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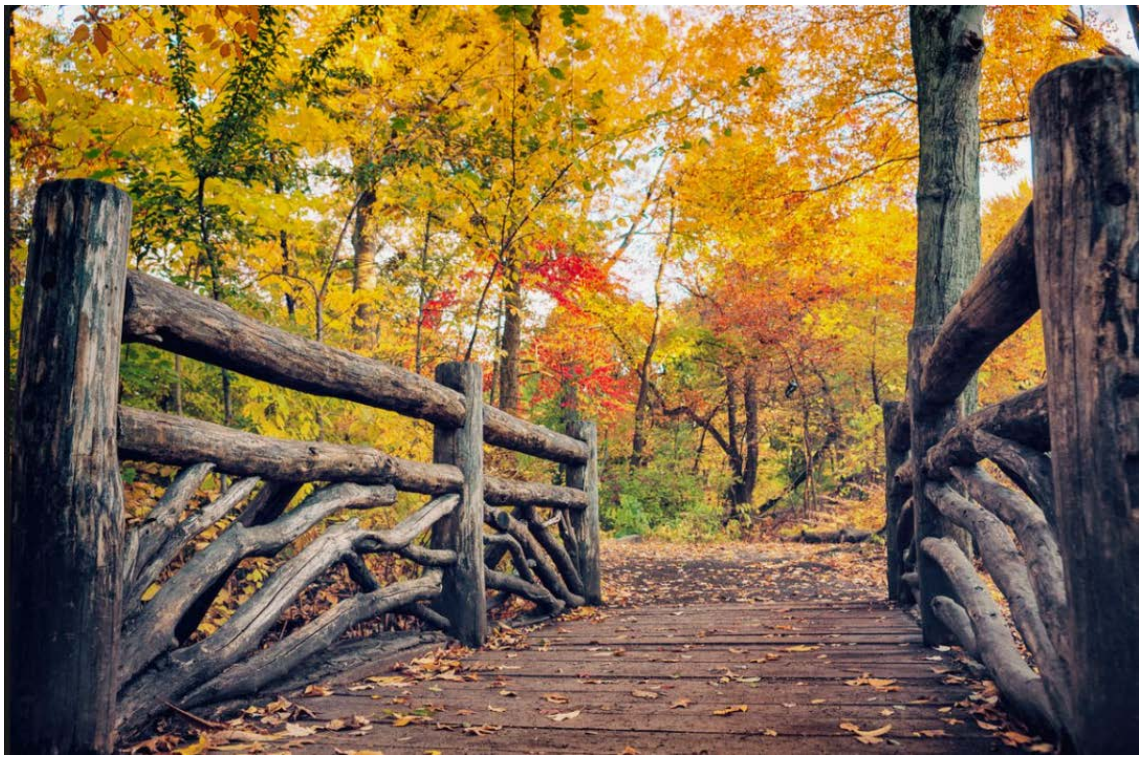
PALLIATIVE APPROACH IN LONG-TERM CARE



A Collaboration between Palliative & End of Life Care and Long-Term Care Programs

TOOLKIT

"We cannot change the outcome, but we can affect the journey."

Ann Richardson

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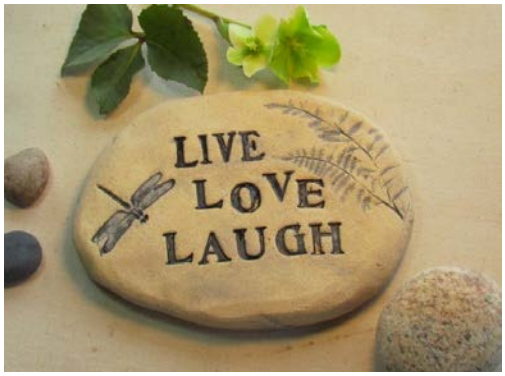
SHIFT YOUR THINKING…
TO A PALLIATIVE APPROACH



A quality improvement and knowledge translation project entitled "Improving End-of-Life Outcomes in Residential Care Facilities" took place between September 2015 and March 2018. It was funded by the Specialist Services Committee and was a collaboration between Island Health Palliative & End of Life Care, and Long-Term Care Services.

As a result of this work, in September 2018 Island Health Long-Term Care recommended that a Palliative Approach be implemented across all sites. Acting on the key learnings, recommendations and tools developed from the project, a working group was established along with 17 early adopter long-term care sites to establish a Community of Practice, which informed the development of this toolkit and the supporting curriculum.

According to 2014 Island Health data, the average length of stay in a long-term care home is less than 14 months, and 17% of residents die within 3 months of admission. Residents admitted to long-term care are further along in their chronic life-limiting disease trajectories and have multiple co-morbidities. A **shift in culture** that identifies residents who would benefit from a Palliative Approach earlier in their life-limiting illness, as opposed to when imminently dying, results in improved quality of life outcomes for the resident, their family and the overall experience of the care providers.

The tools and resources provided are intended to assist leadership in Long-term Care to **adopt** a Palliative Approach to Care, **adapt** it to their site, and **embed** it into everyday practice for sustainability.
(iPANEL 2016)

WHAT IS A PALLIATIVE APPROACH?

Some may think of it as…	A Palliative Approach is…
Final days of weeks of life	May have months or years
Only cancer	Any life-limiting illness
A place such as a hospice	A philosophy of care across all care settings
An action	Action and process
Withdrawing treatment	Active treatment to promote quality of life and includes chronic disease management

"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."

World Health Organization 2019

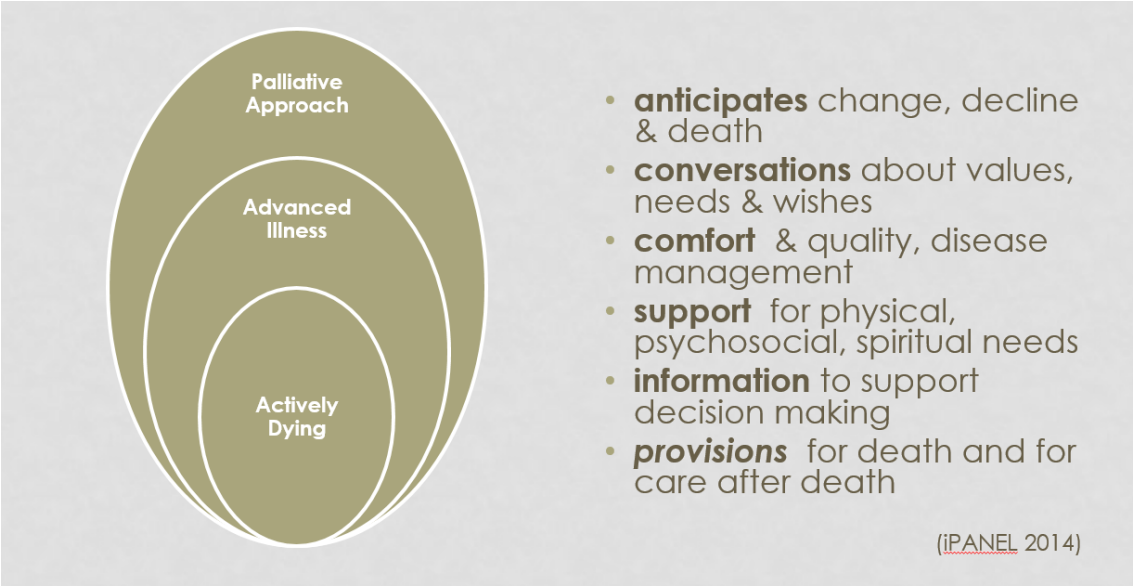
ADOPT A PALLIATIVE APPROACH

Quality of life is improved through integration of chronic disease management along with palliative care principles early in the disease trajectory, as opposed to when the resident is actively dying. Engaging in conversations shortly after admission to long-term care and on a regular basis thereafter helps the resident and family to:

- Understand where the resident is in the course of their illness
- Anticipate decline and how it can be managed in place
- Identify their personal preferences, goals of care
- Prevent transfers to acute care and/or initiation of treatments which do not align with their goals of care
- Reduce anxiety and depression by having everyone on the same page

Embedding the Palliative Approach support tools and processes included in this Toolkit will assist the health care providers to:

- identify residents earlier
- feel supported in engaging in goals of care conversations
- recognize their role within the team to provide a palliative approach to care
- debrief on a regular basis
- identify learning needs.



ADAPT & EMBED

To be fully embedded into practice and sustainable, it takes a team, not one or two individuals. Support from leadership is foundational. Raising awareness of what a Palliative Approach means and the benefits it offers to residents, families and staff will help you identify champions within your interprofessional team. Each site is encouraged to reflect on its strengths to build upon and identify areas for improvement recognizing that a shift in culture takes time and teamwork.

Utilize the following 7 areas of focus along with the suggested resources as a guide to adopt, adapt and embed a Palliative Approach to care at your site. Note that there are 4 columns for dates should you wish to use this as an auditing tool to monitor your progress.

Be sure to check out Supplemental Resources on pages 12 - 14

"You matter because you are you,

And you matter to the end of your life.

We will do all we can not only to help you die peacefully,

But also to live until you die."

Dame Cicely Saunders

*STATUS: **IP** – In Progress **NS** – Not Started **A** – Achieved **NA** – Not Applicable

Area of Focus #1	**Status**			
Site Leadership Engagement **Date:**				
Share this toolkit to inform and engage: • Site Medical Director • Physician Group • Site Manager • Nursing Leadership				

Area of Focus #2	**Status**			
Raising Awareness Within Your Site **Date:**				
Post in areas for staff, residents and families to view: • A Palliative Approach to Care poster (Appendix A) • 4 iPANEL Infographics Shift, Adopt, Adapt, Embed • Discuss at meetings, report, rounds, conferences • Share with family council, volunteers, housekeeping, dietary staff				
Show and share the iPANEL video (4.3 mins) • Shifting Your Care to a Palliative Approach • Discuss at meetings, report, rounds, conferences • Share with family council, volunteers, housekeeping, dietary staff				
• Identify champions within your interprofessional team Managers/DOCs, Physicians , Nurse Practitioners, RNs/RPNs, LPNs, HCAs, pharmacists, PT/OT, Recreation Therapists, Dieticians, Spiritual Care, etc., who are enthusiastic or passionate about embedding a Palliative Approach to care				
• Consider starting a resource centre available to staff, residents and families with pamphlets included in the supplemental resources section of this toolkit				

*STATUS: **IP** – In Progress **NS** – Not Started **A** – Achieved **NA** – Not Applicable

Area of Focus #3	**Status**			
Staff Education **Date:**				
• Include in orientation for all staff: Shifting Your Care to a Palliative Approach (4.3 min. iPanel video) • Connect with your local Palliative Care Coordinator to register nursing leadership and nursing staff to attend LEAP Core 2 day education • Create Learning Hub account (Appendix B) to access eLearning courses: 1. Support and encourage staff to complete: Taking Ownership: Imbedding A Palliative Approach to Care (allow 45 mins to 1 hr. to complete – not the 15 mins. indicated) - suitable for all staff 2. Register a cohort of 4 or 5 staff members of mixed disciplines to attend 1 day Palliative Approach Long-Term Care. Group work for each participating site is required. (the course will soon be available on the Learning Hub). • Familiarize yourself with the Supplemental Resources on p. 12 - 14 for links to additional educational and support materials				

Area of Focus #4	**Status**			
Early Identification of Residents **Date:**				
• Embed the Early Identification Tool (Appendix C) into current practice on a regular basis to identify residents who would benefit from a palliative approach. Suggestions include: - first care conference (recommended) - when a change in condition is identified by the team/family - upon return from hospital visit/stay - • Send Letter to MRP/NP (Appendix D) when the resident is identified • Initiate the Guide for Goals of Care (Appendix E) when the resident is identified				

*STATUS: **IP** – In Progress **NS** – Not Started **A** – Achieved **NA** – Not Applicable

Area of Focus #5	**Status**			
Goals of Care Conversations **Date:**				
• Support/provide staff with opportunities to practice utilizing Ask-Tell-Ask and Wish…Worry…Wonder frameworks included in the Conversation Guide (Appendix F) • Goals of Care Conversations occur with the resident and family on a regular basis. Suggestions include: 1. initial care conference (recommended), 2. when a change in condition has been identified by staff/family. 3. Return from hospital • Goals of Care Conversations are documented in the Advance Care Planning notes that accompany the M.O.S.T. documentation, and are filed in a consistent location in the chart e.g. Green Sleeve • There is evidence of nursing and social workers along with physicians contributing to documentation of Goals of Care Conversations in the Advance Care Planning notes.				

Area of Focus #6	**Status**			
Palliative Rounds **Date:**				
• Utilize the Palliative Rounds tool (Appendix G) and embed on a regularly scheduled basis, suggestions include: 1. Replacing one care conference every 1 or 2 months 2. review one unit/wing per week during report/huddle. • Palliative Rounds: provide opportunities for staff to debrief, identify if any other residents are changing and may be at a higher risk of dying, provide in the moment teaching/learning opportunities • Suggested attendees: Nursing, HCAs, CNL, CNE, SW, Recreation, Dietician, Pharmacist, Physician, Manager, others involved with the residents and their families. • Consider reaching out to Palliative & End of Life Program for support as needed.				

*STATUS: **IP** – In Progress **NS** – Not Started **A** – Achieved **NA** – Not Applicable

Area of Focus #7	**Status**			
Monitoring Progress and Evaluation Suggestions Date:				
• Utilize these 7 areas of focus as a site self-evaluation form to monitor progress at regular intervals • Audit charts on a regular basis to identify: 1. How soon after admission a resident is identified as someone who would benefit from a palliative approach using the Early Identification Tool. 2. How many days before death was the resident identified as someone who would benefit from a palliative approach using the Early Identification Tool. 3. Evidence of documentation of Goals of Care Conversations in the Advance Care Planning notes. 4. Nursing and Social Work, along with Physicians contribute to the documentation of Goals of Care Conversations. 5. Advanced Care Planning notes accompany the M.O.S.T. and are in a consistent area of the chart e.g. Green Sleeve • Consider creating a family and staff satisfaction survey • Track staff education • Consider tracking if there is a decrease on number of residents being transferred to acute in their last 90 days of life				

Adapted from: Pallium Canada: Quality Palliative Care in Long Term Care: Self-Assessment Checklist.

SUPPLEMENTAL RESOURCES

Site Leadership Engagement	**comments**
Choosing Wisely Canada LTC	LTC Medical Directors Association
Consider starting a Resource Centre accessible to residents, families and staff	
Canadian Hospice Palliative Care Association Pamphlets The Palliative Approach in LTC for: • Advanced Dementia • Advanced Frailty • Advanced Lung Disease • Advanced Heart Failure • Advanced Kidney Disease	**please note: for correct double sided printing, use the "flip on short side" option**
When Your Loved One Has Dementia A Roadmap For Families Handout	Dr. Trevor Janz Interior Health
Palliative & End of Life Care • The Program • Accessing Services • Clinical Resources • Learning Resources • Illness Journey • Conversations	Island Health Intranet
Care for Persons With Dementia at the End of Life Handout	Island Health
Canadian Virtual Hospice	Staff and family education and support
Translation Services	Provincial Health Services Authority -able to translate written content in more than 50 languages
10 Myths About Palliative Care	Canadian Virtual Hospice

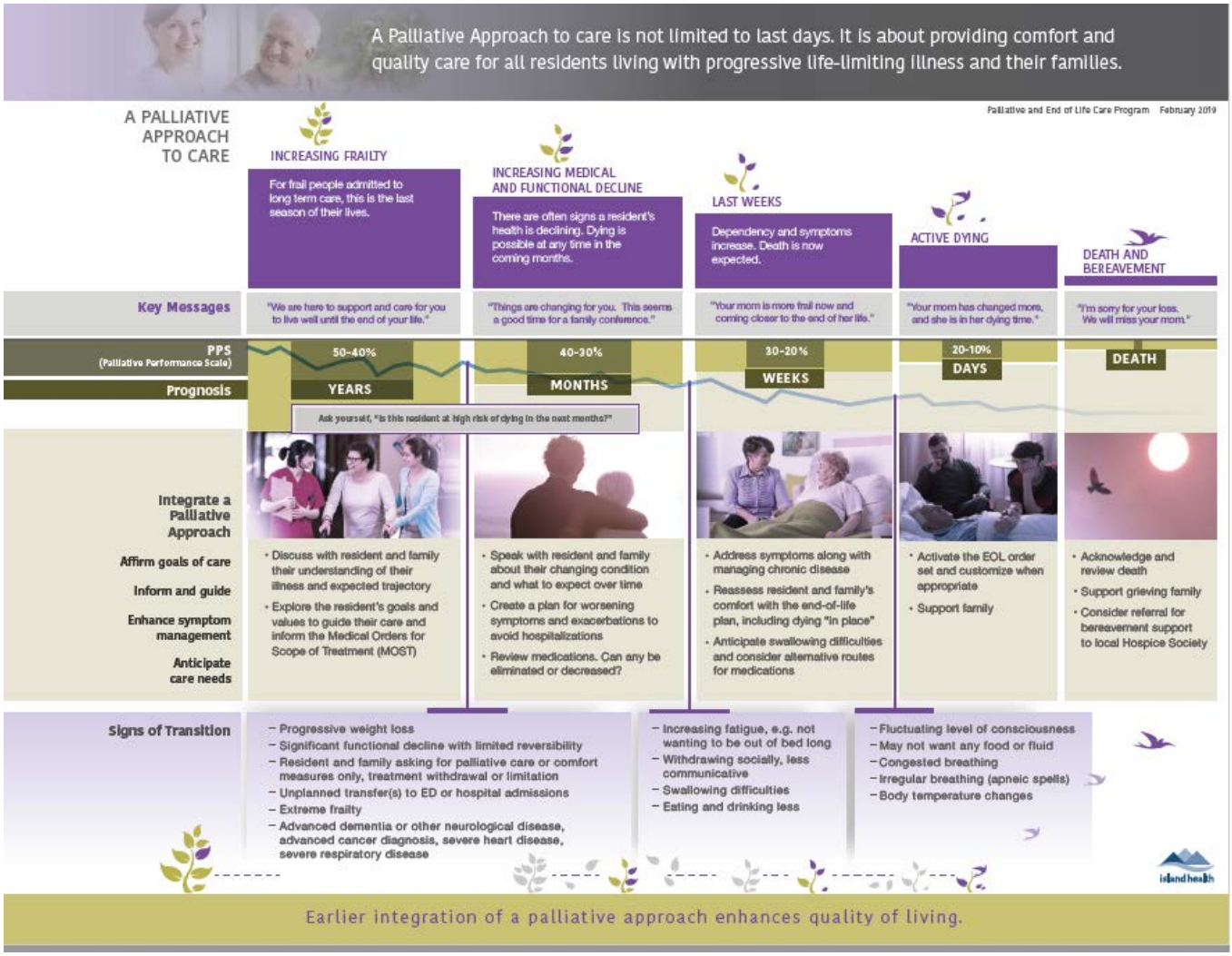
Staff Education	
BC Inter-professional Palliative Symptom Management Guidelines, 2017	BC Centre for Palliative Care
LEAP (Learning Essential Approaches to Palliative Care) Pallium Canada • Contact the Palliative Care Coordinator in your area about upcoming courses	2 day LEAP Core recommended for nursing
Victoria Hospice Courses • 1 week Medical Intensive • Psychosocial Care of the Dying and Bereaved	
A Palliative Approach to Care for Clients With Progressive and Life-Limiting Illnesses • 6 week on-line course	Bloomberg Faculty of Nursing University of Toronto
Life & Death Matters • Essentials in Hospice and Palliative Care: A Practical Resource for Every Nurse textbook and learning activities • Integrating a Palliative Approach: Essentials for personal Support Workers text and workbook	Katherine Murray
Ontario's Palliative Care in LTC Toolkit • Palliative Alliance (1 hr. long video)	
BCIT NSSC 7000 - Palliative Approach in Nursing Practice • 12 week online course	

Early Identification of Residents	
GSF Prognostic Indicator	Gold Standard Frameworks
Clinical Frailty Scale	
Supportive and Palliative Care Indicators Tool (SPICT)	
Palliative Performance Scale	

Goals of Care Conversations	
ACP – MOST video (13 mins)	
How to Talk End-of-Life Care with a Dying Patient Dr. Atul Gawande (3 min. video) • Describes the difference between identifying goals of care vs. assigning a MOST designation	
Accessing Palliative Consultation Services	
Palliative Care Services and Teams	
Local Hospice Society	Volunteers and bereavement support

APPENDIX A

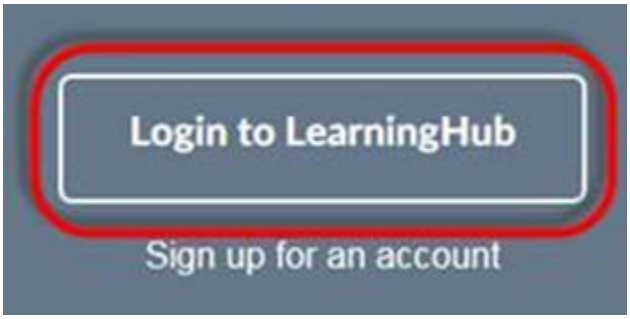
A Palliative Approach to Care Poster



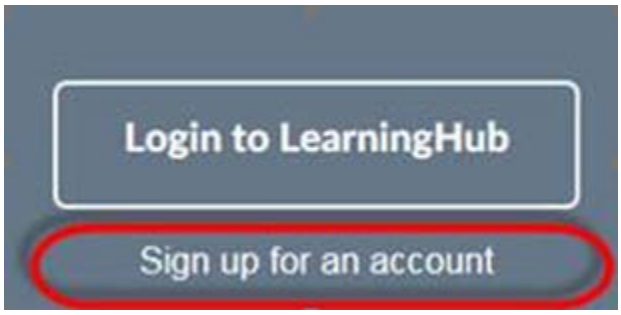
APPENDIX B

Create a Learning Hub Account for Affiliated Sites

1. If you had a learning account in the **old** system (CCRS), you must transition over to the LearningHub. Log in with your old CCRS username and password via learninghub.phsa.ca



2. If you are **new** to the on line learning system, set up your own learner account using any email address. Select Affiliate with Island Health when you set up your account in order to access certain Island Health courses.



3. Link to the LearningHub Help Page, which is helpful when setting up accounts. If you require further assistance, contact LMS@viha.ca

APPENDIX C

A PALLIATIVE APPROACH TO CARE

Early Identification Tool

There are often signs that a resident's health is declining and they are at higher risk of dying. Being attuned to these signs allows health care providers to better inform and guide residents and their families in this final season of their life. **What factors support the care team's impression that the resident is at risk of dying in the coming months?**

CHECK ALL THE FACTORS THAT ARE RELEVENT FOR THE RESIDENT

- ☐ Progressive weight loss (greater than 10% in 6 months)
- ☐ Progressive, irreversible functional decline
- ☐ Resident or family asking for comfort measures only, treatment withdrawal or limitation
- ☐ Unplanned transfers to Emergency Department or hospital admissions
- ☐ Extreme frailty (e.g. persistent pressure ulcers, recurrent infections, delirium, persistent swallowing difficulties, falls)
- ☐ Advanced dementia or other neurological disease (e.g. unable to dress, walk or eat without help, incontinence, unable to communicate verbally, eating and drinking less, swallowing difficulties, recurrent UTI, aspiration pneumonia)
- ☐ Advanced cancer diagnosis
- ☐ Severe heart disease (e.g. breathlessness or chest pain at rest or with minimal exertion)
- ☐ Severe respiratory disease (e.g. breathless at rest or with minimal exertion, on oxygen therapy, recurrent hospitalizations)
- ☐ Advanced illness of any cause with progressive function decline or poorly controlled symptoms

☐ Resident **NOT "identified"** at this time,
to be reviewed on this date: _____

☐ Resident **"identified"** at this time,
date of Identification: _____

Signature: _____

Criteria adapted from Supportive and Palliative Care Indicators Tool (SPICT™) www.spict.org.uk and The Gold Standards Framework Proactive Identification Guidance (PIG) 2016 vs6 © The Gold Standards Framework Centre in End of Life Care www.goldstandardsframework.org.uk/PIG

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APPENDIX D

Letter to Physician/NP

INSERT residential care facility's letterhead here

please respond by fax to [insert facility's fax number here]

Regarding your patient _____ **Date** _____

Dear Dr. _____ ☐ **Attachment included**

Your patient has been identified as being at a higher risk of dying in the next months:

- ☐ Progressive **weight loss** (> 10% over 6 months) _____ (lbs or kgs)
- ☐ Progressive, irreversible **functional decline**
- ☐ **Resident or family asking for comfort measures only**, treatment withdrawal or limitation
- ☐ **Unplanned transfers** to Emergency Department or hospital admissions
- ☐ **Extreme frailty** (e.g. persistent pressure ulcers, recurrent infections, delirium, persistent swallowing difficulties, falls)
- ☐ **Advanced dementia** or other **neurological disease** (e.g. unable to dress, walk or eat without help, incontinence, unable to communicate verbally, eating and drinking less, swallowing difficulties, recurrent UTI, aspiration pneumonia)
- ☐ **Advanced cancer diagnosis**
- ☐ **Severe heart disease** (e.g. breathlessness or chest pain at rest or with minimal exertion)
- ☐ **Severe respiratory disease (**e.g. breathless at rest or with minimal exertion, on oxygen therapy, recurrent hospitalizations)
- ☐ **Advanced** _____ with progressive functional decline or poorly controlled symptoms

Above criteria are adapted from the Supportive and Palliative Care Indicators Tool (SPICT™) www.spict.org.uk and The Gold Standards Framework Proactive Identification Guidance (PIG) 2016 vs6 © The Gold Standards Framework Centre in End of Life Care www.goldstandardsframework.org.uk/PIG

☐ **MOST** on file Date: _____ ☐ No **MOST** on file

Your patient, their family and the care team would appreciate your assessment and input.

Care Team Lead Name/Signature: _____

PHYSICIAN'S RESPONSE

- ☐ I will visit the facility to review my patient's situation in the coming week
- ☐ My Office Assistant will follow-up and book a meeting with the family at my office
- ☐ Comment:

_____

INSERT residential care facility's contact information here

APPENDIX E

Today's Date: _____

Guide for Goals of Care

(following identification of resident for palliative approach to care)

DOMAINS OF CARE	GOALS	ACTIONS
Early Identification	Ensure coordinated team-based support is initiated when resident is identified as in greater need of a palliative approach to care	☐ Complete "Early Identification Tool" ☐ Notify MRP if resident is identified (send form letter if used by this facility) ☐ Communicate to care team that resident has been identified
Information Sharing and Being a Guide to Family	Ensure that the family/ resident have opportunity to discuss the anticipated illness course and the benefits of a palliative approach to care to inform their care plan	☐ Choose a care team member to speak with family/resident about changes the care team has noted ☐ Document wishes and concerns on the Advance Care Planning Notes and Conversation Form (or equivalent) kept in Greensleeve of a resident's chart ☐ Encourage family to make an appointment with the resident's doctor to discuss anticipated illness course, prognosis and MOST ☐ Consider a family meeting with care team and MRP ☐ Provide ongoing check-ins with family
Confirming Goals of Care	Ensure that care provided is in keeping with resident's wishes and values, and is medically appropriate	☐ Revisit "Medical Orders for Scope of Treatment" (MOST) ☐ If MOST designation appears inconsistent with condition notify MRP and encourage family to make an appointment to revisit MOST

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APPENDIX F

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For Nurses and Social Workers

CONVERSATION GUIDE for LONG TERM CARE TEAM

A resident's increasing frailty has been identified and the early identification tool for a palliative approach to care has been completed.

CONVERSATION - LISTENING MORE THAN TALKING
Elements of conversation often take place over many small conversations and do not need to happen in one long session.

STEPS	DESCRIPTION	SCRIPT QUESTIONS / Sample Statements
1 INITIATE discussion	**Contact** the resident and/or family **Ask** permission for discussing change **Gather information** from the team about the specific changes identified **Plan** what you will say to the resident and/or family	**Q:** I'd like to talk with you about the changes in your mom's health. Is that OK? **Q:** Have you been noticing change? What changes have you been noticing?
2 ASK the resident and family	**Ask** the resident and/or family what their thoughts are about the resident's current status **Ask** the resident and/or family about what is important to them	**Q:** What do you understand about what is happening for your mom, with her illness? **Q:** What is most important to your mom now? What is most important to you?
3 TELL share information about changes	**Ask** permission to share information **Share information** on current status; include changes staff have seen, the increasing frailty, and that more change could happen at any time **Give information** in a straightforward way **Use words** the resident and family will understand Use "I **wish**...", "I **worry**...", "I **wonder**..." strategy	**Q:** Is it okay if I tell you the changes the care team has been seeing? As you noticed, your mom is sleeping more and doesn't go to activities. She is also eating less and has lost 5 pounds over the last 2 months. She is more irritable and is in more pain when moving. These changes are all part of what we expect as someone becomes more frail and ... ... they become less able to fight off a cold or infection ... they are moving toward the end of life ... life is getting shorter ... I **wish** things were different. I **worry** time is getting shorter. I **wonder** if we could talk about how we can provide care for your mom at this time

Palliative and End of Life Care Program, January 2018

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APPENDIX F

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	DESCRIPTION	SCRIPT QUESTIONS / Sample Statements
4 ASK share information about changes	**Explore** what is most important, the concerns	Now that we have talked ... **Q:** What is most important to you at this moment? **Q:** What hopes or concerns do you have?
5 NEXT steps	**Outline** next steps **Record** Advance Care Plan (ACP) notes and conversation. Fax form letter to physician (MRP) and attach progress notes if needed. **Share** with team including physician **Update** care plan	– I will write all this down and let the rest of the care team know so we are all on the same page. – I will (the nurse will) connect with the doctor and ask about changing some of the medications. We can reconnect next week. Does that sound OK? – I think it is important to make an appointment with your doctor and have a good discussion about what to expect and the plan of medical care. – ACP notes and conversations example: "Discussed recent changes in condition with family. Family wishes to have medical information and review plan of care. Asked family to make appointment with GP."
GOALS OF CARE	**CLARIFY GOALS OF CARE** (as appropriate)	**Also refer to Conversation Guide on page 2 of MOST**
Answer questions as they are raised	 Use the same approach: **ASK - TELL - ASK**	**FAMILY QUESTIONS:** How much time do they have? Are they dying? **ASK -** What is your sense? What are you expecting? **TELL -** You could be right. Often we aren't able to predict how much time, but we can see that she frail enough and change could happen at any time. This could be her dying time. **ASK -** Is that what you expected to hear? Does that make sense to you? **FAMILY QUESTION:** Should their family member still go to hospital? **ASK -** What are you thinking? How do you think they would benefit from going to the hospital? What would you hope from your mom going to hospital? **TELL –** It is so important to discuss your worries and hopes. We can care for your mom here, focusing on her comfort. For what she now needs, we have the care available. **ASK –** It sounds like you have more questions. Do you want to talk about this with your mom's doctor? Could you make an appointment?

APPENDIX G

Palliative Care Rounds in Long Term Care

What is the intention or purpose of "palliative rounds"?

1. **Review Death of Resident(s)**: The Residential Care Team reviews the death of a resident(s) and issues, challenges and successes related to the death. What went well? What could have been done better? Did the resident have a "good death"?

2. **Debrief on Resident Death(s)**: Compassion fatigue, sense of loss and grief are very real among caregivers. Do staff members need to debrief, to acknowledge sense of loss due to the death of a resident(s)?

3. **Case-Based Discussion and Planning**: Bring forward and review a resident(s) who is experiencing changes that are consistent with transition or dying. These changes may include functional decline, increased or hard to manage symptoms, or expressed goals of care. The Team discusses how best care for the resident, and support family and staff through the change.

4. **Knowledge Exchange:** Informal learning and "teachable moments" often arise during "palliative round" discussions, and common themes help determine topics for further exploration, staff training or future education sessions.

Who should attend "palliative rounds"?

Staff and physician involvement is important and all contributions are valued! "Palliative rounds" should include care aides, nursing staff, team leader and educator, social worker, recreation/rehabilitation staff, dietician, pharmacist, physician, site manager and others who may be involved with the resident(s) and their family.

What are the desired outcomes from "palliative rounds"?

- ✓ Regular interdisciplinary Team meeting(s) with care aide involvement in discussing residents and palliative care
- ✓ Supported Team review, debrief and reflection upon resident death(s)
- ✓ Early identification of resident(s) who would benefit from palliative approach
- ✓ Refreshed knowledge or new learning about palliative care
- ✓ Increased awareness and use of palliative care tools and resources
- ✓ Increased confidence of Team in providing palliative and end of life care to residents in their care home

This mini-guide is informed by "Comfort Care Rounds: A qualitative evaluation of an innovative palliative care improvement strategy" (2012) posted on palliativeallicance.ca (2013), and adapted from versions created by Jamie Linstead, RN CHPCN (C) and Charlotte Robinson, RN MN CHPCN (C) for the Improving End of Life Outcomes in Residential Care Facilities Pilot Project (2017).

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