Palliative Approach to Chronic Disease Management versus End-of-Life Care
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
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
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)
Restorative Care

Admission into LTC

Chronic Illness

Focus of Care

Time

Resident’s Death

Bereavement

Palliative Care
(Therapy to relieve suffering and / or improve quality of life)

Advanced / Life Threatening

End-of-Life

(adopted from CHPCA, 2002)
People aren’t palliative… the care they would benefit from is!!!
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
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.
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?
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
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.
Care planning is done around the resident’s wishes for treatment options, with an emphasis on comfort and quality of living while maximizing medical management of the disease process. The care plan will be adjusted as there are changes in health status and in collaboration with all members of the resident’s health care team, especially the resident and family/SDM. This approach will enable the team to respond to changes and health care crisis more proactively and affect a more acceptable transition to End-of-Life (EOL) care at the appropriate time.
<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100 %</td>
<td>Full</td>
<td>Normal activity &amp; work No evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90 %</td>
<td>Full</td>
<td>Normal activity &amp; work Some evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80 %</td>
<td>Full</td>
<td>Normal activity &amp; work Some evidence of disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70 %</td>
<td>Reduced</td>
<td>Unable Normal Job/Work Significant disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60 %</td>
<td>Reduced</td>
<td>Unable hobby/house work Significant disease</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or confusion</td>
</tr>
<tr>
<td>50 %</td>
<td>Mainly sit/lie</td>
<td>Unable to do any work Extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or confusion</td>
</tr>
<tr>
<td>40 %</td>
<td>Mainly in Bed</td>
<td>Unable to do most activity Extensive disease</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>30 %</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>20 %</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive Disease</td>
<td>Total Care</td>
<td>Minimal to sips</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>10 %</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity</td>
<td>Total Care</td>
<td>Mouth care only</td>
<td>Drowsy or Coma +/- Confusion</td>
</tr>
<tr>
<td>0 %</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Disease-Specific Markers Indicating End-of-Life is Near

- Hepatic Disease
- Heart Disease
- Pulmonary Disease
- Renal Disease
- Dementia
- Cancer
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
<table>
<thead>
<tr>
<th>Pre-palliative Era of Cancer Care</th>
<th>Current End-of-life Care for Frail Older Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information regarding diagnosis withheld</td>
<td>Complexity of comorbidities and lack of applicable evidence-based medicine may lead to avoidance of prognosis discussions</td>
</tr>
<tr>
<td>Lack of awareness of palliative care in cancer</td>
<td>Lack of awareness of implications of frailty</td>
</tr>
<tr>
<td>Comfort care may be withheld leading to patients dying in pain</td>
<td>Lack of attention to how frail patients die</td>
</tr>
<tr>
<td>“Cure culture”</td>
<td>Comfort care may be withheld leading to patients dying in pain</td>
</tr>
<tr>
<td>Spiritual approach at odds with medical care of the dying</td>
<td>Futile treatments may be offered</td>
</tr>
<tr>
<td></td>
<td>Insensitivity to the needs of the dying patient and his or her family</td>
</tr>
</tbody>
</table>
Figure 1
Model of Care Planning for a Patient with Dementia

- Self-efficacy for future healthcare decisions
- Decision making for present health
- Life expectancy
- Risk of adverse outcomes
- Quality of life

- Comprehensive assessment
- Delineate comorbidities
- Comprehensive geriatric assessment (CGA)

Moorhouse & Mallory, The Canadian Review of Alzheimer’s Disease & Other Dementias
Table 2

The Domains of the CGA\textsuperscript{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
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?
Questions?
Comments?
Discussion?
Further Information

Visit our website
www.palliativealliance.ca

Contact us
Email: palliativealliance@lakeheadu.ca
Phone: (807)766-7267

Special Thanks to…