Mississauga Halton Regional Hospice Palliative Care

Early Identification & Prognostic Indicator Guide

Guidance for clinicians to support earlier identification of patients nearing the end of life and who could benefit from a hospice palliative care approach

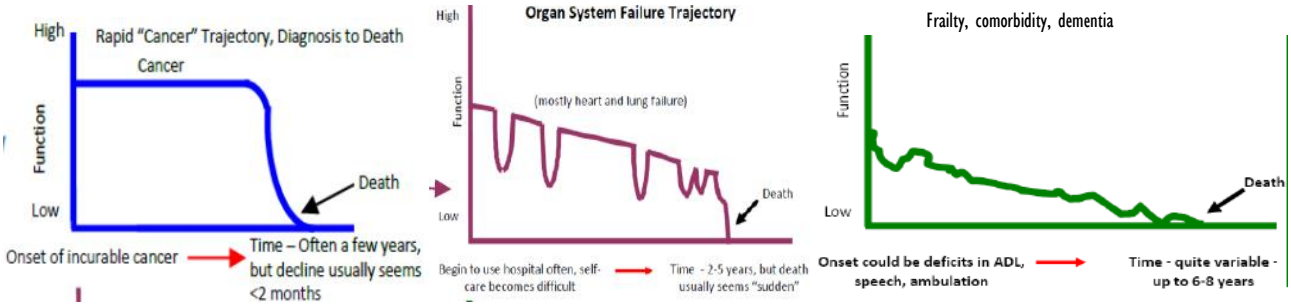
Why is it important to identify people nearing the end of life?

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 hospice palliative care approach to care.

The tool has been adapted from the Gold Standards Framework (GSF) Prognostic Indicator Guidance[1] 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 Trajectories [2]



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 Hospice Palliative Care[3]

Hospice 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.

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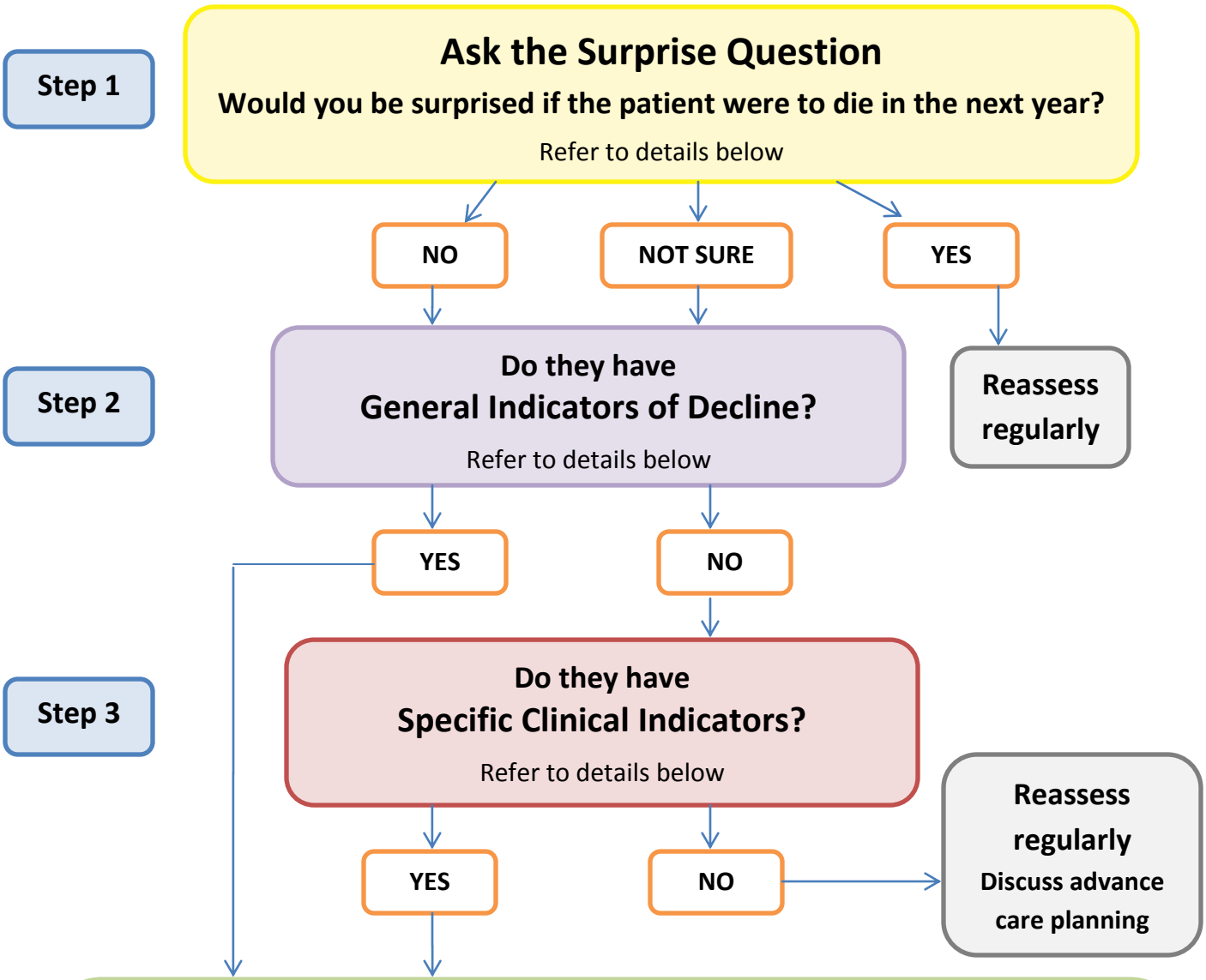

IDENTIFY Flag in patient's medical record with identified palliative care needs
Refer to CCAC Palliative Care Program

ASSESS Assess patient and family needs (i.e. disease management, physical, psychosocial, spiritual, functional status, goals of care)
Record goals of care/advance care planning discussions

PLAN Participate as a member of the primary level palliative care team
If patient/family needs meet complexity criteria, discuss role of secondary level palliative care specialists, i.e. consultation, collaborative care/shared care, direct care

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition.* The Gold Standards Framework Centre In End of Life Care CIC, 2011.

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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 Scale[4](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 hospital admissions
- Sentinel event, e.g. serious fall, bereavement, retirement on medical grounds
- Serum albumin <25g/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)	• Disease assessed to be very severe (e.g. FEV1 <30% predicted[5]) • 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)	• 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

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition.* The Gold Standards Framework Centre In End of Life Care CIC, 2011.

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Renal Disease (CKD)	• 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	• Advanced cirrhosis with one or more complications in past year: – diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome, recurrent variceal bleeds[6] • Liver transplant contraindicated[6] • Child-Pugh Class C
Neurological Diseases	**General** • 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 **Motor Neuron** • 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 **Parkinson's** • 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 **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

1. Thomas.K et al. *Prognostic Indicator Guidance, 4th Edition.* The Gold Standards Framework Centre In End of Life Care CIC, 2011.

c. Frailty/Dementia - gradual decline

Frailty

- 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

- 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

Plus any of the following:

- Weight loss, urinary tract Infection, severe pressures sores (stage 3 or 4), recurrent fever, reduced oral intake, aspiration pneumonia

Stroke

- 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.