

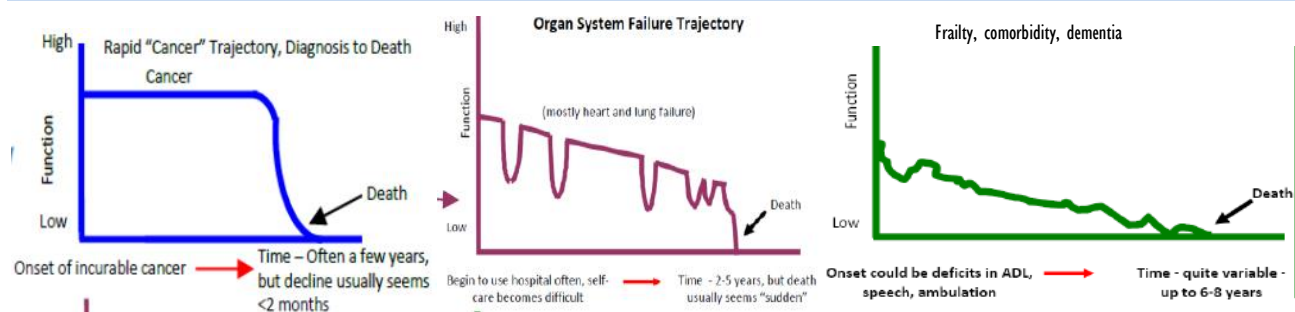
Why is it important to identify people nearing the end of life?

About 1% of the population dies each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, there is good evidence that they are more likely to receive well-coordinated, high quality care.

This Early Identification and Prognostic Indicator Guide aims to help family physicians, specialist physicians and nurse practitioners in earlier identification of those patients nearing the end of life who could benefit from a palliative care approach to care.

The tool has been adapted from the Gold Standards Framework (GSF) Prognostic Indicator Guidance¹ tool developed by the GSF Centre in the UK. The UK has been using the tool along with a comprehensive education program to support GPs, care homes and general hospital staff in identifying patients and placing them on a register to help trigger specific support.

Varying Disease Trajectories²



Three triggers that suggest that patients could benefit from a hospice palliative care approach

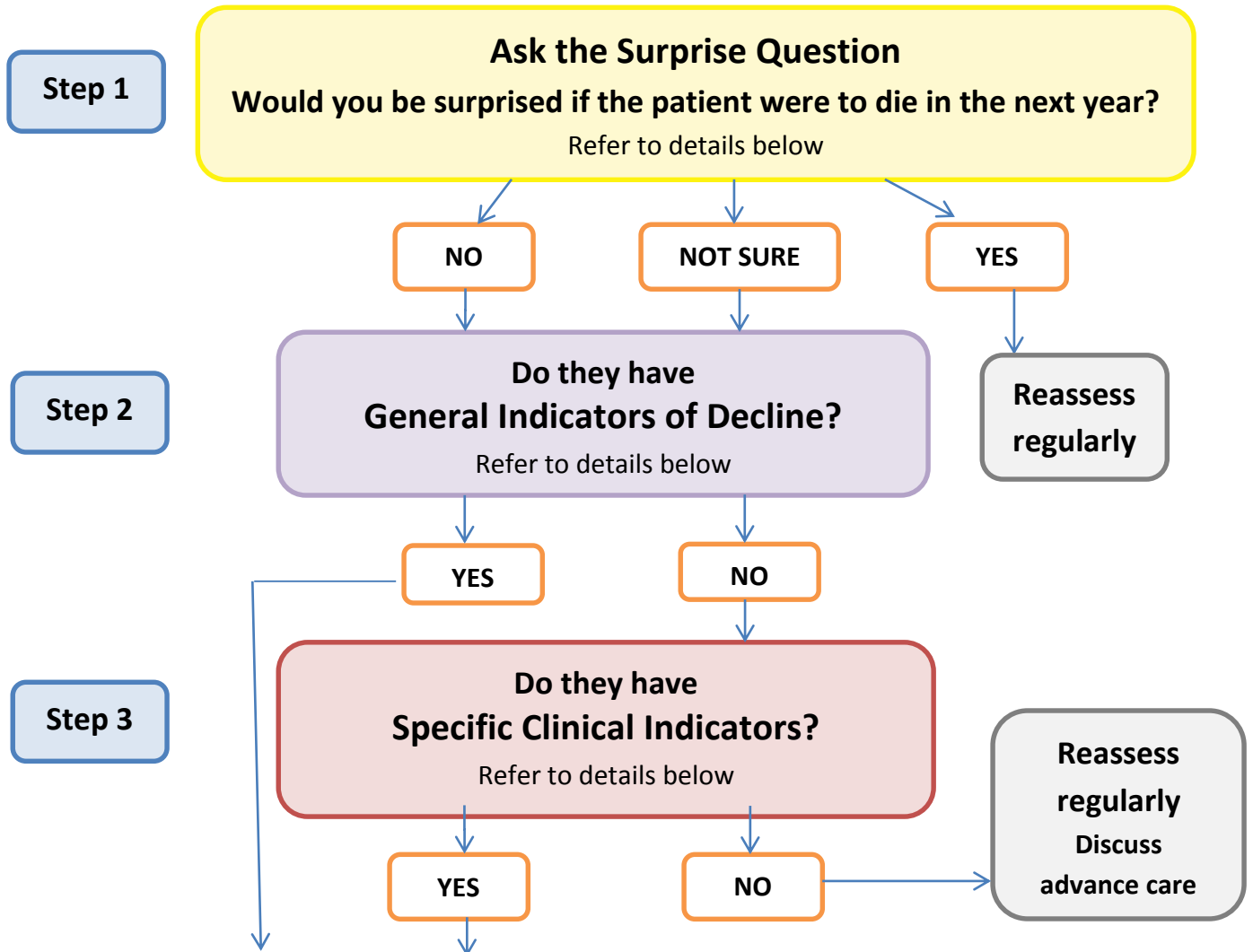
- 1. The Surprise Question: 'Would you be surprised if the patient were to die in the next year?'**
- 2. General indicators of decline: deterioration, advanced disease, decreased response to treatment, choice for no further disease modifying treatment.**
- 3. Specific clinical indicators related to certain conditions.**

Definition of Palliative Care³

Palliative care is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It strives to help individuals and families to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- prepare for and manage self-determined life closure and the dying process;
- cope with loss and grief during the illness and bereavement;
- treat all active issues;
- prevent new issues from occurring;
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

1. Thomas K. et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre In End of Life Care CIC, 2011. Adaptation of guide completed by Mississauga Halton Regional Hospice Palliative Care Committees with permission from K.Thomas



IDENTIFY Ask the “Surprise Question”; Place a flag in patient’s medical record with identified palliative care needs; Refer to CCAC for a palliative approach to care.

ASSESS Assess patient and SDM’s needs (i.e. disease management, physical, psychological, spiritual, functional status), See [Symptom Management Guides \(https://smg.cancercare.on.ca/\)](https://smg.cancercare.on.ca/); Explore patient’s understanding of illness & prognosis, information preferences & goals of care; Encourage patient to discuss goals of care, values wishes and beliefs; Record goals of care/advance care planning discussions.

PLAN Participate as a member of the primary level palliative care team; If needed, discuss role of secondary level palliative care specialists i.e. consultation, collaborative/shared care, direct care. Provide patient/caregiver information/education materials; Continue to reassess performance status to guide planning and family preparation.



More details of indicators – the intuitive surprise question, general decline and specific clinical

The Surprise Question

For patients with progressive life-limiting illness – Would you be surprised if the patient 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 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?

General Indicators of Decline

Are there general indicators of decline and increasing needs?

- Advancing disease – unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further disease modifying treatment
- General physical decline
- Declining functional performance status (e.g. Palliative Performance Scale⁴(PPS) ≤ 60 , reduced ambulation, increasing dependence in most activities of daily living)
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- Weight loss - $>10\%$ in past six months
- Repeated unplanned/crisis emergency department visits or hospital admissions
- Sentinel event, e.g. serious fall, bereavement, retirement on medical grounds
- Serum albumin $<25\text{g/l}$

Specific Clinical Indicators

Flexible criteria with some overlaps, especially with those with frailty or other co-morbidities

a. Cancer - rapid or predicable decline

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PPS, ECOG, PPI, PaP
- The single most important predictive factor in cancer is performance status and functional ability - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less

b. Organ failure - erratic decline

- | | |
|----------------------------|--|
| Lung Disease (COPD) | <ul style="list-style-type: none"> • Disease assessed to be very severe (e.g. FEV1 $<30\%$ predicted⁵) • Recurrent hospital admissions (≥ 3 in last 12 months due to COPD) • Fulfills long term oxygen therapy criteria • MRC grade 4 to 5 – dyspnea after 100m on the level or confined to house • Signs and symptoms of right heart failure • More than 6 weeks of systemic steroids for COPD in preceding 6 months |
| Heart Disease (CHF) | <ul style="list-style-type: none"> • 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 |

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Renal Disease (CKD)	<ul style="list-style-type: none"> • 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
Liver Disease	<ul style="list-style-type: none"> • Advanced cirrhosis with one or more complications in past year: <ul style="list-style-type: none"> – diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome, recurrent variceal bleeds⁶ • Liver transplant contraindicated⁶ • Child-Pugh Class C
Neurological Diseases	<p>General</p> <ul style="list-style-type: none"> • 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 communications and progressive dysphasia <p>Motor Neuron</p> <ul style="list-style-type: none"> • Marked rapid decline in physical status • First episode of aspirational 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 <p>Parkinson's</p> <ul style="list-style-type: none"> • Drug treatment less effective or increasingly complex regime of drug treatments • Reduced independence, needs ADL help • The 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 <p>Multiple Sclerosis</p> <ul style="list-style-type: none"> • Significant complex symptoms and medical complications • Dysphagia + poor nutritional status • Communication difficulties e.g. Dysarthria + fatigue • Cognitive impairment notably the onset of dementia

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c. Frailty/Dementia - gradual decline

- | | |
|-----------------|---|
| Frailty | <ul style="list-style-type: none"> • Multiple co-morbidities with significant impairment in day to day living and: • Deteriorating functional performance status • Combination of at least three of the following symptoms: weakness, slow walking speed, significant weight loss, exhaustion, low physical activity, depression |
| Dementia | <ul style="list-style-type: none"> • Unable to walk without assistance and • Urinary and fecal incontinence, and • No consistently meaningful verbal communication and • Unable to do self- care without assistance • Reduced ability to perform activities of daily living <p>Plus any of the following:</p> <ul style="list-style-type: none"> • Weight loss, urinary tract Infection, severe pressures sores (stage 3 or 4), recurrent fever, reduced oral intake, aspiration pneumonia |
| Stroke | <ul style="list-style-type: none"> • Persistent vegetative or minimal conscious state or dense paralysis • Medical complications • Lack of improvement within 3 months of onset • Cognitive impairment / post-stroke dementia |

References:

1. Thomas K. et al. *Prognostic Indicator Guidance, 4th Edition*. The Gold Standards Framework Centre in End of Life Care CIC, 2011.
2. Lunney JR, Lynn J, Foley DS, Lipson S, Guralnik JM. *Patterns of functional decline at the end of life*. JAMA 2003; 289:2387-92.
3. Ferris, F. et al. *Model to Guide Hospice Palliative Care*. Canadian Hospice Palliative Care Association, 2002.
4. *Palliative Performance Scale (PPSv2) version 2*. Medical Care of the Dying, 4th ed.; p. 121. ©Victoria Hospice Society, 2006.
5. O'Donnell DE et al. *Canadian Thoracic Society recommendations for the management of chronic obstructive pulmonary disease – 2007 update*. Canadian Respiratory Journal, 2007:14 (Suppl B).
6. *Supportive and Palliative Care Indicators tool (SPICT)*. NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group, 2013.

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Additional Information:

Palliative Care Tools

Links to best-practice tools from around the world to support primary care providers in the delivery of palliative care. The tools are organized under the 3-steps of **Identify, Assess, Plan**.

<https://www.cancercare.on.ca/cms/one.aspx?portalId=1377&pageId=76967>

Palliative Performance Scale (PPSv2)

The Victoria Hospice Palliative Performance Scale (PPS, version 2) is an 11-point scale designed to measure patients' performance status in 10% decrements from 100% (healthy) to 0% (death) based on five observable parameters: ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level.

Instructions on how to use the PPSv2 can be found at:

<http://www.victoriahospice.org/health-professionals/clinical-tools>



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

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

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Dyspnea: MRC Grade 4-5

Medical Research Council dyspnea scale for grading the degree of a patient’s breathlessness:

1. Not troubled by breathlessness except on strenuous exercise
2. Short of breath when hurrying or walking up a slight hill
3. Walks slower than contemporaries on the level because of breathlessness, or has to stop for breath when walking at own pace
4. **Stops for breath after about 100 m or after a few minutes on the level**
5. **Too breathless to leave the house, or breathless when dressing or undressing**

Congestive Heart Failure: CHF NYHA Stage 3 or 4

Congestive heart failure New York Heart Association Classification:

- Class 1 – No limitation in physical activity. Ordinary physical activity produces no symptoms.
- Class 2 – Slight limitation in physical activity. No symptoms at rest. Symptoms possible with ordinary physical activity.
- **Class 3 – More severe limitations in physical activity. Usually comfortable at rest. Symptoms with unusual physical activity.**
- **Class 4 – Inability to carry on any physical activity without producing symptoms. Symptoms possible at rest.**

Chronic Kidney Disease Stage 4 or 5

Table 1: Classification of the stages of chronic kidney disease* ⁵		
Stage	Description	Glomerular filtration rate, mL/min/1.73 m ²
1	Kidney damage† with normal or increased glomerular filtration rate	≥ 90
2	Kidney damage† with mild decreased glomerular filtration rate	60–89
3	Moderately decreased glomerular filtration rate	30–59
4	Severely decreased glomerular filtration rate	15–29
5	Kidney failure	< 15 (or dialysis)

*Kidney damage or glomerular filtration rate less than 60 mL/min/1.73 m² for 3 or more months.
 †Pathologic abnormalities or markers of damage, including persistent proteinuria, abnormalities in urine sediment (persistent presence of erythrocytes, erythrocyte casts, leukocytes or leukocyte casts) or abnormal results in imaging studies (evidence of scarring or small kidneys on ultrasound or bilateral cystic changes consistent with polycystic kidney disease).

Cirrhosis: Child-Pugh Class C: 10 to 15 points; one year survival 45%; two year survival 35%

To calculate score: <http://www.mdcalc.com/child-pugh-score-for-cirrhosis-mortality/>

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