



Central Hospice  
Palliative Care  
Network

# Improving Transitions in Palliative Care

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## **EXECUTIVE SUMMARY**

A major priority for the Central LHIN is to improve system coordination to reduce Emergency Room Wait times and to reduce the percentage of Alternate Level of Care patients (ER/ALC strategy). Improvements across the system are necessary to ensure people receive prompt emergency care and that appropriate alternatives to hospital care exist in the community. Improving transitions in palliative care will enhance patient care and help support the Central LHIN's priority.

To this end, the goals of this initiative are to provide an understanding of challenges and opportunities in accessing hospice palliative care services and to identify improvements that can be made to support better transitions across care settings. Through a scenario planning exercise using quality improvement principles, the Central Hospice Palliative Care Network (CHPCN) has suggested the following improvements to be implemented during the 2011/12 fiscal year:

1. Conduct a chart review to gain an increased understanding of key issues in transitions in care, including hospital, long term care and CCAC records.
2. Develop a simple, standardized discharge checklist for all hospital partners to adopt to streamline discharge planning for palliative patients
3. Expand current Record of Care binder initiative across the LHIN
4. Expand use of Cancer Care Ontario Symptom Management Guidelines to provide individuals/caregivers with greater awareness for managing pain and symptoms and to provide a greater skill level for providers across the continuum of care
5. Expand existing resource directory on CHPCN website
6. Develop a communications/education strategy for greater awareness of palliative care resources in the Central LHIN
7. Develop a public awareness campaign to increase visibility of community-based palliative resources
8. Develop an integrated model of spiritual care to better support and prepare palliative individuals throughout the continuum of care

In addition, the CHPCN identified a number of key performance indicators to measure the improvements. To start, the CHPCN must agree on a set of key indicators to develop, gather data and establish a baseline before setting targets that align with the LHIN's ER/ALC strategy.

The scenario planning exercise helped the CHPCN articulate a number of overall goals in developing a clear network mandate moving forward. Overall goals include:

- Consistent access to timely, comprehensive support for palliative patients to have a comfortable death in the setting of their choice, with an emphasis on improving the home death experience for those who prefer it.
- Provide the necessary supports for patients transitioning home from hospital including anticipation and education, and plans to respond to and prevent events and crises that may lead to re-admission.

- Increase the awareness of community palliative resources among formal and informal caregivers, patients and families.

With these goals and a proposed set of improvements to implement, the CHPCN can continue to build on its past successes and move towards improving transitions for palliative care while supporting the LHIN's ER/ALC strategy.

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# 1.0 Background

## What is hospice palliative care?

Hospice palliative care holds a crucial role within the healthcare sector. It offers compassionate and inclusive care, supporting individuals and their families through difficult disease states and conditions. Rather than aggressive, curative treatments intended to prolong life, hospice palliative care focuses on providing supportive, comfort-based care, aiming to minimize pain and symptoms and maximize the quality of life, regardless of the specific prognosis.

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>1</sup> As highlighted in the WHO definition, palliative care can be included in the overall care plan at an earlier stage and is not just for ‘end-of-life’ or the last few remaining days/weeks of the person’s life.

## The Central Hospice Palliative Care Network<sup>2</sup>

The Central Hospice Palliative Care Network (CHPCN) was founded in 2007 to oversee the transition of a number of pre-existing palliative and end-of-life networks into a single network for the region. The CHPCN is an association of professionals and organizations in the Central LHIN region that provide and support hospice palliative care for clients dealing with a progressive life-threatening illness. The CHPCN seeks to improve quality, efficiency, choice, and access to care for persons with a progressive life-threatening illness through timely response to changing patient needs and conditions throughout the continuum of care. Spanning a large geographical region from mid-town Toronto to north Simcoe, network stakeholders including physicians, nurses, social workers, spiritual care providers, communication specialists, hospices, hospitals, long term care homes and others. The network’s role within the healthcare system includes:

- Broad system design for end-of-life care
- Coordination and integration of services at a system level
- Assessment and monitoring of community needs
- Promotion of service innovations
- Creation of strategic alliances between community agencies, hospitals, long-term care homes, and other stakeholders working to improve hospice palliative care
- Liaison with the LHIN

The CHPCN’s strategic goals<sup>3</sup> are:

- Planning and Monitoring
- Coordination and Integration
- Knowledge exchange

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<sup>1</sup> World Health Organization: <http://www.who.int/cancer/palliative/definition/en/>

<sup>2</sup> <http://centralhpcnetwork.ca/index.html>

<sup>3</sup> CHPCN Strategic Plan 2010

- Advice and Direction
- Network development

### Hospice and Palliative Care Providers and Services in the Central LHIN

CHPCN members cover a broad spectrum of services across the continuum of care at all specialized levels of care. There are over 30 hospice and palliative care providers and networks that are funded by the Central LHIN. Each of the various organizations offers a multitude of palliative care services. The table below outlines a select number of service categories and highlights hospice organizations. The list is not an exclusive list. In addition, long-term care facilities, complex continuing care units, a range of community support service agencies and volunteer organizations provide the necessary wrap-around services to meet needs of patients and caregivers<sup>4</sup>. The number of organizations represents both the diversity and complexity of the palliative care sector.

**Table 1: CHPCN Service Inventory**

Networks	Central LHIN Funded Programs	MOHLTC Funded Programs	Visiting Hospices	Residential Hospices	Hospital Palliative Care Units	Physician Groups	CCAC
1. Hospice Palliative Care Network (HPCN)	4. HPC Teams 5. Care to Imagine	6. Palliative Pain & Symptom Management	8. Alliance Hospice 9. Circle of Care	20. Hill House Hospice 21. York Region Hospice ( <i>under consideration</i> )	22. Markham Stouffville Hospital 23. North York General Hospital	26. Freeman Centre for Palliative Care 27. Temmy Latner Centre for Palliative Care	29. Central CCAC and contracted service providers
2. PalCare		7. Community & Facility Palliative Care Interdisciplinary Education	10. Doane House Hospice 11. Evergreen Hospice		24. Southlake Regional Health Centre 25. York Central Hospital	28. PalCare Physician Network for York-South Simcoe	
3. Cancer Care Ontario Palliative Care Program			12. Hazel Burns Hospice 13. Hospice Georgina 14. Hospice King-Aurora 15. Hospice Richmond Hill 16. Hospice Thornhill 17. Hospice Vaughan 18. Jewish Hospice Program 19. Matthews House Hospice				

## Setting the Context

A major priority of the Central LHIN is to improve system coordination to reduce Emergency Department Wait times and to reduce the percentage of Alternate Level of Care patients. Improvements across the system are necessary to ensure people receive prompt emergency care and that appropriate alternatives to hospital care exist in the community. Optimal patient flow through the system requires that appropriate care be provided in the appropriate setting to maximize system capacity and efficiency. Investments made in non-acute sectors have helped to increase the flow across the system; however other patient populations, such as resource intensive palliative patients, continue to experience challenges that restrict optimal flow.

Palliative care is not just an acute care issue, but also a system issue that involves coordinating resources across multiple non-acute care settings, including the patient's home. Despite the availability of non-acute resources, palliative patients and caregivers more often than not continue to choose acute settings to die versus alternative settings. While certain patient conditions may warrant a visit to an acute setting, patients designated as palliative while in the hospital should be given the opportunity to be discharged home with their family with the confidence that community palliative care resources can provide the necessary support.

In the Central LHIN, an initial analysis of discharge disposition shows that of the 647 patients designated as palliative at the time of discharge in 2008/09, 72% of patients died in acute settings while only 10.5% were discharged home. Of the 10.5% discharged home, 59% went home with no supports<sup>5</sup>. These statistics may indicate one of two (or both) observations:

1. Patients that died in hospital were in the appropriate setting based on their acute situation/preference or;
2. The statistics show a trend where a proportion of patients come to die in hospital that could have died at home.

The lack of available data makes it difficult to determine the true root cause(s) for these statistics and to accurately confirm one or both observations. Regardless of the observations, the literature<sup>6</sup> has pointed to many factors that contribute to the inappropriate heavy use of acute resources by palliative patients that are applicable to the Central LHIN experience:

- Improper coding of palliative patient in the hospital
- Death at home is not explored as an alternative setting for discharge disposition. This may be due in part to the lack of awareness of resources in the community.
- No Advanced Care Planning completed, or the inability for hospital staff to view the plan if the plan was completed in the community to convey the patient's wishes and preferences.
- Communication challenges between acute, primary care and community health care providers.
- Intervention at home by community resources not timely enough due to access and capacity issues

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<sup>5</sup> CIHI Discharge Abstract Database data from Central LHIN: An Overview of Hospice Palliative Care Services in the Central LHIN

<sup>6</sup> Common themes from other Hospice Palliative reports: Central East, Waterloo-Wellington, Erie-St. Clair and Mississauga Halton LHINs.

- Anxiety and inability of families to cope with a death at home, believing an acute setting is the only place for their loved one to die
- Ethno-cultural specific behaviours and perceptions regarding death and dying at home
- Limited number of family physicians who conduct home visits and initiate a care plan

The challenge is clear:

***How can the Central Hospice Palliative Care Network better support patients and caregivers with palliative care needs in their own home (including patient's home or a LTC home, retirement home, group home etc.) to support the Central LHIN's ER/ALC priority?***

To address this challenge the CHPCN initiated an environmental scan guided by palliative care scenarios, with the following objectives in mind:

- To gain a better understanding of the current continuum of care in hospice palliative care
- To provide an understanding of challenges and opportunities in accessing hospice palliative care services
- To quantify current impact of palliative patients on ED wait times and ALC metrics
- To identify opportunities for collaboration and system integration
- To identify existing palliative care performance measures and outcome indicators

### **Approach**

A quality improvement framework approach was taken to determine the key action items for the CHPCN to pursue for the 2011/12 fiscal year and beyond. Key activities of the approach included:

- Literature review of existing hospice palliative care network environmental scans
- Individual stakeholder interviews
- Engagement with external stakeholders
- Engagement with the cross-sectoral members of the CHPCN on a limited basis over a 2 month period from February through March 2011

It is important to note that there were limitations to the approach taken for this study. Specifically:

- Limited time to formally engage with all sectors part of the CHPCN
- Lack of data available to develop a population-based model, despite best efforts to obtain aggregated CIHI Discharge Abstract Database data.
- Regrouping of the CHPCN during the initial scoping of the initiative
- Presence of existing Central LHIN documentation already providing an overview of hospice palliative care services

## **2.0 Scenario Planning Using a Quality Improvement Framework**

Optimizing palliative care and patient flow through the system requires change that leads to sustainable improvement in system processes and patient outcomes. The Model for Improvement and adaptation of the Institute for Health Information (IHI) Learning Model using a

four pronged quality improvement model articulates the basis for the proposed palliative care scenarios:

- What are we trying to accomplish?
- What changes can we make that will result in an improvement?
- How will we know when a change is an improvement?
- What will we measure to show improvement?

Scenario planning adopts a systems view of the patient journey to identify key areas of strength, gaps and opportunities. The approach allows for a shared multi-sectoral understanding on how palliative care is provided across transitions in care, which interacts with the patient/caregiver and what information is conveyed at these transition points. Four key scenarios articulate changes to improve transitions in palliative care:

1. Patient discharged home from hospital
2. Routine care at home
3. Patient transitions from home to hospital (triggered by a crisis or medical event)
4. End of life care and bereavement

A detailed description of the scenario planning discussion and findings is presented below.

## **Scenario #1: Patient Discharged Home from Hospital**

**a) What are we trying to accomplish?** The objective is to better facilitate discharge planning from hospital to home.

**b) Scenario Description:** A new or recurring patient is discharged from a hospital inpatient unit or emergency department to an alternate care setting (including home, hospice, LTC, complex continuing care). This scenario begins when the palliative patient is identified and ends when the patient transitions to the alternate care setting.

### **c) Central LHIN Environment Scan**

Studies have shown that remaining in hospital longer than medically necessary can be detrimental to patients' health.<sup>7</sup> Waiting in hospital for a bed to be available is much more expensive than community-based care alternatives, particularly for palliative patients who are typically resource intensive. Many of the Central LHIN hospitals in the region have an inter-professional approach to discharge planning. Initiatives such as the CCAC In-Reach initiative also bridge the acute and community sectors.

**Challenges:** There are a number of challenges commonly expressed by stakeholders across the Central LHIN region:

#### **i) Patient identification and tracking**

- Palliative patients are often not coded properly over the course of their hospital stay.
- The definition of palliative impacts coding; some hospital staff only identify end-of-life patients as palliative.

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<sup>7</sup> Williams, P et al "Balancing Institutional and Community-Based Care: Why Some Older Persons Can Age Successfully at Home While Others Require Residential Long-Term Care", Longwoods Review Vol 7, No1, 2009.

- It is difficult to count the number of palliative beds as they are often not designated as palliative within the hospital, or are distributed across multiple inpatient units or part of other designated beds e.g. complex continuing care.
- Designation of palliative patients is limited for non-malignant conditions such as end stage cardiac, neuromuscular, renal and respiratory diseases. There is a general misconception that only cancer patients are palliative.
- Palliative designation may also vary according to the presence of palliative expertise and the degree of comfort by the hospital care team.

## **ii) Communication**

- Varying level of understanding and philosophies around the definition of palliative.
- Timing of when care should be initiated in the community (earlier identification for when palliative care should be initiated).
- Lack of communication across providers and sectors. For example, a patient's primary physician may be unaware that the patient was admitted to hospital or proper documentation is missing and not provided to community nurses.
- Lack of sufficient information, particularly a palliative designation from hospitals outside the LHIN referring palliative patients back to the Central LHIN.
- Care plan or physician's orders do not follow patient home.

## **iii) Awareness of services and palliative care**

- Hospital staff, patients and caregivers may not be fully aware of all the community resources available. They may not know how to access community services or have limited knowledge regarding eligibility criteria for these services.
- Patients and caregivers may not be aware of end-of-life symptoms and how to manage them.
- Family physicians are unwilling to take patients due to lack of knowledge or comfort.
- Families, retirement homes and/or long-term care facilities may not be comfortable or not knowledgeable enough to care for palliative patients.

## **d) Opportunities for Improvement**

To address the above challenges, there are a number of opportunities for improvement including:

- Harmonize and re-emphasize an inclusive definition of 'palliative patient' and 'palliative care' so that identification and coding practices improve.
- Regional consensus around standardized practices and procedures for identifying palliative patients.
- Develop capacity in front-line nurses and discharge teams in non-palliative hospital settings to better recognize palliative needs, referral practices and the need for advance notification regarding certain care requirements in the community.
- Engage family physicians, community physicians, and physicians in other hospital departments in education and training regarding palliative care management best practices, resources, referral practices and conversation skills regarding advance care planning.

## **e) What changes can we make that will result in an improvement?**

A number of simple initiatives were identified for future consideration and implementation, including:

- Chart Review (including detailed analysis of discharge planning process)
- Discharge Checklist to support palliative and non-palliative units and promote use of common referral process
- Conduct a public awareness campaign by expanding and revising current inventory/directory of palliative resources
- Develop policies and procedures for tracking palliative patients, including discharge destinations
- Develop target metrics in collaboration with decision support teams (across hospitals and CCAC)
- Expand CCAC 'In-reach' pilot to other hospital sites

**f) How will we know when a change is an improvement?**

- Reduction in palliative care deaths in hospitals
- Increased referrals to community sector, potentially impacting ALC targets
- Reduction in ED visits by palliative patients
- Standardization in discharge planning across the region
- Fewer delays in set-up of community supports post-discharge

**g) Key Performance Indicators for Consideration**

- Total # of hospital palliative patients
- Average Length of Stay of patients designated as palliative
- Average Length of Stay of patients designated as palliative and discharged from hospital
- # of admitted palliative patients coded as deceased in hospital
- # of admitted palliative patients discharged home or to other location
- % of ALC patients who are palliative

## **Scenario #2: Routine Care at Home**

**a) What are we trying to accomplish?** To have the necessary supports in the community, reducing the need for acute care visits.

**b) Scenario Description:** This scenario involves a palliative client that has a stable condition and is receiving routine care in a community setting. This scenario begins when services at home will be implemented or have been arranged, and ends when there is a change in symptoms or functional status or when a family member/caregiver is unable to cope.

**c) Central LHIN Environment Scan**

There are a number of structures and strategies already in place to ensure high quality palliative care in the community:

- Hospice Palliative Care (HPC) teams is a valuable resource in the community. Referrals through the HPC teams can be made directly without requiring sign-off from the CCAC or

a physician. HPC teams are also currently engaged in an initiative to educate LTC professionals regarding available supports and consult structures.

- CCAC Palliative Care Teams have existing standards to communicate and notify primary care physicians of any specialist referrals made. Expected Death in the Home (EDITH) protocols are also used across the sector to support any advance care planning conversations.
- CCAC offers a medication management program, essential for palliative patients who are often taking multiple medications.
- A 'Record of Care Binder', including communication algorithms, is available for placement in the home.
- A nurse-led geriatric team is newly available as part of a 'Train-the-trainer' program being initiated in long-term care facilities in an attempt to reduce hospital admissions.
- A hospice initiative currently underway has some volunteers regularly reporting Edmonton Symptom Assessment Symptom (ESAS) statistics to the primary care team in an attempt to better track disease status.

**Challenges:** Even though there are quite a few initiatives underway to support routine care in the community for palliative individuals, there are a number of challenges that continue to impact care teams, patients and caregivers:

- Difficulty in deciphering 'who is in charge' or who is the primary point of contact from the client perspective when the client is at home.
- Many 'orphan patients' who do not have a family physician to provide ongoing monitoring of the care plan.
- Level of engagement from physicians varies greatly and most family physicians will not do home visits.
- Varying skill levels in managing patients/clients with palliative needs (e.g. PSWs lacking palliative skills and are offered minimal training, LTC staff lacking palliative knowledge and appropriate palliative mentorship).
- Varying comfort levels in talking about palliative care and planning ahead. This often leads to conversations occurring too late or confusion/disagreement around philosophies and goals of care with the patient/caregiver and/or within the care team.
- No shared record of client/patient information for all professionals involved in the person's care. For those who have exposure to the record of care binder, there is some confusion around how and when it is being used or should be used.
- Some professionals and caregivers feel as though their voices are not heard and they experience burnout.
- No formal spiritual care exists in the home setting.

#### **d) Opportunities for Improvements**

Potential improvements discussed by the stakeholder group focused on increasing mentorship and education/training opportunities for all professionals, as well as investigation into the development of a central system for viewing patient information. A complete list of potential areas for improvement is as follows:

- Update and promote use of the 'Record of Care Binder'.

- Consider an electronic portal for sharing patient information and communicating with other providers.
- Develop training opportunities for a number of professionals including: PSWs, front-line nurses, physicians, with an emphasis on improving palliative care management skills for doctors and nurses as well as comfort levels and conversation skills around advance care planning.
- Increase mentorship opportunities for doctors and nurses (perhaps tapping into existing HPC mentorship initiatives).
- Develop specific tools that will support professionals in caring for palliative patients.

**e) What changes can we make that will result in an improvement?**

- Updated 'Record of Care Binder' or similar process
- Public Awareness Campaign to promote resources available
- Broad Communications Strategy with key service providers
- Problem Identification Tool (for use in the community, perhaps used by PSWs as well) for identifying changes/problems according to major domains (in alignment with or similar to ESAS domains)
- Build on HPC teams to incorporate a program in LTC similar to Central East NP STAT services
- Expand on existing medication management program or promote/expand CCO symptom management tools/best practices/guidelines
- Patient and family satisfaction survey
- Develop a model for integrated provision of spiritual care

**f) How will we know when a change is an improvement?**

- Standardized documentation in the home
- Increased communication across professionals, care teams, sectors
- Higher level of preparedness during times of crisis for both professionals, clients and families
- Greater awareness of palliative care services, referral procedures for clients/patients
- Accurate coding practices
- Standardization in managing pain and symptoms for palliative individuals
- Greater awareness, skill level and comfort across providers regarding pain and symptom management
- Minimization of crisis states and unnecessary hospital admissions

**g) Key Performance Indicators for Consideration**

- # of palliative clients with Central CCAC
- # of days palliative clients are on Central CCAC caseload
- # patients coded palliative when admitted or discharged from acute care hospitals
- # of visits by HPC teams
- # of clients served by HPC teams
- # Records of Care in use
- # of referrals to Palliative care services
- # OHIP telephone consultation fees billed by palliative physicians

- # consultations provided by HPC Teams Clinical Nurse Consultants
- # Symptom relief Kits dispensed by regional pharmacies
- #CCAC Code 95 patients admitted to hospital
- # CCAC Code 95 patients sent to ER
- Reduced hospitalizations and increased appropriate home deaths

## Scenario #3: Patient Transitions from Home to Hospital

**a) a) What are we trying to accomplish?** To ensure appropriate transitions from home to hospital occur smoothly.

**b) Scenario Description:** This scenario involves a new or recurring patient from home or an alternate care setting being admitted to a hospital inpatient unit or the emergency department. This scenario begins when there is an increase or change in symptoms/disease status/functional status or when the family/caregiver is unable to cope, and ends when the patient has been transitioned to the hospital.

### c) Central LHIN Environment Scan

The CHPCN uses a number of key elements in the community to support patients should they transition to hospital:

- Hospice Palliative Care Teams which are available for consultation in the community and hospital.
- Symptom management kits which are utilized by community nurses in managing pain and symptoms.
- CCAC Case Managers may be notified of patient transitions and notifies the appropriate providers.
- Known patients can be directly admitted to the palliative unit facilitating the transition from home to hospital.

**Challenges:** Although there are basic supports in place to support palliative individuals in their desired care setting, hospital admissions still occur on both on a necessary and unnecessary basis. There are still instances where there is a lack of communication and/or available resources to mitigate a crisis event, and the crisis event causes the family/caregiver to panic, which results in hospital admissions and ER visits. Some of the specific issues identified include the following:

- Minimal review and revisiting of previous assessments to mitigate potential problems and reduce medical issues.
- Patients and families often not aware of options for times of crisis or progressive disease states (not clear who to call or when).
- Confusion around drug history is common at the time of hospital admission (knowing what was prescribed, when, etc.).
- ER is often unaware that the patient is palliative when the patient presents with a specific acute issue even when the patient has been previously admitted as the patient may not have been coded correctly at that time either.
- Very rarely can palliative patients be admitted to a palliative care unit directly.

- Transportation to the hospital has been an issue in rural areas of the Central LHIN.

#### **d) Opportunities for Improvement**

A number of potential improvements were raised, with a focus on process-related improvements and education initiatives:

- Process change to allow for automatic referrals from the community to pain and symptom management in the community for palliative designated patients in order to better control pain related issues and reduce potential future readmission to the ER/inpatient units.
- Incorporation of documentation and communication roles, as part of advance care planning protocols sent to palliative care/inpatient units for those patients who do NOT wish to die at home so that appropriate planning can occur for an in-hospital death.
- Education to patients and families regarding care options, dealing with each stage of the disease trajectory.
- Improve coding and education regarding palliative coding practices across multiple hospital departments.
- Improve availability of palliative crisis support in the community.
- Expand existing resource directory on CHPCN's website

#### **e) What changes can we make that will result in an improvement?**

Many of the initiatives outlined in previous scenarios were identified as appropriate for this scenario as well (e.g. awareness campaign, education and training regarding palliative care management skills for professionals). The following list includes additional initiatives identified through this scenario specifically:

- Develop a 'trigger' or 'flag' at the ED for any palliative patient that is being re-admitted so that they may be appropriately recognized
- Develop a 'trigger' or 'flag' to track palliative patients as they transition between care settings (collaboration required from both hospitals, CCAC and LTC)
- Form additional teams of providers dedicated to dealing with crisis situations in the community (this could build from existing HPC teams and include spiritual care)
- Develop an education program around advance care planning processes, techniques and best practices
- Develop/revise advance care planning practices, processes and documentation to communicate planned in-home deaths versus planned in-hospital deaths, incorporating an integrated model of spiritual care

#### **f) How will we know when a change is an improvement?**

- Reduced ED visits by palliative care patients
- Increased communication across professionals, care teams, sectors
- Accurate coding practices at admission/re-admission
- Greater awareness of palliative care services, referral procedures among clients/patients
- Greater awareness, skill level and comfort among providers re: palliative cases

#### **g) Key Performance Indicators for Consideration**

- # of CCAC Code 95 clients who are admitted to hospital
- # of CCAC Code 95 clients sent to ER
- # CCAC Code 95 patients discharged from ER
- # Patients admitted directly from home to Palliative Care Beds electively for planned End of Life care in hospital.
- Increased at-home deaths
- # of LTC residents readmitted back into hospital

## Scenario #4: End-of-Life and Bereavement

**a) What are we trying to accomplish?** To provide adequate care and support in the palliative care setting of choice during end-of-life, and support families and caregivers through dying and grieving post-death.

**b) Scenario Description:** This scenario involves a patient that has a Palliative Performance Scale (PPS) score of less than 30% or is essentially in end-of-life stages and who is expected to die or has just recently died. The scope of this scenario includes the time leading up to the final days/weeks, the time of death (in any care setting) and the time post-death.

### **c) Central LHIN Environment Scan**

Within the end-of-life and bereavement phase of palliative care there is no consistent approach to the provision of basic grief, bereavement care and spiritual care, or to the identification of risk factors for complicated grief that is widely understood and used.

**Challenges:** Unique to this particular patient scenario, there are a number of challenges that arise towards the end-of-life (EOL) and post death stages of palliative care. Through group discussion, the following challenges were raised as an ongoing concern for EOL and bereavement:

- Awareness regarding early conversations around spiritual care, expectations regarding post-death for the family.
- Level of knowledge and comfort around what to expect with at-home deaths. Family anxiety can too often lead to panic, contact with ER/EMS and even the police.
- Nurse burnout, especially at EOL where the nurse does everything possible, even occasionally giving out a personal cell phone number.
- General burnout of all stakeholders.
- General difficulty in ensuring the care team is updated regularly with all status changes. Too often, the physician or another member of the care team is unaware that a patient has died.
- Inconsistencies around privacy of information and consent to share.
- Existing tools for communicating with patients/clients regarding EOL vary according to the specific diseases/conditions and are not standardized.
- Limited understanding, from the perspective of other professionals in the sector, of CCAC protocols in following up with client families.
- Difficulty for family members/spouses in accessing Canadian Pension Plan funds before patient dies (can take up to 6 months).

#### **d) Opportunities for Improvement**

There were a number of potential areas of improvement discussed that address the unique challenges associated with EOL and bereavement. The key areas of improvement that were suggested include:

- Educate and broaden advance care planning practices to encourage earlier conversation specifically around finances, CPP issues, spiritual care and family bereavement.
- Education and engagement of multiple stakeholders to improve their understanding around CCAC bereavement protocols.
- Increase supports or availability of specialty consultation in off-hours.
- Educate and expand palliative knowledge-base of other professionals involved in the patient's care.
- Potential opportunity to align and collaborate with the new Integrated Client Care Project (ICCP), an initiative being rolled out across Ontario that has a specific focus regarding palliative care.

#### **e) What changes can we make that will result in an improvement?**

Along with the improvements outlined above, there were specific improvements suggested to enhance the EOL and Bereavement phases of palliative care:

- EOL and Bereavement Checklist
- Tool for identifying and referring clients/families for complicated grief support
- Communication Protocols (possibly to be captured in record of care binder or common database if developed)
- Common Database/portal that houses/documents patient and client status updates
- Integrated model of spiritual care
- Review of complicated grief patient scenarios to better understand gaps and opportunities and guide targeted solutions
- Advance Care Planning Improvement Strategy
- Published resource for clients and families around planned at-home deaths
- Standardized Best Practice Tool/Guide for nurses in communicating regarding EOL
- Crisis Information Line for palliative support

#### **f) How will we know when a change is an improvement?**

- Increased and earlier support through EOL stages (i.e. not just the last days of life)
- Earlier conversations re: ACP and patient wishes
- Greater awareness regarding bereavement supports
- Earlier identification of potential complicated grief cases
- Standardization re: model and continuum for EOL, bereavement and spiritual phases of palliative care

#### **g) Key Performance Indicators for Consideration**

- Caregiver / family satisfaction survey, 3-6 months post-death
- # of home deaths
- Fewer hospital admissions during end-of-life

### 3.0 Performance Indicators

Emergency room visits and Alternate Level of Care (ALC) designated patients continue to overwhelm hospitals and remain one of the critical focal points locally and provincially. Hospice palliative care services play an important role in overall system function as it relates directly to the Central LHIN's current priorities and the ER/ALC strategy. The LHIN has recognized the need to build capacity across the continuum of care to better support individuals in non-acute care settings. The LHIN has invested a number of initiatives such as the Pay for Performance, Aging At Home Strategy and the Integrated Client Care Project (ICCP).

In order to align with the LHIN's priorities, the CHPCN must contribute progress towards supporting the LHIN's ER/ALC initiatives. Through the use of the scenarios described in this document, a number of key performance indicators have been discussed and presented. The table below outlines a set of suggested indicators that are relevant and inclusive to both palliative sector goals and broader ER/ALC goals:

**Table 2: Suggested Potential Key Performance Indicators by Scenario**

Scenario	Suggested Potential Key Performance Indicators
1. Patient discharged home from hospital	<ul style="list-style-type: none"> <li>• Total # of hospital palliative patients</li> <li>• ALOS of patients designated as palliative</li> <li>• ALOS of patients designated as palliative and discharged from hospital</li> <li>• # of admitted palliative patients coded as deceased in hospital</li> <li>• # of admitted palliative patients discharged home or to other location</li> <li>• % of ALC patients who are palliative</li> </ul>
2. Routine care	<ul style="list-style-type: none"> <li>• # of palliative clients with Central CCAC</li> <li>• # of days palliative clients are on Central CCAC caseload</li> <li>• # patients coded palliative when admitted or discharged from acute care hospitals</li> <li>• # of visits by HPC teams</li> <li>• # of clients served by HPC teams</li> <li>• # Records of Care in use</li> <li>• # of referrals to Palliative care services</li> <li>• # OHIP telephone consultation fees billed by palliative physicians</li> <li>• # consultations provided by HPC Teams Clinical Nurse Consultants</li> <li>• # Symptom relief Kits dispensed by regional pharmacies</li> <li>• #CCAC Code 95 patients admitted to hospital</li> <li>• # CCAC Code 95 patients sent to ER</li> <li>• Reduced hospitalizations and increased appropriate home deaths</li> </ul>
3. Patient transitions from home to hospital	<ul style="list-style-type: none"> <li>• # of CCAC Code 95 clients who are admitted to hospital</li> <li>• # of CCAC Code 95 clients sent to ER</li> </ul>

Scenario	Suggested Potential Key Performance Indicators
	<ul style="list-style-type: none"> <li>• # CCAC Code 95 patients discharged from ER</li> <li>• # Patients admitted directly from home to Palliative Care Beds electively for planned End of Life care in hospital.</li> <li>• Increased at-home deaths</li> <li>• # of LTC residents readmitted back into hospital</li> </ul>
4. End of Life and Bereavement	<ul style="list-style-type: none"> <li>• Caregiver / family satisfaction survey, 3-6 months post-death</li> <li>• # of home deaths</li> <li>• Fewer hospital admissions during end-of-life</li> </ul>

From the above list, six key indicators and desired outcomes have been prioritized to support the Central LHIN's ER/ALC strategy.

Description of Desired Outcome	Performance Indicators
<i>How will we know when a change is an improvement?</i>	<i>What measure will be used to indicate performance?</i>
1. Total number of hospital palliative patients (for a baseline)	Number of palliative patients coded Z51.5 including CCC and Rehab units
2. Reduce proportion of palliative patients who are designated ALC	Number of palliative patients designated ALC
3. Reduce the number of palliative patients who die in hospital	Number of <b>admitted palliative clients</b> in acute care with discharge location coded as "deceased", including and excluding CCC and Rehab units (2 outcomes to be reported)
4. Increase the number of inpatient palliative patients taken out of hospital	Number of <b>admitted palliative clients</b> discharged to home or any other location
5. Decrease the length of stay in hospital for palliative patients	Number of days that <b>admitted palliative clients</b> spend in an acute care bed
6. Reduce ED visits by palliative clients	Total number of ED visits by palliative clients

Central to the development of each key indicator, it will be to ensure the following questions have been considered:

- What is the desired outcome that CHPCN wishes to achieve that supports the ER/ALC priority?
- What measure will be used to indicate performance?
- Where will the data come from?

- What data points will need to be pulled?
- What is the base-line data to measure from?
- What is the year-end target? Or multi-year targets?
- When will the data be reported? Annually? Quarterly?
- What resources, human and financial, are required to create and maintain a system of comprehensive surveillance of quality and outcome data for the Hospice Palliative Care sector?

In order to develop a performance plan with ongoing tracking and reporting, it is recommended the CHPCN engage in the following key activities over the upcoming months (April – June 2011):

- Establish performance indicators task force/working group
- Identify/confirm key measure(s) that will be used to indicate performance
- Identify/confirm key data source(s) for each indicator
- Identify/confirm key data points that need to be pulled
- Conduct a baseline exercise or establish/agree on baseline numbers where possible
- Establish and agree on expected outcomes
- Establish process for collecting, monitoring and reporting
- Define reporting intervals (e.g. quarterly)

Many of the above activities require additional discussion, especially regarding palliative coding and data retrieval. For example, palliative care unit (PCU) beds in some hospitals are designated as complex continuing care (CCC) beds and are not separated for data reporting making it difficult to distinguish how many palliative patients are occupying those beds. At other hospitals, palliative beds may be dispersed throughout multiple units making it difficult to determine which beds end up being utilized for palliative patients. To this end, solutions must be explored to allow for palliative bed capacity to be captured as accurately as possible. Potential options might include implementing a specific code or 'flag' or alternatively, assigning a percentage of beds within each unit that represents the use of palliative resources on a short-term basis.

In addition, data retrieval is currently an issue. Efforts through this project have demonstrated the lack of available data on a regional and/or hospital by hospital basis. In moving forward with a performance plan, it will be critical for CHPCN to engage with the LHIN and/or potentially each provider to obtain necessary data points. A first step in implementing a performance plan will be to establish a baseline. Without the appropriate data, a baseline and any future data comparisons will be difficult. Part of the CHPCN's mandate should be the stewardship of palliative care data on behalf of the Central LHIN.

## 4.0 Implementation Planning

As part of the scenario planning, participants highlighted improvements that were of particular interest to the region as a whole. To proceed from a strategic and long-term planning standpoint, it is recommended that the Central Hospice Palliative Care Network pause to reflect on its priorities. The CHPCN must continue to build on its efforts to keep palliative care on the LHIN agenda by initiating the following activities:

- Refine and validate the CHPCN mandate and membership
- Formalize an implementation plan to guide the CHPCN to address transitions in care
- Identify and develop standards across the LHIN

- Finalize key outcomes and develop key performance metrics
- Operationalize key initiatives on a regional basis

This document serves as an initial start to broader strategic discussions. The table below highlights initial implementation planning considerations for potential improvements identified to date to aid in improving transitions in palliative care.



**Table 3: Initial Implementation Plan for a Subset of Proposed Improvements**

<b>Improvements</b>	<b>Key Activities</b>	<b>Outcomes</b>	<b>Timing</b>	<b>Lead/Sponsors</b>
<b>Chart Review (From Scenario #1)</b>	<ul style="list-style-type: none"> <li>-Define scope</li> <li>-Select participating organizations</li> <li>-Develop tactical working group</li> <li>-Define chart review parameters and algorithm</li> <li>-Obtain approvals necessary</li> <li>-Random selection of charts to be reviewed</li> <li>-Conduct review</li> <li>-Collate findings</li> <li>-Share findings</li> </ul>	<ul style="list-style-type: none"> <li>-Increased understanding of key issues through discharge planning and where patients ‘fall through the cracks’ across transitions</li> <li>- Key findings to guide the development of the areas of focus for further exploration</li> </ul>	April – August 2011	<ul style="list-style-type: none"> <li>-Sub-working group of multiple stakeholders including a physician lead (TBD)</li> <li>-CHPCN as sponsor</li> </ul>
<b>Discharge Checklist (From Scenario #1)</b>	<ul style="list-style-type: none"> <li>-Define scope for checklist</li> <li>-Develop tactical working group (may be the same as above)</li> <li>-Detailed review of discharge process in hospital and receiving end in the community</li> <li>-Gap analysis and identification of required system changes for the checklist</li> <li>-Develop checklist</li> <li>-Develop pilot plan</li> <li>-Deploy Pilot</li> <li>-Pilot Evaluation (PDSA cycle)</li> </ul>	<ul style="list-style-type: none"> <li>-Increased level of standardization in discharge planning across the region</li> <li>-Streamlined discharge for palliative patients</li> <li>- Increased access to community supports at discharge</li> <li>-Fewer delays in set-up of community supports post discharge</li> <li>-Increased communication between hospital and community providers</li> </ul>	April – December 2011	<ul style="list-style-type: none"> <li>-Same group as above should also lead here as they are connected initiatives</li> </ul>
<b>Record of Care Binder (From Scenario #2)</b>	<ul style="list-style-type: none"> <li>-Detailed review of current binder</li> <li>-Engage current users for feedback</li> <li>-Incorporation of any new items/tools</li> <li>-Identify poor utilization areas</li> <li>-Engage CCAC in developing mandatory protocols</li> <li>-Draft key educational messages</li> <li>-Produce required materials and create promotion plan</li> <li>-Conduct training sessions</li> <li>-Deploy revised binder</li> </ul>	<ul style="list-style-type: none"> <li>-Increased standardized documentation in the home</li> <li>-Increased communication across professionals and care teams</li> <li>-Decreased client confusion</li> <li>-Higher level of preparedness during times of crisis for both professionals and clients/families</li> </ul>	April – October 2011	<ul style="list-style-type: none"> <li>-CHPCN as sponsor with support from HPC and community providers</li> </ul>
<b>Communications/Education Strategy</b>	<ul style="list-style-type: none"> <li>-Define target audience</li> <li>-Develop tactical working group</li> </ul>	<ul style="list-style-type: none"> <li>-Greater awareness of palliative care services, referral procedures</li> </ul>	April – October	<ul style="list-style-type: none"> <li>-Sub-working group of multiple stakeholders</li> </ul>

<b>Improvements</b>	<b>Key Activities</b>	<b>Outcomes</b>	<b>Timing</b>	<b>Lead/Sponsors</b>
<b>(For providers) (Identified through all scenarios)</b>	<ul style="list-style-type: none"> <li>-Draft key messages and targeted learnings</li> <li>-Develop tools/processes</li> <li>-Develop required materials</li> <li>-Deploy strategy</li> </ul>	<ul style="list-style-type: none"> <li>-Improved engagement in accurate coding practices</li> <li>-Increased communication between providers/sectors</li> <li>-Increased confidence and comfort levels re: palliative cases</li> </ul>	2011	<ul style="list-style-type: none"> <li>including a physician lead (TBD)</li> <li>-CHPCN as sponsor</li> </ul>
<b>Promote/Expand CCO Symptom Management Guidelines (From Scenario #2)</b>	<ul style="list-style-type: none"> <li>-Engage CCO stakeholders if necessary</li> <li>-Develop tactical working group</li> <li>-Define target audience and target areas</li> <li>-Organize symptom management guidelines for expansion purposes</li> <li>-Draft key messages</li> <li>-Develop any materials and promotion plan</li> <li>-Develop 'train the trainer' approach and recruit training leaders</li> <li>-Deploy engagement activities</li> </ul>	<ul style="list-style-type: none"> <li>-Increased standardization in managing pain and symptoms for palliative individuals</li> <li>-Greater awareness and skill level across providers regarding pain and symptom management</li> <li>-Potential minimization of crisis states and unnecessary hospital admissions</li> </ul>	April – December 2011	<ul style="list-style-type: none"> <li>-Sub-working group of multiple stakeholders (TBD)</li> <li>-CHPCN as sponsor</li> <li>-CCO collaboration as appropriate</li> </ul>
<b>Public Awareness Campaign (Identified through all scenarios)</b>	<ul style="list-style-type: none"> <li>-Engage communications specialist if possible</li> <li>-Develop working group</li> <li>-Define target audience</li> <li>-Draft key messages</li> <li>-Engage public focus group for feedback</li> <li>-Develop materials</li> <li>-Design distribution and outreach plan</li> <li>-Deploy materials and outreach activities</li> </ul>	<ul style="list-style-type: none"> <li>-Greater awareness of palliative care resources and programs available</li> <li>-Increased referral to community palliative supports</li> <li>-Potential minimization of crisis states and unnecessary hospital admissions</li> </ul>	April 2011 – March 2012	<ul style="list-style-type: none"> <li>-Sub-working group of multiple stakeholders (may include a public/lay person rep)</li> <li>-CHPCN as sponsor</li> <li>-Support from a communications specialist in creating materials if possible</li> </ul>
<b>Expansion of Resource Directory</b>	<ul style="list-style-type: none"> <li>-Develop tactical working group</li> <li>-Define target audiences for directory moving forward</li> <li>-Review of existing directory</li> <li>-Environmental scan of regional resources</li> <li>-Revise directory</li> <li>-Define ongoing management roles for updating/housing</li> <li>-Investigate printing and/or other distribution methods</li> </ul>	<ul style="list-style-type: none"> <li>-Greater awareness of palliative care resources and programs available</li> <li>-Increased referral to community palliative supports</li> <li>-Potential minimization of crisis states and unnecessary hospital admissions</li> </ul>	April – September 2011	<ul style="list-style-type: none"> <li>-Same group as above if resource directory is selected as a main material source</li> </ul>

Improvements	Key Activities	Outcomes	Timing	Lead/Sponsors
	-Deploy updated directory			
<b>Integrated Model of Spiritual Care</b>	<ul style="list-style-type: none"> <li>-Develop a sub-working group</li> <li>-Review models of spiritual care being used in Ontario</li> <li>-Draft a model of spiritual care that is part of the integrated model of hospice palliative care in the CLHIN</li> <li>-Engage stakeholders in a review of the model</li> <li>-Develop the necessary tools for the implementation of the model</li> <li>-Develop a plan for raising awareness of and educating stakeholders about the model</li> <li>- Develop a plan for funding spiritual care</li> </ul>	<ul style="list-style-type: none"> <li>-Spiritual needs of clients met in their palliative and EOL journey</li> <li>-Increased access to spiritual care and more timely spiritual care intervention</li> <li>-Increased understanding of spiritual needs and the role of spiritual care</li> <li>-Increased referrals for spiritual care assessment and care</li> <li>-Potential decrease in crisis states and unnecessary hospital admissions</li> <li>-Higher levels preparedness during times of crisis for both professionals and clients/families</li> </ul>	May 2011 – March 2012	-Work group of CHPCN

## 5.0 Concluding Thoughts

The CHPCN has identified the need to improve transitions in care for palliative patients. To this end, through this scenario planning exercise, the CHPCN has articulated the following goals in creating a clear network mandate moving forward:

- Consistent access to timely, comprehensive support for palliative patients to have a comfortable death in the setting of their choice, with an emphasis on improving the home death experience for those who prefer it.
- Provide the necessary supports for patients transitioning home from hospital including anticipation and education, and plans to respond to and prevent events and crises that may lead to re-admission.
- Increase the awareness of community palliative resources among formal and informal caregivers, patients and families.

To achieve these goals, the CHPCN will need to:

- Move ahead with implementation planning regarding specific initiatives
- Engage appropriate stakeholders at a strategic level for continued future planning and movement/momentum regarding specific initiatives
- Develop standards such as criteria for palliative care beds
- Operationalize a model of care that integrates the continuum of care, including spiritual care

Ultimately, the ideal vision of palliative care includes a system where healthcare professionals have a fundamental level of understanding regarding palliative care and are confident in directing necessary palliative resources at the appropriate time. As a part of this vision, it is critical to build awareness and knowledge of palliative care services as a key component of patient care through various disease states and across the continuum.

With these goals set, the CHPCN can continue its past successes and move towards improving transitions for palliative care while also supporting the LHIN's ongoing ER/ALC strategy.

## 6.0 Appendix A: System/Process Improvements

### Central Hospice Palliative Care Network - Session #1 and #2

Scenario	Strengths/Opportunities	Challenges (incl. information gaps)	Potential (Process) Improvements	Potential Initiatives
<b>1. Patient discharged home from hospital</b>	<ul style="list-style-type: none"> <li>-Hospital healthcare team meets with family for discharge planning – this would include social worker, primary physician, CCAC case manager</li> <li>-Potential to work with 'in-reach' pilot project between CCAC and NYGH where they are bringing in the community CCAC CM to support the discharge planning process</li> <li>-Much easier to advocate and arrange services at the time of discharge planning if the patient has the palliative designation since there are certain referrals that the discharge team can look to (e.g. HPC team)</li> <li>-HPC team is a strength in providing a consult/support to community nurses</li> <li>-Calea offers consultation support</li> <li>-Case Manager on each floor at some hospitals helps facilitate patient discharge</li> <li>-Physician sign-off not required for initiating pal. services in the community</li> </ul>	<ul style="list-style-type: none"> <li>- Patients not coded properly due to symptoms/conditions that are presented to hospital staff</li> <li>- Difficult to count/classify palliative beds</li> <li>-Differing philosophy in timing for setting up palliative care for patients and designating a patient as palliative (short prognosis vs. life limiting/life threatening illnesses)</li> <li>-Designating palliative care patients earlier can depend on the palliative expertise in the hospital (who has a palliative doctor and who does not)</li> <li>-Patients coming from downtown hospitals often do not have a palliative designation but should (they may come in to a central LHIN hosp. and go down a different path due to lack of pal designation) or have a pal designation with no accompanying documentation</li> <li>- Family physicians unaware when patients are admitted into hospital</li> <li>-For some physicians there is some hesitation or differing level of comfort/understanding in designating a patient as palliative</li> <li>-Many patients are discharged without referral to palliative supports in the community; may be due to lack of awareness, not wanting to get involved, lack of palliative care knowledge</li> <li>-Cancer patients may be better handled, more well known; patients with ALS, MS or others can fall through the cracks</li> <li>-Common for patients to slip through the cracks from a surgical ward after stabilizing from a major surgery</li> <li>-Information not communicated to the community providers: PPS scores, proper coding, general</li> </ul>	<ul style="list-style-type: none"> <li>-Harmonize the definition of 'palliative patient' and 'palliative care' across care settings to enable better coding and better handle of the true size of the palliative population</li> <li>-Earlier identification of palliative patients and providing consensus on this process</li> <li>-Develop capacity for front-line nurses, discharge team etc. in non-palliative hospital settings to better recognize palliative cases and know where to refer</li> <li>-Engage family physicians/community physicians and potentially, education</li> <li>-Engage other hospital dept physicians to improve knowledge and comfort levels in recognizing and managing palliative-like patients (e.g. nephrologists, cardiologists)</li> <li>-Educate other professionals involved in discharge across the hospital regarding common referral form and referral processes to the community</li> <li>-Advance Care Planning discussions occurring earlier would help to work through care options (these conversations in some places started in the hospital)</li> <li>-Educate patients on potential resources, e.g. pain symptom</li> </ul>	<ul style="list-style-type: none"> <li>-Expand current inventory/directory for palliative and palliative related resources – promote this inventory</li> <li>- Conduct hospital by hospital chart review to determine root cause of discharge disposition</li> <li>- Develop an overall process/procedure to track palliative discharge destinations and establish targets</li> <li>-Discharge checklist from hospital from non-palliative units to home</li> <li>- Promote common referral process</li> <li>- Expand CCAC in-reach pilot to other hospitals</li> </ul>

Scenario	Strengths/Opportunities	Challenges (incl. information gaps)	Potential (Process) Improvements	Potential Initiatives
		communication channels of involved providers (i.e. community nurses struggle with getting physician support, especially in dealing with crises), incomplete referrals, no designation of MRP written down, no specific referrals for supplies (kit, O2)	clinics, varying levels of hospice support -More advanced notice for home set-up would facilitate care at home	
<b>2.Routine care at home</b>	<ul style="list-style-type: none"> <li>-HPC can go in to the home on their own; referral process does not have to go through CCAC or a physician</li> <li>-CCAC team is knowledgeable about keeping the GP in the loop – won't make a specialist referral without consulting the GP</li> <li>-Record of Care Binder in development, which includes communication algorithms, who to call for patients etc.</li> <li>-CCAC medication management program</li> <li>-Regarding LTC: the HPC team has some funding to do an education initiative within the LTC care setting and teach them how to link in to local consultants and round-the-clock supports</li> <li>-Nurse-led geriatric team (from the hospital) newly available as part of a train-the-trainer program that is going into LTC facilities (linked to trying to cut admissions)</li> <li>-Initiative going on with hospice where volunteers are being trained to help support the client in checking the ESAS weekly so that this information can be communicated to the care team</li> <li>-EDITH protocol used for advance care planning across the board</li> </ul>	<ul style="list-style-type: none"> <li>-Difficult to decipher who is in charge, especially from the client perspective (clients instructed to call the agency for immediate issues) (community team will consult the case manager)</li> <li>-Whoever comes on the scene first is often who ends up being in charge</li> <li>-Many patients do not have a family physician (almost 40-50% could be 'orphan patients')</li> <li>-Engaging community physicians (some much more engaged than others)</li> <li>-Challenge in figuring out how and where the record of care binder is being used</li> <li>-Varying comfort levels in talking about palliative care with the client and planning ahead</li> <li>-No common place to view patient/client information for all professionals involved</li> <li>-Often multiple professionals needed because one professional cannot do it all due to time constraints</li> <li>-GPs will not do home visits</li> <li>-Better skills needed for frontline PSWs</li> <li>-Lack of agreement in goals of care (getting hung up on definition of palliative care)</li> <li>-Palliative case managers and HPC nurses are responsible for initiating advance care planning conversations but there are varying comfort levels across professionals and this often is completed too late</li> <li>-In the community, there is no formal spiritual care in the home</li> <li>-Caregiver burnout is a frequent issue in the home</li> <li>-PSWs often feel their voices are not heard or that they are not recognized as professionals involved</li> </ul>	<ul style="list-style-type: none"> <li>-Update and promote use of Record of Care Binder</li> <li>-Electronic portal for easier communication</li> <li>-Training opportunities for front-line workers, PSWs especially</li> <li>-Education on earlier advance care planning (and process for updating wishes?)</li> <li>-Education and mentoring for family physicians (in the process of investigating LEAP)</li> <li>-Incorporating all domains of care in home setting (e.g. education to include more formal access to spiritual care)</li> <li>-Allow more time for nurses to be more holistic (often constrained by time and cannot fulfill in a way they would like)</li> <li>-Focus on philosophy of comprehensive care planning (and considering 'perfect care' rather than a fine line of what is palliative and what is not)</li> <li>-In LTC: palliative education; mentorship program; link in with HPC education initiative</li> </ul>	<ul style="list-style-type: none"> <li>-Updated record of care binder or similar process</li> <li>-Public awareness campaign to promote resources in the community</li> <li>-Overall communications strategy with key service providers</li> <li>-Tool for identifying problems/changes according to major domains (or could implement the ESAS to be kept in the home) (could be used by PSWs specifically)</li> <li>- Develop NPSTAT-like program in LTC (Build on HPC teams)</li> <li>- Patient/family satisfaction survey</li> <li>-Develop or investigate model for integrated provision of spiritual care</li> <li>-Expand medication management program</li> <li>-Promote/expand CCO symptom management tool/bests practices/ guidelines (inter-professional)</li> </ul>

Scenario	Strengths/Opportunities	Challenges (incl. information gaps)	Potential (Process) Improvements	Potential Initiatives
		<p>in 'the team'</p> <ul style="list-style-type: none"> <li>-In LTC: palliative knowledge; lack of appropriate mentorship, especially for physicians; cannot designate palliative beds and do not have a special palliative unit since all vacancies must be filled regardless of case; no resource team available within the organization</li> </ul>		
<b>3.Patient transitions from home to hospital</b>	<ul style="list-style-type: none"> <li>- HPC team available for consult</li> <li>- Patients admitted to palliative unit are familiar to the palliative care team</li> <li>- Community nurses have and utilize symptom management toolkit</li> </ul>	<ul style="list-style-type: none"> <li>-Lack of revisiting various assessments to mitigate potential problems and reduce medical issues</li> <li>-Patients and families not adequately aware regarding options in times of crisis, progressive disease states</li> <li>- Patients and families are not clear on who to call when to call</li> <li>-The varying drugs that the patient comes into the hospital with and knowing why they were prescribed, when etc.</li> <li>-ED often not aware that the patient is palliative when they present with a specific acute issue (even when there is a re-admittance, they may have not been coded as palliative at a previous visit)</li> <li>-Very rarely can patients be directly admitted to a PCU</li> <li>-Transportation to hospital is an issue, in particular in rural areas of the LHIN</li> </ul>	<ul style="list-style-type: none"> <li>-Automatic referral to pain and symptom management for palliative designated patients</li> <li>-Part of Advance Care Planning: back-up paperwork for PCUs so that for those who do not want to die at home, some plans may work out</li> <li>- Education to patients and families re: resources and care options along the disease trajectory, avoiding panic</li> <li>-Education and system set-up re: appropriate coding in the hospital so that palliative patients are flagged</li> <li>-A crisis team that floats in the community for those struggling at home and who otherwise go to ED (like NP STAT)</li> </ul>	<ul style="list-style-type: none"> <li>- Develop trigger at ED for palliative patients being readmitted</li> <li>- See above for suggested ideas</li> </ul>
<b>4.EOL and Bereavement</b>	<ul style="list-style-type: none"> <li>-PPS tool has been widely implemented across sectors, serving as a common identification tool and best practice for communication re: palliative care</li> <li>-Opportunity to identify complicated grief</li> <li>-May be opportunities to align with ICCP initiatives moving forward</li> </ul>	<ul style="list-style-type: none"> <li>-Difficult to get CPP before patient dies (can take up to 6 months)</li> <li>-Need for earlier education on spiritual issues and gaining comfort as the end becomes closer....these conversations should begin to happen earlier</li> <li>- Limited understanding (from the perspective of other professionals in the sector) of CCAC protocols in following up with client families</li> <li>-Often times, the doctor or some other member of the healthcare team is not aware that a client/patient has died (difficulty ensuring the entire</li> </ul>	<ul style="list-style-type: none"> <li>-Advance Care Planning conversations that include education on finances, CPP issues, spiritual issues</li> <li>-Engaging stakeholders to gain better understanding of CCAC bereavement protocols</li> <li>-Increase supports or availability of specialty consultation in off-hours OR expand knowledge-base of other professionals that may be</li> </ul>	<ul style="list-style-type: none"> <li>-Tool for identifying and referring clients for complicated grief support</li> <li>-EOL and Bereavement checklist</li> <li>-Communication protocols captured through the record of care binder (as an interim to a common database)</li> <li>-Common database or portal that provides/documents status</li> </ul>

Scenario	Strengths/Opportunities	Challenges (incl. information gaps)	Potential (Process) Improvements	Potential Initiatives
		<p>team is notified of status changes) (there also exists issues around privacy of information and consent to share)</p> <ul style="list-style-type: none"> <li>- Often family members have increased anxiety re: EOL that may result in contact with the ER/EMS and panic (may even lead to police arriving and unneeded trauma); level of comfort around a planned death at home and understanding expectations</li> <li>- nurses have potential to burn out as they sometimes attempt to support their patients as best they can (may offer their personal cell numbers) because they don't have confidence in on-call non-pal nurses</li> <li>- Existing tools for communicating with patients/clients regarding EOL vary according to the specific diseases/conditions and are not standardized</li> <li>- General burn-out of multiple stakeholders</li> </ul>	<p>involved in the patient's care</p>	<p>updates</p> <ul style="list-style-type: none"> <li>- Integrated model of spiritual care</li> <li>- Exercise in reviewing scenarios/triggers that may lead to complicated grief (for earlier anticipation of supports required)</li> <li>- Advance Care Planning improvement initiatives (education of healthcare professionals, outlining roles, process and potential tools)</li> <li>- Published resource for clients and families around planned home deaths, to increase level of understanding</li> <li>- Standardized best practice tool/guide or education program for nurses in communicating re: EOL</li> <li>- 'Telehealth-like' crisis/information line for palliative support (and possibly consultation?)</li> </ul>