keeping the person safe and comfortable."**

## This Piece

**When a seriously ill patient suddenly seems confused, restless, unusually sleepy or "not themselves," think delirium. Recognize it, look for treatable contributors when appropriate, relieve distress and prepare the family.**

## Useful links

Ontario Health — Clinical and Quality Standards (Delirium)
BC Centre for Palliative Care — Symptom Management Guidelines
Ontario Health — Plan and Manage Toolkit

## References

1. Ontario Health. Delirium: Care for Adults — Quality Standard. 2021; current Ontario Health quality standard.
2. BC Centre for Palliative Care. Inter-professional Palliative Symptom Management Guidelines: Delirium. Current guideline collection, accessed August 2026.
3. Ontario Health. Palliative Care Toolkit: Step 3 — Plan and Manage. Updated June 4, 2026.
4. Canadian Virtual Hospice. Delirium — professional practice resources, including BC Inter-professional Palliative Symptom Management Guidelines.

# Who Is Caring for the Caregiver?

Family and care partners are essential members of the palliative care team. Their ability to continue providing care can affect symptom management, safety, transitions in care and whether a person can remain at home.
Ontario Health's Palliative Care Quality Standard specifically recommends ongoing assessment of family and care-partner needs, with access to resources, respite care, and grief and bereavement support according to their preferences.

## Don't rely on “How are you coping?” alone

Care partners may minimize their own needs, see exhaustion as part of the role, or be reluctant to say that caregiving is becoming too much. A brief validated tool can make caregiver strain visible and provide a starting point for a more specific conversation.

**“We spend a lot of time asking how the patient is doing. I also want to understand how caring for them is affecting you.”**

## A practical validated tool: Modified Caregiver Strain Index

The Modified Caregiver Strain Index (MCSI), developed by Thornton and Travis, is a brief 13-item instrument designed to detect strain among informal caregivers. In its validation study of 158 family caregivers, it demonstrated strong internal reliability (Cronbach's alpha 0.90) and two-week test-retest reliability of 0.88.
The MCSI examines multiple dimensions of caregiving strain, including physical, psychological, social, personal and financial effects.
Each item is scored:
Yes, on a regular basis = 2
Yes, sometimes = 1
No = 0
**Total scores range from 0 to 26. Higher scores indicate greater caregiver strain. The original validation paper established reliability but did not establish a universal diagnostic cut-off. Use the score to support clinical assessment, identify specific areas of strain and monitor change over time rather than treating it as a diagnosis.**

## When should we assess caregiver strain?

Increasing patient dependency or functional decline.
Repeated crises, emergency visits or hospitalizations.
Progressive dementia or behavioural symptoms.
Escalating symptom-management needs.
Sleep disruption or around-the-clock supervision.
Caregiver health problems or visible exhaustion.
Concern about the caregiver's ability to safely provide required care.
A change in the patient's preferred setting of care.
Approaching the last days or weeks of life.
Any time the caregiver, patient or team expresses concern.

## The score is only the beginning

A total score tells you that strain is present; the individual responses help tell you what to do about it. Explore the areas causing the greatest burden.
Sleep: Is caregiving preventing adequate rest?

Physical demands: Is lifting, transferring or personal care becoming unsafe?
Time: Can the caregiver leave the home, attend appointments or meet their own needs?
Emotional burden: Are they frightened, overwhelmed, grieving or feeling trapped?
Work and finances: Is caregiving affecting employment or creating financial strain?

Skills and confidence: Do they know what to do when symptoms change?
Backup: Who can help if the primary caregiver becomes ill or needs a break?

## One question worth asking directly

**"Is there anything about providing this care that you are worried you may not be able to continue?"**
This question can uncover a looming breakdown in the care plan before it becomes a crisis.

## Act on what you find – Hospice Orillia has multiple supports for caregivers.

Screening without a response is of limited value. Match support to the source of strain.
Arrange or advocate for home-care services and respite when available.
Provide practical teaching about medications, symptom management, transfers and what to expect.
Create a clear plan for whom to call when symptoms change.
Engage social work for financial, practical or family concerns.
Consider occupational therapy, physiotherapy or equipment when physical caregiving is difficult.
Connect caregivers with hospice, peer, grief/bereavement and community supports.
Encourage the caregiver to attend to their own health needs and primary care.
Revisit the setting-of-care plan if the current plan depends on a level of caregiving that is no longer sustainable.

## Reassess

Caregiver strain is dynamic. A manageable situation today may become unsustainable after a fall, delirium, worsening dyspnea, loss of mobility or several nights without sleep. Ontario Health recommends ongoing assessment of care-partner needs.

**Consider repeating the same tool after a meaningful change in the patient's condition, caregiving demands or available supports.**

## This Piece

**Supporting the caregiver is part of caring for the patient. Ask, assess, act — and reassess. A sustainable plan of care must work for the person receiving care and for the people providing it.**

## Useful links

**Modified Caregiver Strain Index**

## References

1. Thornton M, Travis SS. Analysis of the reliability of the Modified Caregiver Strain Index. J Gerontol B Psychol Sci Soc Sci. 2003;58(2):S127-S132. doi:10.1093/geronb/58.2.S127.
2. Ontario Health. Palliative Care: Care for Adults With a Serious Illness — Quality Standard. Quality Statement 9: Care Partner Support. Published 2024; last updated June 26, 2026.
3. Ontario Health. Palliative Care Toolkit: Step 2 — Assessment. Updated June 4, 2026.
4. Ontario Health. Palliative Care Toolkit: Step 3 — Plan and Manage. Updated June 4, 2026.
5. Canadian Virtual Hospice. Tools for Practice: Assessment Tools. Current online professional resource; accessed August 2026.

# Indigenous Perspectives in Palliative Care

## Cultural Humility, Relationships and Asking What Matters

Providing culturally safer palliative care to First Nations, Inuit, and Métis peoples begins with an important recognition: there is no single Indigenous approach to serious illness, dying, death or grief. Nations, communities, families and individuals are distinct, and care should be guided by the person and community rather than assumptions.

## Start With Cultural Humility

Cultural humility is different from becoming an expert in someone else's culture. Instead of asking, "What do Indigenous people believe about dying?", ask, "What does this person and family want me to understand about what is important to them?"
Useful questions include:

- Is there anything about your culture, traditions or beliefs that you would like us to know?
- Who would you like involved when we talk about your care?
- Are there cultural or spiritual practices that are important to you?
- Would you like us to connect you with an Elder, Knowledge Keeper, Indigenous health provider or other community support?
- Is there anything we could do that would help you feel safer or more comfortable receiving care here?

## Understand Why Trust Matters

In Canada, healthcare encounters for Indigenous patients and families occur in the context of historical and continuing colonialism, systemic racism and inequitable access to care. Cultural safety therefore goes beyond accommodating ceremonies or traditions. It includes building trust, recognizing power differences, listening carefully, and addressing barriers within the health system.

## Don't Assume How Death Should Be Discussed

Western health care often values explicit conversations about prognosis, dying and advance care planning. That approach may not be appropriate for everyone. Ontario's Palliative Care Competency Framework notes that some communities may not use an equivalent term for "palliative care" and that openly discussing death and dying may not always be acceptable.
Consider asking: "Some people want very direct information about what may happen with their illness. Others prefer that we approach these conversations differently. How would you like us to talk about this?"

## Ask Who Is Family

Do not assume that "family" means only immediate biological relatives. Extended family, multiple generations and community members may have important roles.
Ask: "Who are the important people you want involved in your care and decisions?"

## Make Space for Traditional and Spiritual Care

For some patients, connection with an Elder, Knowledge Keeper, Healer, ceremony, medicines, sacred items, language, Land or community may be important. For others, these may not be important at all. The provider's role is not to decide which traditions a patient should want, but to ask, facilitate and remove unnecessary barriers.

## Remember the Whole Person

A holistic approach may include physical, emotional, mental and spiritual wellness as well as relationships with family, community, Land, language, ancestry and culture. Alongside symptom assessment, consider asking: “What would help this person feel whole, connected and supported?”

## This Piece

**Culturally safer Indigenous palliative care does not begin with knowing the right ceremony. It begins with the right relationship.**
Don't assume. Ask who matters. Ask how the person wants information shared. Ask what gives meaning, comfort and connection. Ask whether cultural, spiritual or community supports are wanted. Then work with the patient, family and Indigenous partners to make those things possible.
**The goal is not to become an expert in another person's culture. The goal is to create enough safety, trust and respect for the person to tell you what good care means to them.**

## Useful Links

Barrie Area Native Advisory Circle
Mamaway Wiidokdaadwin Primary Care Team
OSMH Indigenous Patient Navigator 705-325-2201 x 6291
Learning Hub – Indigenous Cultural Safety Training
Living My Culture "Quality palliative care helps you honour your culture, spirituality and traditions. At LivingMyCulture.ca, people from various cultures share their stories and wisdom about living with serious illness, end of life and grief to support others."

## References

1. Ontario Health. Ontario Palliative Care Competency Framework: A Reference Guide for Health Professionals and Volunteers. See Appendix B: First Nations, Inuit, Métis and Urban Indigenous Palliative Care Competencies. https://www.ontariohealth.ca/clinical/palliative/competency-framework
2. Centre for Education and Research on Aging & Health (CERAH), Lakehead University. Walking Alongside Indigenous Peoples who are Seriously Ill: Education for Community Caregivers. https://cerah.lakeheadu.ca/resources/indigenous-health/cerah-resources/walking-alongside-indigenous-peoples/
3. Centre for Education and Research on Aging & Health (CERAH), Lakehead University. Indigenous Peoples’ Health & Aging Resources, including Preparing for the Journey and culturally safer palliative-care resources. https://cerah.lakeheadu.ca/indigenous-peoples-health-aging-resources/
4. Improving End-of-Life Care in First Nations Communities Research Team, Lakehead University. Developing Palliative Care Programs in First Nations Communities: A Workbook. https://eolfn.lakeheadu.ca/develop-palliative-care-programs-workbook
5. Fruch V, Monture L, Prince H, Kelley ML. Coming Home to Die: Six Nations of the Grand River Territory Develops Community-Based Palliative Care. International Journal of Indigenous Health. 2016;11(1):50–74. doi:10.18357/ijih111201615303. https://eolfn.lakeheadu.ca/project-results/publications
6. Ontario Health. Model of Care: Adults Receiving Palliative Care in Community Settings. https://www.ontariohealth.ca/clinical/palliative/moc/adults-community

# Palliative Care for People with Intellectual & Developmental Disability (PWIDD)

***See the Person. Adapt the Care. Include the People Who Know Them Best.***

People with intellectual and developmental disabilities (IDD) may develop cancer, heart disease, dementia, frailty and other serious illnesses. Their palliative care needs can be recognized late, communicated differently, or mistakenly attributed to the person's disability. High-quality palliative care requires the same fundamentals as good palliative care for anyone else—but providers may need to change how they assess, communicate and deliver care. A Knowledge-to-Action Guide was published in August 2026 to support learning about the needs of people with IDD and co-morbidities that may be life limiting, who may benefit from a palliative approach to care.

**"The IDD Palliative Care Resource Guide and Toolkit, developed in Ontario, is intended to be an IDD specific supplement used with current gold standard palliative care models.**
**The Toolkit includes IDD specific tools to aid providers cross sector (developmental services, healthcare, and palliative care specialists) in earlier identification of needs, screening and assessment, care team integration, and proactive care planning and delivery." The Toolkit is available at this link.**
**https://iddpcn.org/**

## Don't Let the Disability Hide the Illness

A change in behaviour may be communication. Pain, constipation, nausea, breathlessness, delirium, fear or other distress may present as withdrawal, agitation, changes in sleep, refusing food, vocalization, aggression, reduced participation in usual activities, or simply "not being themselves."
Do not assume that a new behaviour is part of the person's developmental disability. Ask: "What has changed from this person's usual baseline?" The people who know the person well may be essential to answering that question.

## Communication Is a Clinical Skill

Do not assume that a person with IDD cannot understand or participate because conventional conversation is difficult. Adapt the communication.
Use plain, concrete language; one idea or question at a time; pictures, symbols or visual aids when helpful; familiar words used by the person and caregivers; additional time for processing and responding; observation of non-verbal communication; repetition; and checking understanding.

## Talk to the Person — Not Just About Them

Having an intellectual or developmental disability does not automatically mean that a person is incapable of making health-care decisions. Capacity should not be assumed solely from a diagnosis of IDD.
Whenever possible, involve the person directly. Adapt information so that the person has the best possible opportunity to understand, express preferences and participate in decisions. When a Substitute Decision-Maker is required, the person's voice, preferences, behaviours, relationships and known values still matter.

## Partner With the People Who Know the Person Best

Family members, developmental service workers, residential staff and other long-standing caregivers may know how the person normally communicates, what behaviours indicate pain or distress, what comforts or frightens them, their routines and preferences, and who and what matters most to them.
That knowledge is clinically valuable. Ask: “How do you know when this person is comfortable?” and “How do you know when something is wrong?”

## Preserve Familiarity Where Possible

For someone who has lived in the same home or developmental-services setting for many years, familiar people, routines and surroundings may provide security. A move to hospital or another unfamiliar environment can be particularly disruptive.
When clinically feasible, consider whether palliative supports can be brought to the person's usual home rather than automatically moving the person to another setting. Ontario's January 2026 Developmental Services Worker Program Standard explicitly includes adapting supports as people with developmental disabilities age, including palliative care and supporting the right to die at home.

## Build One Team Around the Person

Palliative-care providers bring expertise in serious illness and symptom management. Developmental-services providers may bring deep knowledge of the person's communication, behaviour, routines and support needs. Family and other care partners may understand the person's history, relationships and values.
We need all of these perspectives. Ontario Health's Palliative Care Quality Standard emphasizes coordinated, integrated, interprofessional care, attention to care-partner needs, seamless transitions, and ongoing discussion about preferred setting of care and place of death.

## Ask What a Good Day Looks Like

Quality of life should not be judged by someone else's assumptions about living with disability.
Ask the person and those who know them: “What does a good day look like for this person?” It may be attending a day program, listening to favourite music, going for a drive, having coffee at a familiar place, seeing a particular family member, following a favourite routine or simply being surrounded by familiar people.
Those things are not extras. They are part of the care plan.

## This Piece

**The principles of palliative care don't change because someone has an intellectual or developmental disability. Our approach may need to.**
See the person before the disability. Look for changes from their usual baseline. Adapt communication rather than assuming inability. Include the person in decisions to the greatest extent possible. Listen to the people who know them best. Bring palliative-care expertise together with developmental-services expertise.
**Instead of asking, “Can this person understand palliative care?”, ask: “What do we need to change about the way we communicate and provide care so that this person can be included?”**

## References

1. Ontario Ministry of Health. Progress on Ontario’s Provincial Framework for Palliative Care. June 4, 2025. The report describes Ontario’s work toward equitable access to palliative care and reports education in Ontario Health West on palliative care for people with intellectual/developmental disabilities. https://www.ontario.ca/page/progress-ontarios-provincial-framework-palliative-care
2. Ontario Ministry of Colleges, Universities, Research Excellence and Security. Developmental Services Worker Program Standard, Ministry Code 51641. January 2026. The standard includes adapting supports as people with developmental disabilities age, including palliative care, senior services and supporting the right to die at home. https://www.ontario.ca/page/college-program-standard-developmental-services-worker-ministry-code-51641
3. Ontario Health. Palliative Care: Care for Adults With a Serious Illness — Quality Standard. April 2024; Ontario Health page updated June 26, 2026. Includes holistic assessment, 24/7 access, symptom management, psychosocial care, care-partner support, coordinated transitions, preferred setting/place of death and interprofessional team-based care. https://www.ontariohealth.ca/clinical/quality-standards/qs-details?cf=palliative-care

4. Ontario Health. Palliative Care Competency Framework. Updated June 4, 2026. A reference guide describing the knowledge, attributes and skills required by health professionals and volunteers to deliver high-quality palliative care in Ontario. https://www.ontariohealth.ca/clinical/palliative/competency-framework
5. Correa-Morales JE, Umbacia MA, Mantilla-Manoslava N, et al. Enhancing Palliative Care for Individuals With Intellectual and Developmental Disabilities: A Scoping Review of Communication Strategies for Assessing Health Needs. Journal of Pain and Symptom Management. 2026;71(3):e261-e280. doi:10.1016/j.jpainsymman.2025.08.021. https://pubmed.ncbi.nlm.nih.gov/41690716/

Palliative Pieces

# Psychosocial and Spiritual Care – addressing suffering

Pain, dyspnea and nausea matter, but serious illness can also threaten a person's identity, relationships, independence, sense of meaning and hopes for the future. High-quality palliative care therefore attends to psychological, social, cultural, spiritual and practical concerns as well as physical symptoms.
**A useful clinical question is:** *"If the physical symptoms are reasonably controlled, what else is hurting?"*

## Think in Four Dimensions

| Dimension | What may be causing distress? |
|---|---|
| Physical | Pain, dyspnea, fatigue, nausea, weakness, loss of function |
| Psychological | Fear, anxiety, depression, uncertainty, loss of control |
| Social | Changing roles, isolation, finances, caregiver burden, family conflict |
| Spiritual / existential | Meaning, purpose, hope, identity, guilt, faith, legacy, fear of dying |

These dimensions overlap. A patient's repeated request for medication, for example, may reflect physical discomfort, fear, loneliness, loss of control—or several of these at once.

## A Simple Clinical Approach: Notice, Ask, Listen, Connect, Revisit

### 1. Notice

Be alert to withdrawal, persistent anxiety, anger, hopelessness, tearfulness, family tension, loss of meaning, repeated reassurance-seeking or distress that seems greater than the physical findings.

### 2. Ask

You do not need a lengthy assessment to open the door. A few well-chosen questions can reveal what matters most.

### 3. Listen

Resist the urge to immediately reassure, redirect or solve the problem. Naming and acknowledging fear, grief, loss or uncertainty can itself be therapeutic.

### 4. Connect

Ask who and what sustains the person. Consider family and friends, community, faith or cultural supports, social work, spiritual care, Indigenous providers, mental health professionals, grief counsellors, hospice programs and trained volunteers.

### 5. Revisit

Psychosocial and spiritual needs change as illness progresses. Reassessment is especially important after a major decline, hospitalization, change in prognosis, transition in care or new caregiver stress.

## Five Questions You Can Use Tomorrow

"What is weighing on you most right now?"
"What are you most worried about?"

"What gives you strength or helps you through difficult times?"
"Who are the people you most want involved in your care?"
"Is there anything important to you that we haven't talked about?"

## Spiritual Care Is Not the Same as Religious Care

Spirituality can include religion, but it is broader than religion. It may involve meaning, purpose, connection, hope, identity, values, relationships, nature, culture or legacy. For some people, faith and a religious community are central; for others, they are not.
**Avoid assumptions.** A neutral opening such as "What gives you strength?" allows the patient to define what spirituality means to them.

## FICA: A Brief Spiritual History

**F — Faith, belief or meaning:** What gives your life meaning? Do you have spiritual or religious beliefs that are important to you?
**I — Importance and influence:** How do these beliefs, values or sources of meaning affect the way you are coping or making health-care decisions?
**C — Community:** Are you part of a spiritual, religious, cultural or other community that supports you?
**A — Address in care:** How would you like us to take these beliefs, values or supports into account in your care?

FICA is a conversation guide, not a checklist that must be completed word-for-word. Its purpose is to help identify sources of strength, distress and support, and to determine whether additional spiritual-care expertise would be helpful.

## Remember the Family and Care Partner

Serious illness affects the whole family system. Care partners may be managing anticipatory grief, exhaustion, financial or practical pressures, uncertainty about what to expect, and fear about whether they can continue providing care.
**Try asking:** *"How are you managing with all of this?"*
When needs exceed the clinician's scope or available time, identify and connect the patient or family with the appropriate interdisciplinary supports.

## When to Reach for More Help

Consider additional psychosocial, mental-health, spiritual-care or palliative-care support when there is:
Persistent or severe emotional or existential distress
Complex family conflict or communication difficulties
Significant caregiver strain
Complicated grief or major losses affecting coping
Spiritual or religious concerns that are important to treatment decisions
Cultural or spiritual needs that the current team cannot adequately address
Distress that interferes with decision-making, symptom management or the patient's quality of life

## This Piece

**Palliative care attends to suffering, not just symptoms.**
**Sometimes the most therapeutic intervention is giving someone permission to tell you what is really worrying them.**

## References and Resources

**Hospice Orillia has many resources to support patients, families and caregivers including children.**
**Know the social workers and spiritual care advisors that are active in your area to support your clinical team.**
**Know how to request an Ethics consult in your setting.**

# Provider Checklist for a Palliative Care Plan at Home

Supporting a patient with serious illness at home requires more than arranging home care. Successful home palliative care depends on anticipation, communication, coordination and a realistic assessment of the patient's and caregiver's needs. **Before considering the home-care plan complete, ask:**

## Goals and Plan of Care - Care Team Conversations

☐ Have the patient's goals, values and priorities been explored and documented?
☐ Is the desired place of care and death understood?
☐ Has advance care planning been discussed appropriately?
☐ Is the Substitute Decision-Maker identified and documented?
☐ Do the patient, family and providers share a common understanding of the plan?
☐ Are there clear plans for what should happen if the patient's condition deteriorates?

## Clinical Responsibility and Communication – CFHT Palliative Nurse Navigator Referral

☐ Is there a clearly identified physician or nurse practitioner responsible for medical management?
☐ Does the patient/family know whom to call during regular hours?
☐ Is there a clear plan for evenings, nights, weekends and holidays?
☐ Do home-care providers know how to reach the responsible prescriber?
☐ Are relevant clinical information, goals of care and medication plans available to the providers who may become involved?
☐ EDITH and Nurse Pronounce Orders (Expected Death in the Home Protocol)

## Anticipate Symptoms — Don't Wait for the Crisis – OH at Home Palliative Nursing Referral

☐ Have likely symptoms and complications been anticipated?
☐ Are appropriate PRN medications prescribed and available in the home?
☐ Is a Symptom Relief Kit indicated and, if so, has one been arranged?
☐ Do the patient and caregivers understand when and how medications should be used?
☐ Is there a plan for symptoms that cannot be controlled with the initial interventions?
☐ Are routes of medication administration appropriate if swallowing becomes difficult?

## Home and Equipment – OH at Home referral

☐ Is the home environment safe and suitable for the patient's changing needs?
☐ Have mobility, transfers, toileting and personal-care needs been assessed?
☐ Is necessary equipment available—or ordered before it is urgently required?
☐ Are medications and supplies accessible and organized?
☐ Are additional nursing, PSW, therapy or other supports required?

## Caregiver Capacity – Hospice Orillia Referral for Caregiver Support

**The feasibility of home palliative care depends heavily on the people providing day-to-day care.**
☐ Who is the primary caregiver?
☐ Does the caregiver understand what will be expected?
☐ Is the caregiver physically and emotionally able to provide the required care?
☐ Are there other family members or friends who can help?
☐ Has caregiver distress or burden been assessed?

☐ Is respite needed?
☐ What is the backup plan if the caregiver can no longer manage?

**A plan that depends on an exhausted or overwhelmed caregiver is not a sustainable home-care plan.**

## Prepare for Deterioration – Team & Family, Caregiver Conference

Don't wait for a crisis to answer these questions.
☐ What changes are reasonably foreseeable?
☐ Which changes can be managed at home?
☐ Who should the family call first?
☐ Is clinical advice available 24/7?
☐ What circumstances should prompt transfer to the Emergency Department?
☐ When should 911 be called?
☐ Does the family understand the difference between an expected change in the illness and an emergency requiring immediate intervention?

## If Dying at Home Is the Goal – OH at Home

☐ Has the possibility of dying at home been discussed explicitly?
☐ Does the family understand what the last days and hours may look like?
☐ Are anticipatory medications and necessary equipment in place?
☐ Is there a plan for nursing and medical support as the patient deteriorates?
☐ Does the family know whom to call when death appears imminent?
☐ Do they know whom to call when death occurs?
☐ Have expected-death procedures and documentation been addressed where appropriate?
☐ Is there an alternative plan if remaining at home is no longer feasible or desired?

## Remember the Person

Good home palliative care is not simply successful symptom management.
**Ask: "What matters most to this person now?" What cultural, spiritual and faith based supports may matter?**
The care plan should preserve opportunities for relationships, meaningful activities, comfort, dignity and ordinary life—not allow health care to consume the time the patient has remaining.

## Red Flags: The Home Plan May Be Fragile

☐ Caregiver exhaustion, distress or inability to continue.
☐ Repeated Emergency Department visits or unplanned hospital use.
☐ Symptoms remain uncontrolled or are escalating.
☐ Necessary medications or equipment are not yet in the home.
☐ No clear after-hours or 24/7 plan.
☐ Patient or family is uncertain about whom to call.
☐ Providers do not share a common understanding of goals or the care plan.

## Residential Hospice Referral and Back Up Plan – OH at Home Hospice Referral Process

Team members may open the subject of residential hospice admission as a back up plan when the home care plan is fragile or caregivers need relief. When a referral is in place, paramedics can transport for direct admission to Mariposa House Hospice if the care plan has to be adjusted.

## This Piece

**A successful home palliative care plan anticipates rather than reacts.**
Before deciding that the existing home plan is adequate—make sure there is a clear plan, a responsible provider, medications and equipment, caregiver capacity, 24/7 contingency planning, and a shared understanding of what to do when the patient's condition changes.
**The question is not simply "Can this patient be cared for at home?"**
**It is "Have we put everything in place to make care at home safe, sustainable and consistent with what matters to this patient?"**

# How to Lead an Effective Patient, Family, Caregiver and Team Conference

A well-led care conference can turn fragmented information, uncertainty and competing concerns into a shared understanding and a clear plan. A poorly structured meeting can leave everyone more confused.
Patients and their family/care partners are active members of the interprofessional palliative care team. The quality standard calls for goals-of-care discussions with the interprofessional team and collaborative development of an individualized care plan.

## Before the meeting: prepare the team

A few minutes of preparation can prevent mixed messages.
Clarify why the meeting is being held and what a useful outcome would be.
Confirm who the patient wants involved, including the substitute decision-maker when relevant, cultural and spiritual supports if requested.
Identify the clinical lead/facilitator and who will explain key medical information.
Make sure the team has a shared understanding of the diagnosis, trajectory, realistic treatment options and unresolved decisions.
Identify known family concerns, conflict, cultural or spiritual considerations, communication needs and whether an interpreter or other support is required.
Decide who will document the discussion, decisions and follow-up.
Ensure that neutral third-party translators are available if needed. Avoid using family member translators for high-stakes conversations.
Include those who are responsible for discharge planning and community referrals if the patient is leaving the hospital.

**Team huddle: "What do we need this meeting to accomplish, and are we giving the patient and family a consistent message?"**

## 1. Open with purpose and introductions

Start by reducing uncertainty about the meeting itself.

**"Thank you for meeting with us. Let's introduce ourselves and our roles. The purpose today is to make sure we all have the same understanding of what is happening, hear what matters most to you, and agree on the next steps."**
**"Before we start, is there anything you were particularly hoping we would talk about today?"**

## 2. Begin with the patient and family perspective

Do not begin with a long medical presentation. First find out what people already understand.

**"Can you tell us your understanding of what has been happening?"**
**"What changes have you noticed?"**
**"What are you most concerned about right now?"**

Listen for differences in understanding before trying to resolve them.

## 3. Create a shared clinical picture

The most responsible clinician or appropriate team member should give a concise, jargon-free summary. Separate what is known from what is uncertain and avoid having multiple clinicians deliver competing versions.

**"Would it be helpful if I summarized where things stand medically?"**
**"The most important thing I want everyone to understand is…"**

Pause and check understanding rather than continuing to add information.

## 4. Respond to emotion

Strong emotion is not an interruption to the meeting; it is part of the meeting. Acknowledge emotion before moving into problem-solving. If emotions are high and unregulated, you may have to reschedule the meeting.

**"I can see how difficult this has been."**
**"It sounds as though you're worried that we may be giving up."**
**"Tell me more about what worries you most."**

## 5. Bring the conversation back to the patient

When opinions differ, the organizing question is not simply what each family member wants. The patient's own wishes, values, beliefs and goals should remain central. If the patient lacks capacity for a treatment decision, Ontario's consent framework determines the role of the substitute decision-maker.

**"What would be most important to you if your health became worse?"**
**"If they could speak for themselves right now, what do you think they would tell us matters most?"**

Avoid asking family members to make isolated choices about procedures without first establishing the clinical context and the patient's values.

## 6. Make a recommendation

Patients and families should not be left to assemble a treatment plan from a menu of interventions. Once the team understands the illness and what matters to the patient, the clinician can make a recommendation that connects the two.

**"Based on what you've told us is most important, and what we know about the illness, I would recommend…"**

Then invite questions, disagreement and clarification.

## 7. Finish with a clear plan

A successful conference should end with fewer uncertainties than it began with.

Summarize what everyone agrees on.
Identify any unresolved questions or decisions.
Clarify the treatment and symptom-management plan.
Name who is responsible for each next step.
Clarify who the patient/family should contact and how.
Identify when the plan will be reviewed or when the next conversation should occur.
Document the discussion, including the patient's expressed values and preferences and any treatment decisions/consents.

**"Before we finish, let me summarize what I heard and what we have agreed to do next."**
**"What questions are still unanswered for you?"**

## When there is disagreement

Do not rush to force consensus. Clarify whether the disagreement is about facts, prognosis, values, treatment options, roles or trust. Return to the patient's voice, acknowledge emotion and identify what everyone can agree on. Complex conflict may require additional meetings and support from palliative care, ethics, social work, spiritual care, Indigenous health supports or other appropriate resources.

## A simple structure to remember

PREPARE — huddle first.
PURPOSE — say why you are meeting.
PERSPECTIVE — hear the patient and family first.
PICTURE — create a shared understanding of the illness.

PRIORITIES — identify what matters most.
PLAN — recommend, agree on next steps and document.

## This Piece

**The goal of a care conference is not simply to exchange information. It is to create shared understanding, keep the patient's voice at the centre, and leave everyone knowing what happens next.**

## Useful links

VitalTalk — Family Conference Quick Guide
VitalTalk — Communication Quick Guides

## References


1. Ontario Health. Model of Care: Adults Receiving Palliative Care in Hospital Settings. Updated June 4, 2026.
2. VitalTalk. Family Conference Quick Guide. Current online clinical communication resource; accessed August 2026.
3. Cahill PJ, Lobb EA, Sanderson C, Phillips JL. What is the evidence for conducting palliative care family meetings? A systematic review. Palliat Med. 2017;31(3):197-211. doi:10.1177/0269216316658833.
4. Singer AE, Ash T, Ochotorena C, et al. A Systematic Review of Family Meeting Tools in Palliative and Intensive Care Settings. Am J Hosp Palliat Care. 2016;33(8):797-806. doi:10.1177/1049909115594353.

Palliative Pieces

# Effective Management of the Last Days of Life

*When the goal shifts from preparing for decline to preparing for death*

## Recognizing and managing dying is a clinical skill

No single sign tells us exactly when a person will die. The diagnosis of dying is based on the overall trajectory and a cluster of changes. Recognizing that a person may be entering the final days allows the team to change priorities, anticipate symptoms, communicate clearly and prepare the family. A well-managed death will always be remembered. A poorly managed death will never be forgotten. Thos left behind become our patients too.

## Common changes

Profound weakness; spending nearly all time in bed.
Increasing sleepiness, reduced interaction or fluctuating consciousness.
Markedly reduced interest in food and fluids; difficulty swallowing.
Reduced urine output.
Changes in breathing pattern, including irregular breathing or periods of apnea.
Cooler or mottled extremities and circulatory changes.
Increasing difficulty taking oral medications.
Delirium, restlessness or altered perceptions may occur.
These changes are not universal and can also have reversible causes. Consider the clinical context and whether investigation or treatment is consistent with the person's goals.

## What should change in the care plan?

Tell the patient, when appropriate, and family what you are seeing and what it may mean.
Review goals and preferred place of care/death.
Stop medications, monitoring and investigations that no longer contribute to comfort or agreed goals.
Ensure essential symptom medications can be given by a feasible route if swallowing is lost.
Anticipate pain, dyspnea, nausea, delirium/agitation and respiratory secretions.
Clarify who to call if symptoms worsen, if death occurs, or if the family becomes unsure what to do.
Attend to cultural, spiritual and religious practices that may be important before or after death.

## Words that work

**"I'm seeing several changes that make me concerned that time may be getting short — possibly days. I can't predict the exact timing, but I think we should prepare for that possibility. Tell us what matters the most right now."**
**"Our priority now is to keep them comfortable and make sure you know what to expect and who to call."**

## This Piece

**Recognizing dying is not about predicting an exact time. It is about recognizing a pattern early enough to prepare, communicate and provide excellent care in the final days.**

## Useful links

Ontario Health — Palliative Care Competency Framework

Canadian Virtual Hospice — When Death Is Near

Ontario Health — Plan and Manage Toolkit

## References

1. Ontario Health. Palliative Care Competency Framework. Last Days and Hours domain. Updated June 4, 2026.
2. Ontario Health. Palliative Care Toolkit: Step 3 — Plan and Manage. Updated June 4, 2026.
3. Canadian Virtual Hospice. When Death Is Near. Current resource, accessed August 2026.
4. Harlos M. When Death Is Near. Canadian Virtual Hospice. Current hosted resource.
5. BC Centre for Palliative Care. Inter-professional Palliative Competency Framework. Revised December 2024.

Palliative Pieces

# The Last Hours

*What families need from us when death is near*

## Families remember this time

The final hours of life can be unfamiliar and frightening. Even when symptoms are well managed, normal physical changes may alarm family members if no one has explained what to expect. Preparing families is an important clinical intervention. Explain that not every person experiences every change and that timing remains uncertain

## Explain what they may see

Increasing sleep and reduced responsiveness.
Little or no interest in food and fluids.
Difficulty swallowing medications or fluids.
Irregular, shallow or noisy breathing and pauses between breaths.
Coolness, colour changes or mottling of hands and feet.
Very little urine.
Possible restlessness, confusion or altered perceptions.

## Food and fluids: relieve guilt

Families may worry that reduced eating and drinking means their loved one is suffering or being "starved." Explain that appetite and thirst commonly diminish as the body shuts down. Offer mouth care, small sips or tastes when safe and desired, and avoid forcing intake that causes distress.

## Noisy breathing can sound worse than it feels

Pooled secretions can create noisy breathing when a person becomes too weak to clear them. Repositioning and selected medications may help. The sound can be very distressing to families, so explanation and reassurance are as important as treatment.

## Give families something they can do

Sit quietly, hold a hand or speak normally.
Play familiar music, read, pray or observe meaningful rituals.
Provide mouth and lip care if taught how.
Tell the team about signs of pain, breathlessness or distress.
Rest, eat and step away when needed — being constantly at the bedside is not a requirement for loving care.

## Make the practical plan explicit

Before death is imminent, families should know whom to call day or night, what to do if symptoms change, whether and when 911 is appropriate, what to do when death occurs, and what documentation or arrangements are already in place. Ontario's competency framework specifically identifies this preparation as part of good last-days-and-hours care.

## Words that work

**"These changes are expected as the body slows down. We will continue watching closely for anything that suggests discomfort."**

**"You do not have to make them eat or drink. Your presence and mouth care may be much more helpful now."**
**"There is no right way to be at the bedside. Talk, sit quietly, step out, rest — do what feels right for you and for them."**

## This Piece

**In the last hours, excellent care includes caring for the family. Explain what is happening, relieve guilt and fear, anticipate symptoms, honour culture and rituals, and make sure everyone knows what to do next.**

## Useful links

Canadian Virtual Hospice — When Death Is Near
Ontario Health — Palliative Care Competency Framework
Ontario Health — Palliative Care Quality Standard

## References

1. Ontario Health. Palliative Care Competency Framework. Last Days and Hours; Loss, Grief and Bereavement domains. Updated June 4, 2026.
2. Canadian Virtual Hospice. When Death Is Near. Current resource, accessed August 2026.
3. Harlos M. When Death Is Near. Canadian Virtual Hospice.
4. BC Centre for Palliative Care. Inter-professional Palliative Competency Framework. Revised December 2024.
5. Ontario Health. Palliative Care: Care for Adults With a Serious Illness — Quality Standard. 2024; last updated June 26, 2026.

Palliative Pieces

## Where Can I Get More Education and Training in Palliative Care?

*Four great places to start - locally, provincially and nationally*

Providing a palliative approach is increasingly part of everyday clinical practice. You don't have to become a palliative-care specialist to become more confident in recognizing palliative needs, managing common symptoms, having serious illness conversations and supporting patients and families.

Whether you have an hour, a day or want more advanced training, there are excellent education opportunities available to health care providers in Ontario.

### 1. Start Local: North Simcoe Muskoka Hospice Palliative Care Network

For clinicians working in North Simcoe Muskoka, the North Simcoe Muskoka Hospice Palliative Care Network (NSMHPCN) is an excellent first stop. The Network provides courses, workshops, presentations and regional learning opportunities.

Fundamentals of Hospice Palliative Care (FHPC)

Comprehensive Advanced Palliative Care Education (CAPCE) for nurses

Advance Palliative Practice Skills (APPS)

Canadian Serious Illness Conversations (CSIC)

Essential Pain Management (EPM)

LEAP courses

Palliative Approach & Dementia

Grief and Bereavement education

**Best for: Local, practical education and connection with palliative-care resources across North Simcoe Muskoka.**

**North Simcoe Muskoka Hospice Palliative Care Network**

Current education opportunities, courses and regional learning.

Visit education page

### 2. Build Your Clinical Skills: Pallium Canada

Pallium Canada is a national leader in interprofessional palliative-care education and is best known for LEAP - Learning Essential Approaches to Palliative Care. LEAP courses are evidence-informed, case-based and designed for different professions, specialties and care settings.

LEAP Core is an excellent starting point for clinicians whose primary practice is not palliative care. Other offerings include courses tailored to hospital, long-term care, oncology, lung disease, paramedicine and other settings.

Earlier identification of patients who may benefit from a palliative approach

Pain and symptom assessment and management

Advance Care Planning and goals-of-care discussions

Psychosocial and spiritual needs

Essential palliative-care conversations

Care during the last days and hours

**Best for: Structured, evidence-informed education that can be applied immediately in clinical practice.**

**Pallium Canada**

LEAP courses and other palliative-care education for health professionals.

**Explore Pallium courses**

**Pallium Pocketbooks**

## 3. Explore Ontario Resources: Hospice Palliative Care Ontario

Hospice Palliative Care Ontario (HPCO) offers education for health professionals, hospice teams, PSWs, volunteers, administrators and caregivers. Its resources are particularly useful for learning within the Ontario context.
Webinars and continuing education
Person-Centred Decision-Making education addressing Advance Care Planning, Health Care Consent and Goals of Care
Skills-building workshops
PACE for PSWs - Palliative Care Education for Personal Support Workers
On-demand learning resources
Palliative Talks podcast
Conferences and other educational events
**Best for: Ontario-specific education, interdisciplinary learning, communication and decision-making education, and flexible learning opportunities.**

**Hospice Palliative Care Ontario**
Ontario education, webinars, decision-making resources and professional development.
Explore HPCO education

## 4. For Physicians: Canadian Society of Palliative Care Physicians

The Canadian Society of Palliative Care Physicians (CSPCP) is the national professional organization for physicians working in or interested in palliative medicine. Its work includes physician education, development of palliative-care competencies, advocacy and professional networking.
Physicians looking for more advanced learning can explore CSPCP educational opportunities, including its Advanced Learning in Palliative Medicine activities and national professional resources.
**Best for: Family physicians, specialists and palliative-care physicians seeking physician-focused education, professional development and advanced learning.**

**Canadian Society of Palliative Care Physicians**
Physician-focused palliative medicine education, competencies and professional resources.
Visit CSPCP

## Where should I start?

New to palliative care -> Fundamentals through NSMHPCN or LEAP Core through Pallium Canada.
Working in hospital -> Explore LEAP Hospital and local NSMHPCN education.
Nurse seeking advanced education -> Explore CAPCE through NSMHPCN.
PSW -> Explore Fundamentals/APPS through NSMHPCN and PACE for PSWs through HPCO.
Want more confidence with difficult conversations -> Explore Canadian Serious Illness Conversations, LEAP and HPCO decision-making education.
Physician seeking advanced learning -> Explore Pallium's advanced offerings and CSPCP resources.

## Try this in practice

Pick one area where you would like to feel more confident - symptom management, earlier identification, serious illness conversations, Advance Care Planning and Goals of Care, dementia, last days and hours, or grief and bereavement.
Then choose one learning opportunity that matches that need.
**You don't have to learn everything at once.**

## This Piece

**Palliative care is a core clinical skill - and there are excellent resources to help you build it.**
Start locally. Coose education that fits your role. Build one skill at a

# Using the COHT Palliative Patient Pathway

## Early Identification – Role of the Current Care Team

Anyone who knows the patient may identify that a palliative approach may be of benefit and should be discussed. Using tools like the Gold Standard Framework Proactive Identification Guide, the current care team can find cues that the disease process is advancing, frailty is increasing and care needs are requiring more attention and coordination. This should prompt discussions to establish the current understanding held by the patient, family, caregivers and others that the patient wants involved.
The current care team may be in primary care or in any cancer or chronic disease management program. The key is for those who know the patient and their condition to open discussions within the trusting relationship they hold. The Palliative Approach is best introduced with reassurance that the current care plan is not being abandoned, and appropriate treatment will continue.

## Learn and Use Skills to have Serious Illness Conversations

Helping the patient, family and caregivers express what matters most will inform the Goals of Care. Determine the status of Advance Care Plans and confirm the Substitute Decision Maker. Consider measures of Caregiver Distress. Talk to them about quality of life and discuss the burdens and benefits of ongoing treatment, offering choices. Refer them to programs and resources like the Waiting Room Revolution Hope for the Best Plan for the Rest books and workshops available through Hospice Orillia.

## Comprehensive Assessment - Most Responsible Provider and Team

When the patient is in a community setting (home, Long Term Care Home, Retirement Residence, Congregate Living Home, Residential Hospice), the MRP and Team uses prognostic and symptom surveillance tools like the Palliative Performance Score and the Edmonton Symptom Assessment Scale to document the patient's functional status and comfort level. Goals of Care are reviewed and confirmed with any new information or circumstances. Pain and symptom management is a priority and Team members like social work and spiritual care providers may be included to address psychosocial issues.

## Ongoing Care Coordination – MRP & Team

At home, the team educates the patient, family and caregivers about what is happening and what to expect. Challenging dynamics are managed with carefully planned team, family caregiver conferences and communication plans. Community providers are engaged purposefully and communication is aimed at anticipation and prevention of crises.

## The Cycle of Care Continues to End of Life

The cycle of care shows how care wraps around the patient, family and caregiver on an ongoing basis until End-of-Life Planning is needed. The cycle repeats throughout the patient's disease trajectory which may be any measure of time: Update Goals of Care, Adjust the Care Plan, Provide the Care, and Assess Ongoing Needs.

## End of Life Decisions and Plans are made

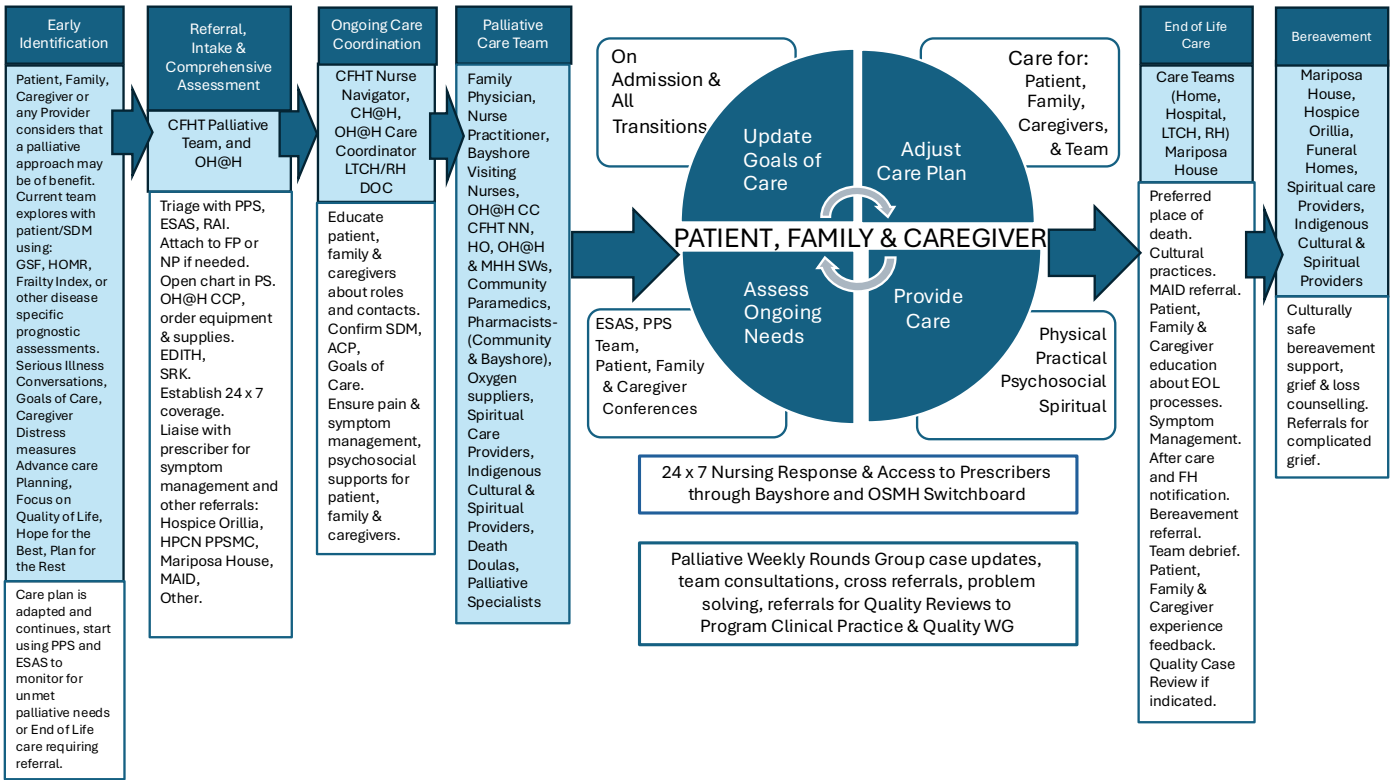
Whether the patient will be cared for at home, in Long Term care, at a Retirement Residence, in a Congregate Living Home or Residential Hospice, the community providers need to know the current goals of care, preferred setting of death, and any issues that will need to be addressed.

## Effective End of Life Care

In any setting, EOL Care includes best efforts to accommodate the person's preferred place of death, attention to cultural practices that matter to the person, MAID referral if requested, Patient, Family & Caregiver education about EOL processes, Symptom Management, after care and Funeral Home notification.
Remember to offer resources for Bereavement services, Team debriefs of the care provided, and to invite Patient, Family & Caregiver experience feedback.
Consider a Quality Case Review if anyone has identified issues that could result in future quality improvements.

# COHT Palliative Patient Pathway

Couchiching Ontario Health Team Palliative Patient Care Pathway 2026




## Legend

ACP – Advance Care Plan
CC – Care Coordinator
CCP – Collaborative Care Plan
CFHT- Couchiching Family Health Team
CFHT NN –Nurse Navigators
DOC- Director of Care
EOL – End of Life
ESAS – Edmonton Symptom Assessment Scale
EDITH- Expected Death in The Home protocol
FH – Funeral Home
FP – Family Physician
GSF PIG–Gold Standard Framework Proactive Identification Guidance
HO –Hospice Orillia Community Hospice
Home – Includes Congregate Living, Shelters, Correctional Facilities & Street Involved
HOMR – Hospital One Year Mortality Risk
HPCN Hospice Palliative Care Network
LTC- Long Term Care
MAID – Medical Assistance In Dying
Mariposa House – Residential Hospice
NP – Nurse Practitioner
OH@H- Ontario Health atHome
OSMH – Orillia Soldiers' Memorial Hospital
PPS – Palliative Performance Score
PPSMC - Pain & Symptom Management Consultant
PS – Practice Solutions Electronic Medical Record
RAI - Resident Assessment Instrument
RH - Retirement Home
RVH – Royal Victoria Hospital
SDM – Substitute Decision Maker
SPICT - Supportive & Palliative Indicators Tool
SRK – Symptom Relief Kit
SW - Social Worker

# Palliative Services in COHT

## Couchiching Service Area is Orillia, Oro-Medonte, Rama First Nation, Ramara & Severn

### Couchiching Family Health Team Palliative Nurse Navigator

(705)-329-3649 x 290 M-F 0800-1700hrs

Palliative trained nursing assessment, system navigation and palliative provider support.
Access to palliative care physicians and nurse practitioners for unattached patients in Couchiching.

### Hospice Orillia

(705)-325-0505 M-F 0900-1630 hrs

Practical, emotional, spiritual, grief and bereavement support for patients, families and caregivers.

### Mariposa House Hospice

(705)-558-2888 Open 24 hrs

Residential Hospice end of life care and bereavement services.

### North Simcoe Muskoka Hospice Palliative Care Network

(705)-325-05058 M-F 0900-1630 hrs

Comprehensive education and resources for health care providers of all disciplines.
Palliative Pain & Symptom Management Consultant Nurses for case-based team support.

### Ontario Health at Home

1-833-515-1234 7 days per week 0830-2000 hrs

Access to in-home nursing, PSW and other professional services, medical supplies, oxygen, equipment and medications for home palliative care.
Palliative Care Nurse Practitioner.

### Medical Assistance in Dying (MAiD)

1-866-286-4023 M-F 0900-1700 hrs

Ontario Health at Home Care Coordination Service