

Palliative Approach In-service

Quality Palliative Care in Long Facilitators Guide



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Acknowledgements

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For more information regarding the project please visit www.palliativealliance.ca or email our team at palliativealliance@lakeheadu.ca

Introduction

The following education module was created as an introduction to the palliative care approach for staff working in long term care homes. This presentation should take approximately 30 minutes to complete. It should take 20 minutes to present the slides followed by a 10 minute question and answer period. You may want to consider contacting your local pain and symptom management consultant to help deliver this education or to be available for questions. Please make this presentation your own by including personal stories or case studies to highlight the information presented in this guide.

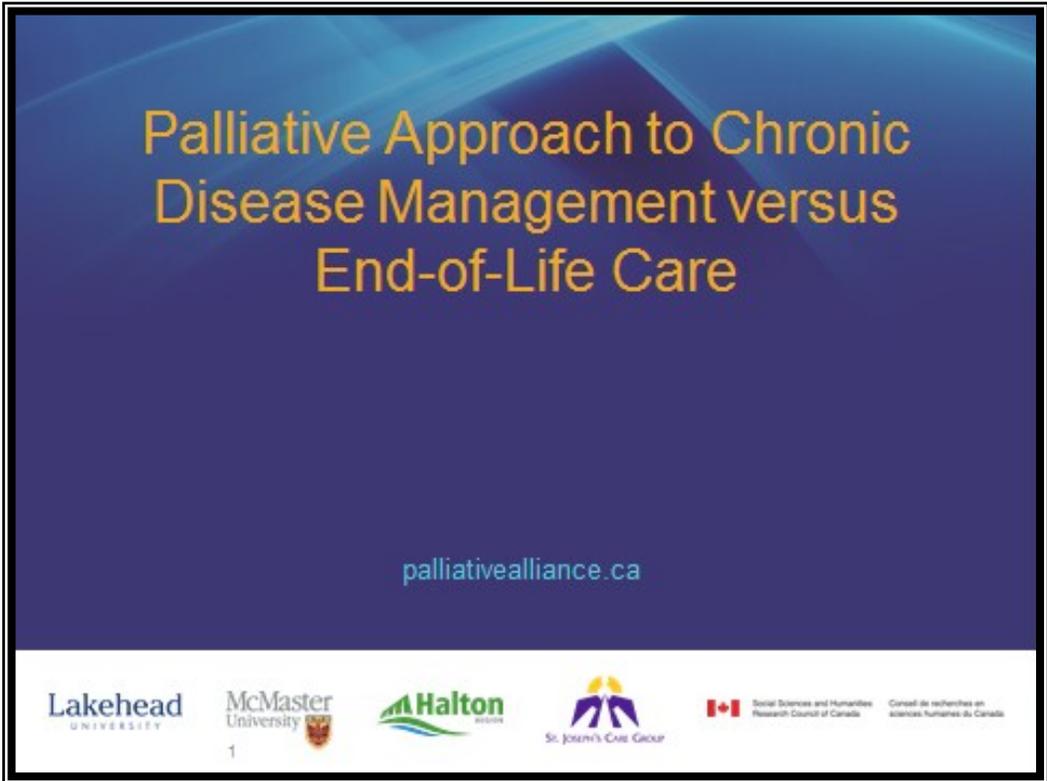
In-Service Objectives

This in-service will:

- Focus on the difference between palliative care and end-of-life care in a long term care context.
- Highlight that people are not palliative, but care can be palliative
- Explain how restorative care and palliative care can be complimentary and contribute to quality resident-centred care.
- Offer suggestions on how to identify if a resident could benefit from palliative care.
- Describe the current stigma around palliative care and offer suggestions on how staff may overcome this when talking to residents and family members .
- Allow long term care staff to think critically about the policies and procedures in their home and how they effect resident centred and palliative care.

After this presentation, long term care staff should be able to identify ways in which long term care homes can enhance their palliative care programs through education for staff and families, promoting a palliative approach within the long term care homes, and building close relationships with residents and family members to foster quality resident-centred care.

Presentation Guide



Welcome long term care staff to this in-service.

Acknowledgements

Marg Poling, RN, Palliative Pain and Symptom Management Consultant North West Community Care Access Centre (Thunder Bay) for creating this in-service

The Quality Palliative Care in Long Term Care Alliance for supporting the development of this in-service

The Social Sciences and Humanities Research Council (SSHRC) with funding the research of the Alliance and Canadian Institutes for Health Research (CIHR) for funding project knowledge translation

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This presentation was created by the Palliative Pain and Symptom Management Consultant for the Northwestern Ontario region.

The creation of this presentation was supported by the Quality Palliative Care in Long Term Care Alliance funded by the Social Science and Humanities Research Council and the Canadian Institutes for Health Research.

This in-service will give you, as long term care staff information on palliative and end-of-life care that is specific to a long term care home context.

Definition of Hospice Palliative Care

Hospice Palliative Care **aims or strives** to:

- relieve suffering
- improve the quality of living and dying
- help residents and families to address holistic issues
- addresses expectations, needs, hopes and fears
- prepare for and manage self-determined life closure
- prepare resident and family for the dying process
- assist residents cope with loss and grief during the illness and bereavement
- treat all active issues and prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization

The CHPCA: A Model to Guide Hospice Palliative Care, 2007

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- The term *palliative care* was first used when working with individuals who had cancer.
- Due to palliative care's link with cancer it had a stigma meaning that death was near and inevitable.
- Now palliative care is a term used with many complex chronic and terminal health conditions including heart failure, dementia, etc., which are diseases that effect most of the resident's living in long term care homes.
- We must now fight the stigma that palliative care means dying as in most cases it means that there is no cure, however the resident can be effectively managed medically by resident-centred care, treating active issues, and providing holistic care that will allow resident's to live with good quality of life
- Thus, palliative care is now a longer trajectory then when it was introduced for cancer patients.
- The following statements are from *A Model to Guide Hospice Palliative Care* created by the Canadian Hospice Palliative Care Association.

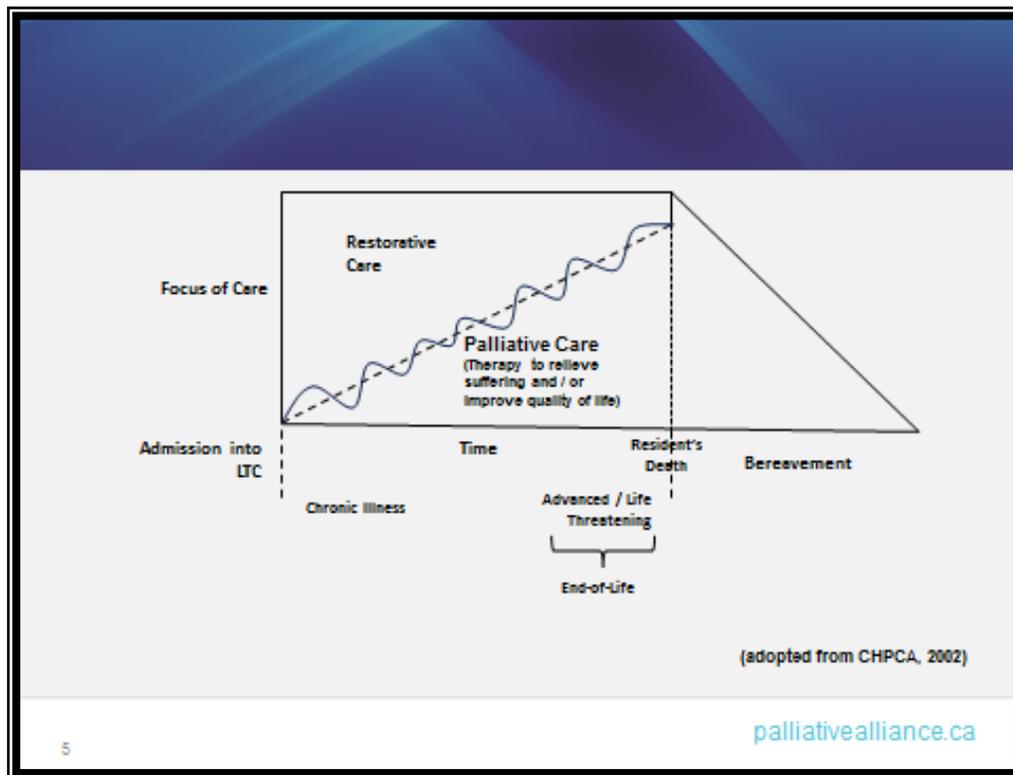
What is Palliative Care?

- complements and enhances restorative care and in later stages may become the total focus of care
- appropriate for any patient and family living with, or at risk of developing a life-threatening illness due to any diagnosis, any prognosis, regardless of age, at any time they have unmet expectations and/or needs and are prepared to accept care”

(CHPCA 2002)

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- Due to the increase support of homecare in the community many people moving into long term care homes have several health issues.
- Therefore long term care homes now support residents with several complicated medical issues and residents who are younger with severely debilitating diseases such as Multiple Sclerosis.
- It is important to note that palliative care can complement restorative care which will be depicted on the next slide.
- It is also important to note that palliative care is appropriate only when the resident and/or family, however defined by the resident, are ready to accept this type of care.
- Thus, it requires staff to mention to residents and families to talk about palliative care and care goals prior to beginning the talk about introducing palliative care goals within the resident’s care plan to ensure that the resident and family are fully understanding the resident’s disease trajectory and that they are prepared for such a discussion.



- This picture was adapted from the Canadian Hospice Palliative Care Model to better depict the trajectory of residents living in long term care homes.
- The bottom axis of the model shows the period of time a resident lives in long term care. Although the amount of time will differ from resident to resident on average residents live in long term care 18 to 24 months before dying.
- The side axis shows the focus of care through the resident's stay. When a resident moves into long term care he or she may have palliative care goals of care but will primarily have restorative goals of care.
- As the resident lives in long term care he or she will continue to change goals of care from restorative to palliative, however please note that they are complementary and do not take away from each other.
- End-of life care is the last section of palliative care before the resident dies.
- After the death of a resident there is a bereavement stage for families, residents and staff members.

*People aren't palliative...
the care they would benefit
from is!!!*

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- In order to help fight the stigma around palliative care it is beneficial to note that people are not palliative and that in fact the care is palliative, for example you don't refer to a resident as the 'gallbladder' in room 6, so you wouldn't refer to a resident as the palliative in room 6
- There is benefit in seeing the whole person and not just one thing such as heart failure or frailty.
- It is also important to note that palliative care benefits even those who are not diagnosed with a terminal condition.
- An example in long term care would be a 95 year old who is frail who is not diagnosed with a terminal illness. It would still be important to re-evaluate the resident's medications and goals of care throughout his or her stay in long term care as frailty can lead to death.

Then End-of-Life Care is?

EOL Care

- Multidisciplinary, holistic, client-centred
- Still focuses on symptom control but...
- Treatment goal not curative
- Death is inevitable PPS is 30% or less
- Trajectory is short (6 months)
- A greater focus is on supporting patient and family choices
- Anticipatory grief

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6

- End-of-Life care is the last stage in the palliative care trajectory before the resident dies.
- It is shorter in length. Generally its when the resident is actively dying.
- This stage can be confusing if a resident was recently transferred back to long term care from hospital. The hospital may indicate that the resident requires palliative care however the resident may improve once returned.
- End-of-life is a normal process where the focus is on the whole person and not a group of symptoms.
- At this point, it is important to look at the care plan to determine if it is resident-centred or if actions, such as requiring a resident to take medication even when the resident is refusing, is due to organizational policies or staff needs.
- The care plan should be review and evaluated by staff, residents, and families.
- It is important to: use bench marks such as the Palliative Performance Scale (PPS); follow organizational tools for end-of-life such as end-of-life orders; and for communication between staff members and families during this stage of care.

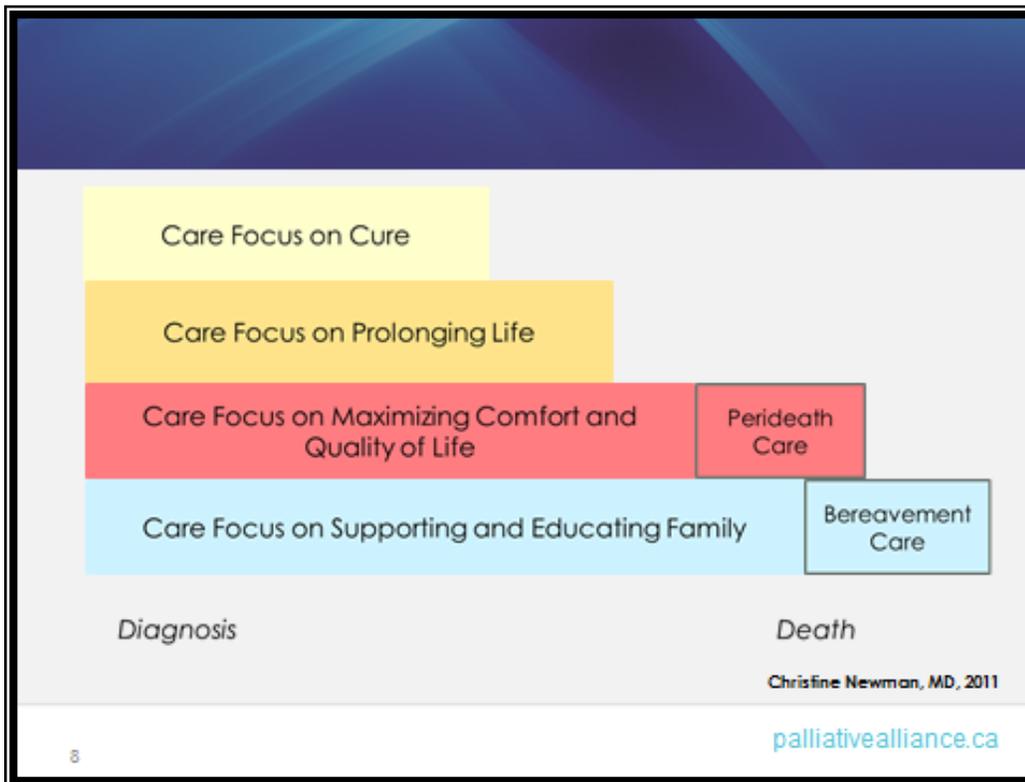
End-of-Life Care

- There are disease specific flags that indicate an increased possibility that the resident may die within the next 6 months. (*Disease Specific Markers*).
- The resident's health status has changed to a stage where medical management is maximized but no longer able to manage the symptoms and death has become inevitable. The resident's Palliative Performance Scale (PPS) has fallen below 50%.
- Goals of care must be reviewed and care planning done to include the End-of-Life Drs. Order Sheet if appropriate.

7

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- Tools such as the Disease Specific Markers can be red flags or cues that the resident is transitioning into end-of-life care
- The Palliative Performance scale which can be filled out by any nursing staff including personal support workers and can provide the interprofessional with insight on where the resident is on his or her care trajectory
- When the resident's PPS falls below 50% and death is inevitable the team should change the residents care plan to goals of care which reflect the palliative focus and residents wishes
- When the resident falls below 30% the resident is transitioning into end-of-life
- Goals of care should be reviewed as the resident is transitioning and end-of-life care doctors orders should be completed when appropriate according to your organizational policies.



- Often times the goal of providing care to residents is to provide them with the longest life possible without sacrificing quality of life
- Symptoms should be controlled as best as possible through: management of pain through pharmacological and non-pharmacological therapies, management of medication, maximizing comfort
- This diagram shows that the goals of the care plan should shift overtime from a curative focus to supporting and educating the family
- One component that we should not forget about is the bereavement care of the families, other residents, and staff members

Palliative Approach Assessment

1. Would you be surprised if the resident died within the next year?
2. Have there been hospital admissions recently?
3. Are there distressing physical or psychological symptoms?
4. What are the goals of care? What is the resident's/family's understanding of the disease processes, prognosis, and treatment options?
5. Are there significant social or spiritual concerns affecting daily life? (Limited social support)
6. Has the resident and family (if applicable) participated in advance care planning?
7. Has resuscitation been discussed?

10

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- After completing the palliative approach assessment the team can determine if the resident would benefit from a palliative approach
- If it is decided that yes the person would benefit a conversation should take place with the team, family, and resident (if possible).
- It is important to note that conversations with residents and families should be non-threatening
- Residents and families must also agree that palliative care planning is appropriate or this should not continue

Criteria

- The 'surprise question' has been answered 'no' (Would you be surprised if the resident died within 12 months?)
- Difficult to control physical or psychological symptoms and more than one admission to hospital in the last several months
- Complex care requirements
- Decline in function, food and fluid intake, and unintended weight loss
- Cognitive impairment
- Disease Specific Makers and Palliative Performance Scale

Palliative Performance Scale (PPSv2)
Version 2

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

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- This slide shows the palliative performance scale (PPS). This tool can support staff communication when residents are transitioning through levels of care
- Please note that 70-100% is stable 40-60% is transitional (would benefit from increased palliative care focus) and 0-30% indicates that a resident is at end-of-life

Disease-Specific Markers Indicating End-of-Life is Near

- Hepatic Disease
- Heart Disease
- Pulmonary Disease
- Renal Disease
- Dementia
- Cancer

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15

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- Refer to the appendices for Disease Specific Markers that should alert the care provider that the disease has become end-stage. i.e. frequent bouts of aspiration pneumonia in a resident with advanced dementia.

Components of a Palliative Approach Assessment

Includes:

- a pain/symptom assessment
- a social/spiritual assessment
- an assessment of the individual/family's understanding of the illness, prognosis, and treatment options
- an identification of resident-centered goals of care.

12

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- It is important for the team to come together and do resident and family assessments
- When a resident requires palliative or end-of-life care, staff should ask “who is this benefiting?” when creating a care plan or providing care to ensure a resident centered approach
- One example could be that your organizational policy may require a resident who is bed bound be turned every hour to avoid bedsores. This is a logical and beneficial policy however if the resident is at end-of-life and he or she is in significant pain when turned, are you considering the best interest of the resident for comfort care?

PATH: A New Approach to End-of-life Care

Due to advances in medical care, aging patients have survived the accumulation of many chronic diseases, including dementia. In an effort to help foster decision making and plan ahead to meet the challenges of end-of-life care in dementia, two physicians created the PATH model, a process which promotes careful consideration of the complex issues relevant to frail older adults nearing the end of their lives.

By Paige Moorhouse, MD, MPH, FRCPC; and Laurie Mallery, MD, FRCPC

16

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- This is one example of an interesting approach to understanding and incorporating whole person care into planning for quality end of life care in chronic diseases which include dementia and frailty.

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Table 1

Pre-palliative Era of Cancer Care vs. Current End-of-life Care for Frail Older Adults

Pre-palliative Era of Cancer Care

- Information regarding diagnosis withheld
- Lack of awareness of palliative care in cancer
- Comfort care may be withheld leading to patients dying in pain
- "Cure culture"
- Spiritual approach at odds with medical care of the dying

Current End-of-life Care for Frail Older Adults

- Complexity of comorbidities and lack of applicable evidence-based medicine may lead to avoidance of prognosis discussions
- Lack of awareness of implications of frailty
- Lack of attention to how frail patients die
- Comfort care may be withheld leading to patients dying in pain
- Futile treatments may be offered
- Insensitivity to the needs of the dying patient and his or her family

Table 2

The Domains of the CGA^{14,15}

- Cognition: memory, executive function, emotion and behavioral symptoms
- Mobility: transfers and ambulation, falls, balance
- Function: instrumental and basic activities of daily living
- Nutrition: appetite, weight loss, bowel and bladder function
- Social situation: living arrangements, formal and informal assistance, and caregiver stress
- Comorbidities
- Medications

Moorhouse & Mallory, The Canadian Review of Alzheimer's Disease & Other Dementias

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Table 3

PATH Decision Framework

Questions to Ask During a Health Crisis

1. Which health conditions are easily treatable? Which are not?
2. How many patients are diagnosed as frail? How will frailty make treatment risky?
3. How can symptoms be safely and effectively managed?
4. Will the proposed treatment improve or worsen function and memory?
5. Will the proposed treatment require time in hospital? If so, for how long?
6. Will the proposed treatment allow more good quality years, especially at home?
7. What can we do to promote comfort and dignity in the time left?

Moorhouse & Mallory, The Canadian Review of Alzheimer's Disease & Other Dementias

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Questions?
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Discussion?

Further Information

Visit our website

www.palliativealliance.ca

Contact us

Email: palliativealliance@lakeheadu.ca

Phone: (807)766-7267

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For additional information, please contact:

Centre for Education
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Aging & Health

Lakehead
UNIVERSITY

Centre for Education and Research on Aging and Health (CERAH)

955 Oliver Road

Thunder Bay, Ontario P7B 5E1

Telephone: 807-766-7271

Fax: 807-766-7222

Website: www.palliativealliance.ca