The Palliative Approach to Care in the Mississauga Halton LHIN

Mississauga Halton Palliative Care Network www.mhpcn.net

What primary care clinicians can do to support their patients’ needs
Palliative Care—It is more than end-of-life

“...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness...” ¹

90% of those individuals who die each year, die after a period of progressive illness due to one or more diagnoses ²

“Once I was out of the hospital, I had to follow-up with my family doctor and she made a half an hour appointment for us to sit down and she talked to us about everything that was going to take place, what to do, how to do it. It was just fabulous. I went in scared, I didn’t know what was going to happen, but I came out of there and I said to my daughter, my god I feel 100% better...she is fabulous.” (Patient)⁴

Where are Mississauga Halton LHIN Patients Dying? ³

56% Hospital
30% Home or Residential Hospice
14% LTCH

Although some deaths are unexpected, many can be predicted. If we were better able to predict people who are in the final year of life, whatever their diagnosis, there is good evidence that they are more likely to receive well-coordinated, high quality palliative care.

What do patients want? ⁵

- Adequate pain and symptom management
- Avoidance of inappropriate prolongation of dying
- A sense of control
- Relief of burden
- Strengthened relationships with loved ones
What is the Palliative Approach to Care?

**Identify**
- Identify if a patient would benefit from a palliative care approach early in their illness trajectory

**Assess**
- Assess the patient/caregivers’ current and future needs

**Plan/Manage**
- Plan and collaborate with partners for ongoing care to address the patient/caregivers’ needs

Through strong relationships with patients, family physicians can play a powerful role in the essentials of palliative care.

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### Step 1: Identify (refer to page 4)

**Ask the Surprise Question**
- Would you be surprised if the patient were to die in the next year?

- **No**

- **Unsure**

- **Yes**

#### General Indicators of Decline?

#### Disease Specific Indicators?

#### Has the patient indicated a preference, decision or need for comfort care?

- **No**

- **Minimal/No**

- **Reassess regularly**

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### Step 2: Assess (refer to page 6)

- **Symptoms**
- **Performance Status**
- **Understanding of patient/family**

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### Step 3: Plan/Manage (refer to page 8)

- **PPS ≥ 70**
- **PPS ≤ 60**

- **Symptom Management**
- **Palliative and End of Life Care Planning/Goals of Care**
- **Refer to Mississauga Halton LHIN Palliative Care Program**

Source: Cancer Care Ontario
STEP 1: IDENTIFY

“Palliative care early is better than palliative care late” – Pallium Canada

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

1. **Surprise Question**
   - “Would you be surprised if the patient were to die in the next year?”

2. **Indication of progressive disease and/or decline**
   - General indicators of decline: deterioration, advanced disease, decreased response to treatment, choice of no further disease modifying treatment
   - Disease specific indicators related to certain conditions

3. **Expressed need for a palliative care approach**
   - Has the patient expressed a preference or need for a palliative care approach?

What is the benefit of early identification?

Compared to standard care, early palliative care resulted in:

- Less depression and anxiety
- Better quality of life
- Less aggressive care at the end of life, but longer survival
What are your opportunities for identification?

- After an acute event or sentinel event
- At the time of general review of the patient’s health status
- If there has been a significant change in the patient’s health status
- If the patient or family are concerned about the patient’s health status

General Indicators of Decline\textsuperscript{7,9}

- Advancing, unstable disease
- Decreasing response to treatments/decreasing reversibility
- No further disease modifying treatments available
- General physical decline/declining functional status
- Multiple co-morbid conditions
- Repeated unplanned hospital admissions
- “Sentinel event”
- Weight loss >10% in 6 months
- Albumin <25 g/L

Disease Specific Indicators\textsuperscript{9}

a. Cancer—rapid or predictable decline
b. Chronic Organ Failure—erratic decline
  ⇒ Lung Disease, Heart Disease, Renal Disease, Liver Disease, Neurological Disease
c. Dementia/Frailty—gradual decline

d. Varying Disease Trajectories\textsuperscript{10}
Consider the expected disease trajectory of your patient when considering if they would benefit from a palliative care approach, and what can this tell us about what to expect for them in the future.

You’ve identified your patient may benefit from palliative care. Now what?
Assessing the patient and family’s current and future needs across all domains of care are essential.

- Disease management
- Physical
- Psychosocial
- Spiritual
- Practical
- Grief/loss
- Goals of care
- End-of-life care

Type and timeliness of assessment will depend on severity, interference with life, urgency and complexity of issues identified.

**Assess Understanding**

- Does the patient and family understand:
  - The nature of his/her illness?
  - The prognosis and what to expect in the future?
  - The potential limits to reversibility?
- Has the patient thought about his/her preferences, values and goals of care if the end of their life were approaching?
- Does the patient know who their Substitute Decision Maker is and have they spoken to them about their wishes?

**Record** advance care planning, goals of care and consent discussions in the medical record. Include the patient’s Substitute Decision Maker and caregivers in these conversations to ensure they too understand the illness, expectations and goals. Revisit these conversations regularly.

**Advance Care Planning Resources**

Speak Up Ontario  
Hospice Palliative Care  
Ontario  
[www.speakupontario.ca](http://www.speakupontario.ca)

**Caregiver Burnout**

90% of care is provided by informal caregivers\(^\text{11}\)—they need support too.
Assess Symptoms

Assess symptoms regularly. Screen for distress and other needs using validated screening tools. It is recommended to complete these tools with every encounter, if possible.

Edmonton Symptom Assessment System (ESAS)  
A reliable and valid assessment tool to screen for the intensity of nine common symptoms experienced by patients. The score guides further focused assessments and symptom management approaches. This is a useful tool to track symptom changes over time, and response to treatment.

Edmonton Symptom Assessment System Revised (ESAS-r)  
Please circle the number that best describes how you feel NOW:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Possible</th>
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<tbody>
<tr>
<td>No Pain</td>
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<td>Pain</td>
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<td>No Tiredness</td>
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<td>Tiredness</td>
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<td>Drowsy</td>
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<td>No Nausea</td>
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<td>Nausea</td>
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<td>No Lack of Appetite</td>
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<td>Lack of Appetite</td>
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<td>No Shortness of Breath</td>
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<td>Shortness</td>
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<td>No Depression</td>
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<td>Depression</td>
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<tr>
<td>No Anxiety</td>
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<td></td>
<td>Anxiety</td>
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<td></td>
<td></td>
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<td>Wellbeing</td>
</tr>
</tbody>
</table>

Other Problem

Assess Performance Status

- What is his/her functional status (PPS)?
- Are their needs being met?
- How well are the caregivers coping?

Palliative Performance Scale (PPS)

A reliable and valid tool to assess and quickly describe a patient’s functional performance, can be used to prognosticate, plan for care and communicate status to other providers. **PPS is only validated as a prognostic tool in cancer patients due to the nature of the cancer disease trajectory (see page 5). In other diagnoses, it is simply a tool to describe functional status change over time.**

PPS, along with prognosis, is often used to help determine if a patient qualifies for certain services. If there is a change in PPS or prognosis, it is important to notify the care team so supports can be adjusted accordingly. To use the PPS tool, navigate from left to right, top to bottom, across the table to find the row that best describes your patient’s function.
## STABLE PHASE (Cancer PPS 70-100%, or otherwise stable in identified trajectory for non-cancer)

- Begin **goals of care** discussions and **end-of-life planning**, including identifying the Substitute Decision Maker, document in the medical record.
- Complete **Do Not Resuscitate Confirmation (DNR-C) Form**, if appropriate.
- Refer to **Mississauga Halton LHIN Palliative Care Program** for community support if prognosis <1 year and needs are unmet, (905) 855-9090. (refer to page 11 for potential supports)
- Assess coping of patient and family, consider **community hospice** referral for support. (refer to page 12 for list of hospices)

## TRANSITIONAL PHASE (Cancer PPS 40-60%, or changing needs in non-cancer trajectory)

**REVISIT** the items above AND...

- Based on goals of care, begin **making plans for end-of-life**, including preferred place of care and document in the medical record.
- Refer to **residential hospice**, if appropriate. (refer to page 12 for list of hospices)
- Complete **Planned Death in Home Form**, if appropriate. Consider completing “just in case” even if primary plan is not home. Discuss in detail what to do when/if death occurs at home. Ensure your 24-hour contact for notification of death at home is on the form.
- Consider ordering a **Symptom Management Kit** if PPS <50 or risk of severe symptoms.
- Refer to **Mississauga Halton LHIN Palliative Care Program** for community support if prognosis <1 year and needs are unmet, 905-855-9090. (refer to page 11 for potential supports)
END-OF-LIFE PHASE (Cancer PPS 10-30%, or end stage of illness for non-cancer trajectories, usually PPS 10-20%)

REVISIT the previous items outlined in the Stable and Transitional Phases AND...

✓ Confirm plans for end-of-life, including preferred place of death, back-up plans—document in the medical record.

✓ Collaborate with your patient’s home care nurses and Mississauga Halton LHIN Palliative Care Coordinator to setup a plan of care and notify relevant community providers, such as hospice, of the change in health status. If the patient is at end of life they may qualify for 24/7 care through the Mississauga Halton LHIN Palliative Care program.

✓ Discuss common end-of-life symptoms (e.g. stop eating/drinking, breathing changes, skin changes, potential for terminal delirium) in advance to help prepare families for the end-of-life process, and how to access help if needed.

✓ Consider that the patient will not likely be able to leave their home in this phase. Ensure provision for possible home visits by prescribing practitioner if complex (see secondary supports if needed).

✓ Consider the patient’s ability to take oral medication. When nearing end-of-life, discontinue non-essential medication. Anticipate transition to parenteral (subcutaneous) comfort medications as swallowing becomes difficult. In addition, consider ordering a subcutaneous pain pump to replace routine oral pain medication. Need help making the conversions? In the Mississauga Halton LHIN region, Bayshore pharmacists can help: 1-888-313-6988.

✓ If not hypoxic, but feeling short of breath, consider using bedside fan or cool cloth on face or pharmacologic management (opiates) to reduce sensation of dyspnea.

BEREAVEMENT SUPPORT PHASE

✓ Discuss bereavement supports with patient’s support system; family, friends and caregivers. Take steps to identify those at risk for complicated grief ahead of patient’s death, connect them proactively with community hospice supports. (refer to page 12 for list of hospices)

✓ Discuss local bereavement supports tailored to children, if needed.

✓ Consider a supportive follow-up visit with the primary caregiver a few weeks after death to reflect and offer support.

Symptom Management Tools

Cancer Care Ontario Symptom Management Guide— www.cancercareontario.ca
Pallium Canada Palliative Pocketbook— www.pallium.ca
BC Centre for Palliative Care—Inter-professional Palliative Symptom Management Guidelines— www.bc-cpc.ca/cpc/

You are not alone—the Mississauga Halton LHIN Palliative Program and community nurses will support you in caring for your patient.
When to refer to a Specialist and/or Secondary Level Supports

Consider if complexity is present:

- Moderate to severe symptoms that have not come under control despite best efforts to manage
- Symptoms that require secondary/tertiary interventions – ascites, pleural effusions, malignant bowel obstruction, etc.
- Ongoing barriers to appropriate decision-making, particularly with rapidly progressive illnesses
- Psychological distress that persists despite best efforts to manage

If patient/family needs meet complexity criteria or if you feel unable to meet their needs, consider a referral to your local palliative care specialists for support through consultation, shared/collaborative care, or direct care.

Phone a Friend” - 24/7 Support

Palliative Care Specialist telephone support is available in the Mississauga Halton LHIN region to primary care physicians.

Dorothy Ley Hospice Physician Group 416.620.7667
Credit Valley Palliative Physician Group 905.813.4466
Oakville Palliative Physician Group 905.483.0635
(Ask for the Palliative Physician On Call)
Mississauga Halton LHIN Palliative Care Program—905.855.9090
The Mississauga Halton LHIN Palliative Care Program provides ministry funded palliative care services at home for patients with palliative care needs. The program helps ensure patients have access to the services they need to remain at home safely as long as they wish and to support them in dying in their place of choice. With a specialized team of Palliative Care Coordinators, the program coordinates the services of palliative care nurse practitioners, community nurses who are accessible 24/7, personal support workers, occupational and physio therapists, social workers, hospice services and many more. In addition, medical equipment, such as a hospital bed, may be provided. If a patient wishes to die at home, 24/7 support can be put into place to support their wishes in their last 30 days of life.

Mississauga Halton LHIN Palliative Care Nurse Practitioners—905.855.9090
The Mississauga Halton LHIN Palliative Care Nurse Practitioners are available to engage in shared care with primary care physicians. Their responsibilities include, but are not limited to, pain and symptom management, goals of care discussions, supporting health care professionals in the community, prescribing medications, Medical Assistance in Dying (MAID) assessments and general education, and capacity building. They complete home visits and provide direct nursing services to support complex patients with palliative needs and their families. They also provide rapid/crisis response, and are available Monday to Friday 9am-9pm.

Palliative Pain and Symptom Management Consultants—905.827.8111
The Palliative Pain and Symptom Management Consultants at Acclaim Health are LHIN funded to support clinicians in multiple care settings, including Long Term Care. They are available to provide consultation, linkages to other specialized hospice palliative care resources, education and mentoring to service providers including physicians. They do not provide direct patient care.

e-Consults
Local palliative care teams are available for consults via OTN e-Consult and Champlain BASE e-Consult platforms.

Outpatient Clinics
Credit Valley Hospital and Queensway Health Centre
Oncology Palliative Care Clinic
Tel: 905.813.1100 x 5143  Fax: 905.813.4024

Dorothy Ley Hospice Ambulatory Clinic
Tel: 416.626.2138  Fax: 647.689.5880

Oakville Trafalgar Memorial Hospital
Oncology Palliative Care Clinic
Tel: 905.845.2571 x 4659  Fax: 905.338.4114
Non-Oncology Palliative Care Clinic
Tel: 905.845.2571 x 4659  Fax: 905.815.5109

Community Home Visiting Teams
Oakville Palliative Care Team
Dr. Lynne Benjamin, Tel: 905.483.0635  Fax: 905.815.0529
Dr. Glenn Surbey, Tel: 905.847.1851  Fax: 905.847.9782
Dr. Yasmine Hussain, Tel: 905.845.1659  Fax: 905.844.5537

Georgetown/Acton
Dr. Paul Zeni, Tel: 905.873.3013  Fax: 905.873.3018

Dorothy Ley Community Physicians Team
(Mississauga—east of Hurontario, Etobicoke/West Toronto)
Tel: 416.626.2138  Fax: 647.689.5880

Trillium Health Partners Palliative Care Program
(Mississauga—west of Hurontario)
Tel: 905.813.1100 x 5143 Fax 905.813.4024
Useful Resources

General Information & Clinical Tools

- Mississauga Halton Palliative Care Network: [www.mhpcn.net](http://www.mhpcn.net)
- Ontario Palliative Care Network: [www.ontariopalliativecarenetwork.ca](http://www.ontariopalliativecarenetwork.ca)
- Mississauga Halton Local Health Integration Network: [www.mississaugahaltonlhin.on.ca](http://www.mississaugahaltonlhin.on.ca)
- Mississauga Halton Central West Regional Cancer Program: [www.mhcwcancer.ca](http://www.mhcwcancer.ca)
- Canadian Hospice Palliative Care Association: [www.chpca.net](http://www.chpca.net)
- Hospice Palliative Care Ontario: [www.hpco.ca](http://www.hpco.ca)
- Virtual Hospice: [www.virtualhospice.ca](http://www.virtualhospice.ca)

Residential Hospices are home-like environments where adults and children with life-threatening illnesses receive end-of-life, compassionate care and comfort in the last stages of their life.

Dorothy Ley Hospice, Etobicoke
[www.dlhospice.org](http://www.dlhospice.org)

Carpenter House, Burlington
[www.thecarpenterhospice.com](http://www.thecarpenterhospice.com)

Ian Anderson House, Oakville
[www.ianandersonhouse.com](http://www.ianandersonhouse.com)

Bethell Hospice, Inglewood
[bethellhospice.org](http://bethellhospice.org)

The Darling Home for Kids
[www.darlinghomeforkids.ca](http://www.darlinghomeforkids.ca)

Community Hospices provide in hospice and/or at home end-of-life emotional, spiritual and bereavement support to adults, children and their caregivers.

Dorothy Ley Hospice
[www.dlhospice.org](http://www.dlhospice.org)

Heart House Hospice
[www.hearthousehospice.com](http://www.hearthousehospice.com)

Acclaim Health
[www.acclaimhealth.ca](http://www.acclaimhealth.ca)

Bereavement Support (in addition to the hospices listed above)

Lighthouse for Grieving Children
[www.grievingchildrenlighthouse.org](http://www.grievingchildrenlighthouse.org)

Bereaved Families of Ontario
[www.bereavedfamilies.ca](http://www.bereavedfamilies.ca)
Palliative care is a special kind of health care for individuals and families who are living with a life-limiting illness. The goal is to provide comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family.  

**Useful Resources**

**Advance Care Planning**
- Speak Up Ontario: [www.speakupontario.ca](http://www.speakupontario.ca)

**Education**
LEAP (Learning Essential Approaches to Palliative and End-of-Life Care) is a two day course aimed to provide healthcare providers the basic elements of palliative care. The program utilizes multiple approaches including small group case-based studies, video-triggered discussion, didactic sessions and pre and post course surveys. Courses are offered regularly in the Mississauga Halton region. To find out more information visit Pallium Canada’s site at [www.pallium.ca](http://www.pallium.ca) or contact Leah Clarke at 905.855.9090 ext. 2725 or [leah.clarke@lhins.on.ca](mailto:leah.clarke@lhins.on.ca)

**Other**
- Ontario Medical Association [www.learn.oma.org](http://www.learn.oma.org) (OHIP Payments for Palliative Care Services - Quick Reference Guide)
- **Medical Certificate of Death**: Per the *Vital Statistic Act*, ensure the Medical Certificate of Death - Form 16 you are using is an original, current version (not a copy) of the prescribed form supplied by the Office of the Registrar General. To obtain a current version of this form, call your local Division Registrar's Office (City Hall), fax a written request to 1.807.343.7459 or call 1.807.343.7458 for more information.
- To obtain a supply of the **Do Not Resuscitate (DNR) Confirmation Form**, send your request to the Ministry of Health and Long-Term Care Forms Warehouse by fax to 416.679.8192.Requests should be submitted on official letterhead of the health care provider / institution and will be provided at no cost. Note: Each form contains a unique 7-digit serial number.
  - Form Number: 4519-45 (08/01)    Catalogue Number: 7530-5678
References

2. LEAP Core Courseware Version 3.0, Pallium Canada, 2018
3. 2016/17 System Level Measures Report, Ontario Palliative Care Network, 2018
4. New Ambulatory Models of Care (NAMOC) Patient/Family Experience Interviews. Quality Improvement Project at Trillium Health Partners Oncology Program in partnership with the Division of Palliative Care and the Mississauga Halton Central West Regional Cancer Program. 2017
12. Edmonton Symptom Assessment System Revised (ESAS-R), Alberta Health Services, 2015
13. Palliative Performance Scale (PPSv2) version 2, Victoria Hospice, 2001
15. What is Palliative Care?, Hospice Palliative Care Ontario, https://www.hpco.ca/who-we-are/about-hospice-palliative-care/

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