

A Palliative Care Approach for Oncology



Cancer Care Ontario

Integrating a palliative care approach earlier in the disease trajectory improves the quality of living and dying, and relieves suffering for patients and families living with life-limiting illnesses. This tool outlines the approach through three steps, beginning with **The Surprise Question**.

STEP 1 IDENTIFY

Use the following triggers to identify patients who could benefit from a palliative care approach:

- ✓ **The Surprise Question:** “Would you be surprised if this patient were to die in the next year?”
- ✓ Does the patient have general indicators of decline or specific indicators related to certain conditions?
- ✓ Has the patient indicated a preference or need for palliative care?

STEP 2 ASSESS

- ✓ **Symptoms** Assess symptoms and needs across all domains. Screen using Edmonton Symptom Assessment System (ESAS) for:
 - Pain
 - Nausea
 - Depression
 - Tiredness
 - Lack of Appetite
 - Anxiety
 - Drowsiness
 - Shortness of Breath
 - Wellbeing
- ✓ **Performance Status** Use Palliative Performance Scale (PPS) as a trigger for when to assess:
 - how well the patient’s care needs are being met
 - need for current resources in the home
 - level of caregiver coping/distress

Key Features of Specific PPS Ratings:

 - **(PPS 70)** Can no longer carry out normal job, work, occupation or some hobbies or housework activities
 - **(PPS 60)** A few times a week needs assistance with at least one of: Transfer out of bed, walk, wash, toilet, eat
 - **(PPS 50)** Mainly sits in chair or lies in bed. Needs help every day to do some of the activities listed
 - **(PPS 40)** Mainly lies in bed
- ✓ **Understanding**
 - Ensure the patient and family/substitute decision-maker (SDM) understand incurable and progressive nature of the illness
 - Understand the patient’s values, beliefs and goals of care. Be prepared to address “what to expect”.
 - Document discussion.

STEP 3 PLAN/MANAGE

- ✓ **Manage Symptoms**
 - Manage symptoms using guidelines (CCO Symptom Management Guides, Fraser Health Guidelines)
 - Consider local community resources and connecting with Community Care Access Centre (CCAC).
- ✓ **Plan Care – If PPS:**
 - ≥ 70 : Initiate Advance Care Planning (ACP) with patient and their SDM
 - ≤ 60 : Initiate End Of Life (EOL) Care Planning with patient and their SDM
 - ≤ 50 : Initiate urgent assessment of understanding, goals of care and EOL Care Plan.
- ✓ **Consults and Referrals**
 - If $PPS \leq 60$, refer to CCAC
 - Consider consult to palliative care and psychosocial resources for complex symptom management issues
 - Consider local resources for additional care support.

Evidence

This tool has been adapted from the Gold Standards Framework (GSF), which has been endorsed by the National Health Service (NHS) and widely implemented within UK general practices, to support earlier identification of patients who could benefit from a palliative care approach. It follows the GSF structure of *Identify, Assess and Plan*, with care tools and resources used in the Canadian context.

The evidence has shown:

- Improvements in quality of life, less aggressive care at the end of life, and increased survival for those receiving palliative care concurrently with oncological care.
- Early palliative care is significantly associated with improved care satisfaction and symptom severity scores in cancer patients.

References

- Myers J, Kim A, Flanagan J, Selby D. Palliative performance scale and survival among outpatients with advanced cancer. *Support Care Cancer*. 2014.
- Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733-42.
- Thomas K, et al. Prognostic Indicator Guidance, 4th Edition. The Gold Standards Framework Centre in End of Life Care. 2011.
- Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet*. 2014;383(9930):1721-30.

The Surprise Question

“Would you be surprised if this person were to die in the next year?”

The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a complete 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 further decline?

General Indicators of Decline

- Decreasing activity
- Co-morbidity
- General physical decline and increasing need for support
- Advanced disease – unstable, deteriorating complex symptom burden
- Decreasing response to treatment, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past 6 months
- Repeated unplanned crisis/hospital admissions
- Sentinel events
- Serum albumen <25g/l

Disease Specific Indicators of Decline

Cancer – Rapid or Predictable Decline

- Metastatic cancer
- Performance status and functional ability – if patients are spending more than 50% of their time in bed/lying down, prognosis estimated to be 3 months or less

Symptoms

- Assess symptoms and needs across all domains, including emotional, spiritual, social, nutritional, informational, practical, loss
- Screen regularly using validated tools. Edmonton Symptom Assessment Tool (ESAS) should be used regularly to screen for the intensity of nine common symptoms
 - Ideally, patients complete their own ESAS. If unable, should be completed with assistance.

Performance Status

- Assess patient performance status using tools such as the Palliative Performance Scale (PPS) and Eastern Cooperative Oncology Group Performance Status (ECOG)
- Functional status can also be evaluated through other measures, such as frailty with a clinical frailty scale
- Performance and functional status can be helpful in planning for death and prompting more comprehensive assessment.

	PPS Level	ECOG/PRFS*	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level		
Stable Phase	100%	0/0	Full	Normal activity and work No evidence of disease	Full	Normal	Full		
	90%	1/1		Normal activity <i>with effort</i> Some evidence of disease				Normal or reduced	
	80%								
Transitional Phase	70%	2/2	Reduced	Unable to do normal job/work Significant disease	Full	Normal or reduced	Full		
	60%			Unable to do hobbies/housework Significant disease				Occasional assistance necessary	Full or confusion
	50%	3/3	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required		Full or drowsy +/- confusion		
	40%		Mainly in bed	Unable to do most activities Extensive disease				Mainly assistance	
End of Life Phase	30%	4/4	Totally bed-bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy +/- confusion		
	20%							Minimal to sips	Full or drowsy +/- confusion
	10%							Mouth care only	
	0%					5/ —		Death	—

*ECOG: Eastern Cooperative Oncology Group Performance Status; PRFS: Patient Reported Functional Status

Understanding

Identification of a patient who would benefit from a palliative care approach should prompt a conversation to assess their understanding of their illness.

- Should not be viewed as a lengthy conversation that aims to explain palliative care or plan for where and how the patient would spend their final days or weeks.
- Should be viewed as first in a series of conversations over time involving different members of the care team (oncologists, nurses, social workers, family practitioner, palliative care clinician, etc.)

Intent of Conversation:

INFORM: information is new and has not been previously addressed

or **CONFIRM:** previous conversations have occurred and the purpose is to assess accuracy of understanding.

Conversation Outcome:

Patient and family member(s)/SDM understand both the incurable and progressive nature of the cancer.

“INFORM” Conversation

Below is a modified SPIKES algorithm for “difficult conversations” to inform a patient of the incurable/progressive nature of their disease

S: SET UP the interview

- Ask your patient who else to include in the interview (e.g., the substitute decision-maker)
- Consider involving a colleague (e.g., nurse, trainee or other appropriate member of the team who has developed a relationship with the patient)

P: Assess the patient’s PERCEPTION

- Ask how the patient perceives his or her medical situation with questions such as:
What have you been told about your medical situation so far?
Tell me what the last year has been like for you. What are your thoughts about the future?

I: Obtain the patient’s INVITATION

- Determine what the patient wants to know

K: Give KNOWLEDGE and information

- Provide small chunks of information in simple language, checking periodically for understanding

E: Address EMOTIONS with empathic responses

- Identify emotions as they arise with statements such as:
I can tell you weren’t expecting to hear this. It sounds like you are feeling overwhelmed by this.
- Use exploratory questions or statements if there is silence, such as:
Could you tell me more about what is worrying you?

S: STRATEGY and SUMMARY

- Summarize the major areas discussed
- Make a plan for the next meeting

“CONFIRM UNDERSTANDING” Conversation

- It is important to establish patient preferences for how much information is to be given, to whom information should be provided and with whom care decisions should be made
- For each patient, regularly take a few moments to stop and check in about the big picture. *I know in the past we have discussed your cancer and what to expect for the future. So I’m sure we are on the same page, what do you remember about our previous chats when we discussed your cancer and the future?*

1. Understands incurable nature of illness?

What does this mean to you? Is it curable? Can we get rid of the illness? What do you think the intravenous medicine is doing? What information related to your treatments not being able to get rid of your illness would be helpful or important to you?

Understands progressive nature of illness?

What do you expect to happen? What worries you about the future? What information about the impact your illness will have would be helpful or important to you?

2. Reassure care will continue as planned

3. With patient determine plan for involving family physician

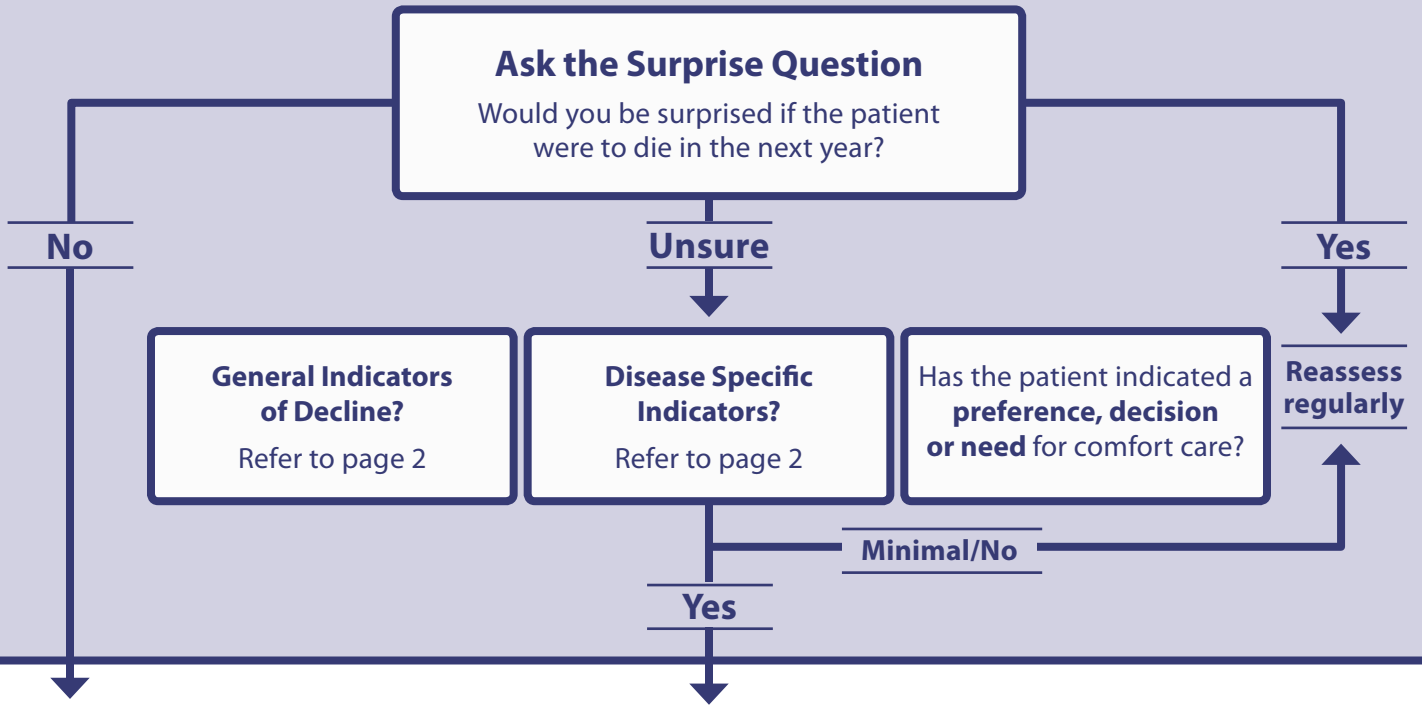
4. Collaborate with team to initiate Advance Care Planning or End of life Care Planning.

Prognosis – “How long do I have left to live?”

- Ask exploratory questions in response, usually there is something underlying the question: *What has brought you to ask this today; is there something specific in your mind as you ask this?*
- Avoid specific time frames or probabilistic statistical information, as these estimates are not accurate. If important to address, consider “time-based categories” (hours to days, days to weeks, etc.)

Fig. 1 Identify, Assess, Plan/Manage Tool

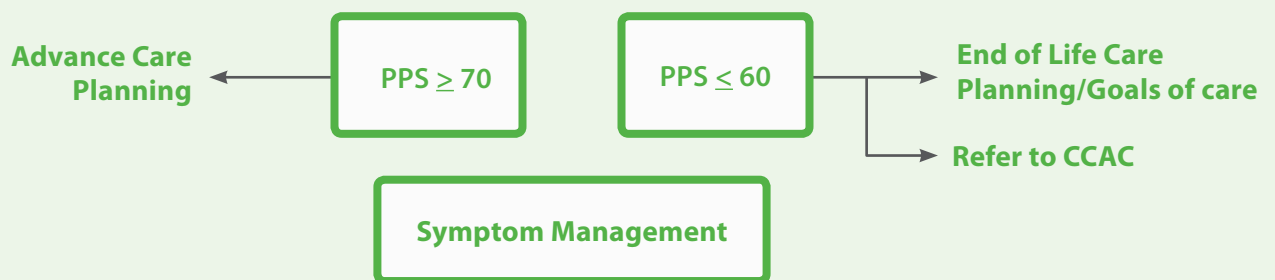
Step 1: Identify



Step 2: Assess



Step 3: Plan/Manage



STEP 3 PLAN/MANAGE

Symptoms

- ✓ Promptly manage identified symptoms and needs through use of symptom guides:
 - CCO Symptom Management Guides – *Mobile app available*
 - Fraser Health Guidelines
 - Pallium Pocketbook – *e-Book available*

Care Planning

- Use functional status to prompt care planning and assess needs in home/community
 - If PPS is ≥ 70 , then Advance Care Planning (ACP) with patient and their substitute decision-maker (SDM)
 - If PPS is ≤ 60 , End of Life (EOL) Care Planning with patient and their SDM and **refer to CCAC**.

✓ Advance Care Planning (ACP)

- ACP is an ongoing reflection, discussion and communication of decisions about what kind of care an individual would want (or not want) if they are no longer able to speak for themselves.
- ACP improves communication with healthcare team and quality of life and reduces stress and anxiety for patients, families and caregivers.

How to Implement ACP:

- Introduce the topic of ACP
- Make a second appointment to discuss ACP. Ask your patient to bring their SDM to that appointment. Allow time for reflection and decision-making
- Refer patients to the Speak Up: Advance Care Planning Workbook – Ontario Edition – to help them explore their values and wishes
- Record values and wishes. Make sure patient and their SDM have copies
- Ensure there is a copy in their chart
- Involve other healthcare professionals and practice staff as needed.

Find more information and resources at Speak Up website:
www.advancecareplanning.ca

✓ Goals of Care

Discussions should complement advance care planning and should be directed at preferences around specific clinical interventions.

✓ Also consider the following checklist:

- Recommend complementary therapeutic interventions if needed
- Obtain consent for treatments
- Consider consult with or referral to palliative care for complex symptom management issues
- Identify most responsible physician if transfer of care required
- Facilitate communication of the plan of care when there is a transfer to a new setting.

✓ End of Life Care Planning

- Discuss and document goals of care with patient and family, if not done already
- Revisit ACP and discuss treatment withdrawal or withholding
- Screen for specific end of life psychosocial issues for patient and family
- Identify if patient could benefit from specialized palliative care services
- Proactively develop and implement a plan for expected death (refer to Collaborative Care Plans)
- Plan for home care including connecting with CCAC early (not just for last 2-4 weeks), ensuring proper resources are in place; consider an emergency home kit.

Consult/Referrals

The following are examples of resources that can be considered to support patients and families. Connect with CCAC and other community services to determine how to access support if needed:

Consider for All Patients and Family Members

- Community Care (CCAC) –
 - Nutrition/dietician
 - Physical/occupational therapy
 - Spiritual services
 - Psychology/psychiatry
 - Social work
 - Community support services
- Palliative/Pain/Supportive Clinic – *Consider for complex symptom management issues*
- Primary care
- Hospice

Production of this tool has been made possible through financial support from the Canadian Partnership Against Cancer and Health Canada. For more information and tools used in this step, see www.cancercares.on.ca/toolbox/pallcaretools

An initiative of / Une initiative du