

A Palliative Care Approach for Primary Care



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 the 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:

- In a family medicine clinic, about 1% of the patients on the panel die every year
 - Only about 10% of deaths are sudden; the majority have prolonged trajectories and can be predicted.
- 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.
- Early palliative care can benefit patients across non-cancer diseases, with predictable trajectories.

References

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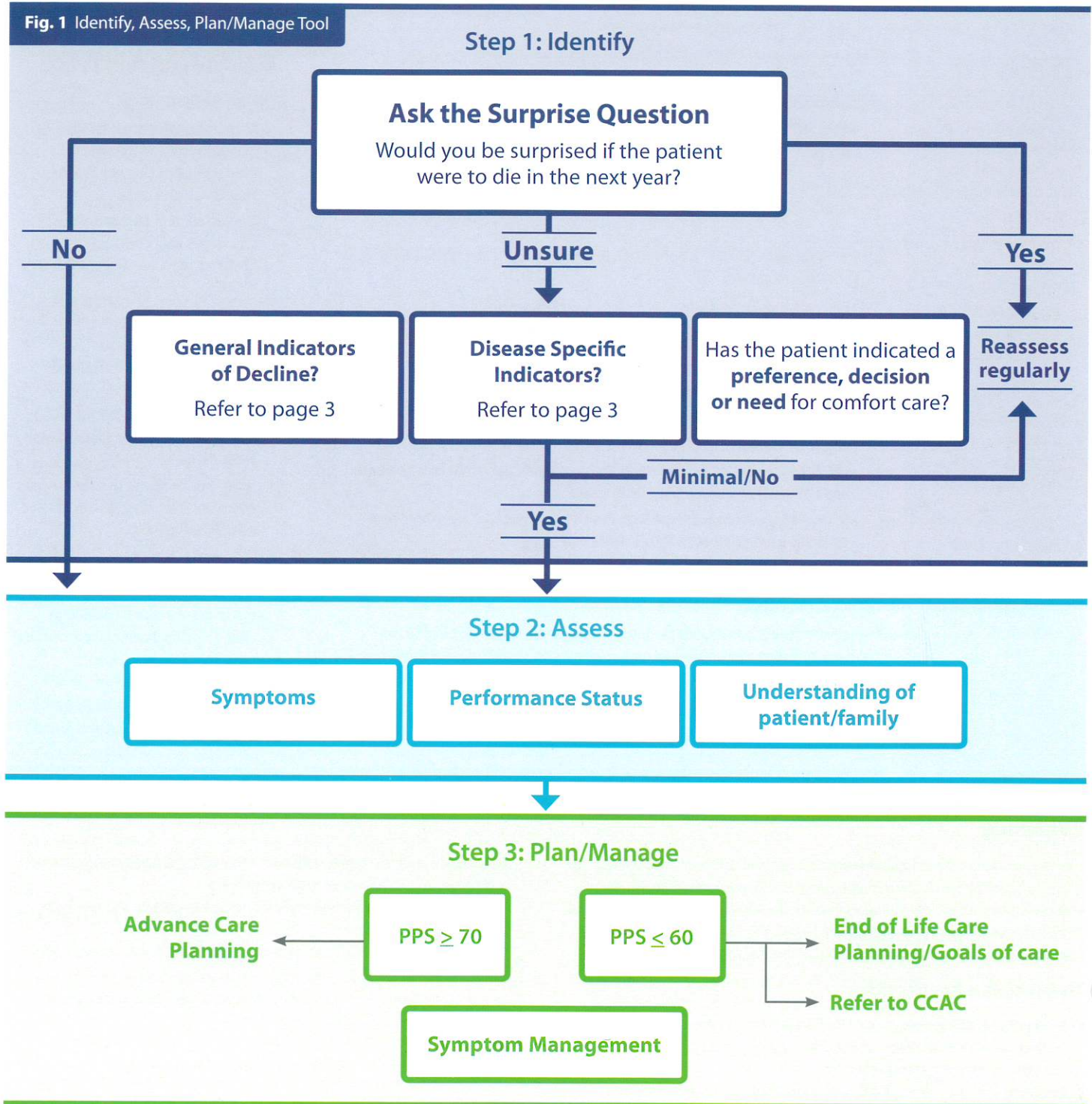
STEP 1 IDENTIFY

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?

Fig. 1 Identify, Assess, Plan/Manage Tool



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	Full	Normal	Full
	90%	1/1		No evidence of disease		Normal or reduced	
	80%			Normal activity <i>with effort</i> Some evidence of disease			
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	Normal or reduced	Full or confusion
	50%	3/3	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required		
	40%		Mainly in bed	Unable to do most activities Extensive disease	Mainly assistance		Full or drowsy +/- confusion
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	Drowsy or coma +/- confusion
	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
- 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
- Key aspects of the conversation include:

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. Collaborate with team to initiate Advance 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.)

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 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

Organ Failure – Erratic Decline

Chronic Lung Disease (e.g. Chronic Obstructive Pulmonary Disease (COPD))

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long-term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house
- Signs and symptoms of right-side heart failure
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

Heart Disease (e.g. Congestive Heart Failure (CHF))

- CHF NYHA Stage 3 or 4 – shortness of breath at rest on minimal exertion
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

Liver Disease

- Advanced cirrhosis with one or more complications in the past year: diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome, recurrent variceal bleeding
- Liver transplant contraindicated
- Child-Pugh class C.

Chronic Kidney Disease (CKD)

- Patient with stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating
- Patients choosing the “no dialysis” option, or discontinuing dialysis (by choice or due to increasing frailty, co-morbidities). Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

General Neurological Diseases

- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure.
- Speech problems: increasing difficulty in communicating and progressive dysphasia.

Plus the following:

Motor Neuron Disease

- Marked rapid decline in physical status
- First episode of aspiration pneumonia
- Increased cognitive difficulties
- Weight loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs Activities of Daily Living (ADL) help
- Condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty – see below.

Multiple Sclerosis

- Significant complex symptoms and medical complications
- Dysphagia + poor nutritional status
- Communication difficulties (e.g. dysarthria + fatigue)
- Cognitive impairment, notably the onset of dementia

Frailty/Dementia – Gradual Decline

Frailty

- Multiple co-morbidities with significant impairment in day-to-day living
- Deteriorating functional score (e.g. performance status)
- Combination of at least 3 of the following symptoms:
 - weakness
 - slow walking speed
 - significant weight loss
 - exhaustion
 - low physical activity
 - depression

Stroke

- Persistent vegetative or minimally conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment/post-stroke dementia.

Dementia

- Unable to walk without assistance
- Urinary and fecal incontinence
- No consistently meaningful conversation
- Unable to do ADL

Plus any of the following:

- Weight loss
- Urinary tract infection
- Severe pressure sores – stage 3 or 4
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started early to ensure that they can discuss how they would like the later stages managed while they have mental capacity.

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) –
Consider for functional/performance level needs (PPS ≤ 60)
- Palliative/Pain/Supportive Clinic – *Consider for complex symptom management issues*
- Nutrition/dietician
- Physical/occupational therapy
- Spiritual services
- Psychology/psychiatry
- Social work
- Community support services
- Hospice

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