Meeting the Needs of People at the End of Life: The End of Life (Last Hours to Days) Pathway Revision Project

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Covenant Health Research Day 2017
Conflict of Interest - Declaration

- I have no conflict of interests to declare
Objectives

• Describe the rationale and process for the creation of the End of Life (Last Hours to Days) Pathway revision (referred to as the EOL Pathway)

• Outline how Covenant Health becomes a “Living Lab” in the pilot project for implementing the updated End of Life Pathway
What is the End of Life Pathway?

- A tool to enhance quality of care by:
  - improving outcomes
  - promoting safety
  - increasing satisfaction with care
  - optimizing the use of resources

- Guidance for any member of the health care team

- A coordinated approach to care and communication

- Within any care setting

When a person is identified being in their last few hours or days of life
• Standardizes care
• Best practice
• Outlines care and interventions
• Continuing Care Health Service Standards
• Does not replace clinical judgement
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997</td>
<td>Liverpool Care Pathway (LCP) developed and utilized across United Kingdom</td>
</tr>
<tr>
<td>2005</td>
<td>Identified by Continuing Care Accreditation (Edmonton region) a lack of evidence to indicate standard for end of life care was being met</td>
</tr>
<tr>
<td>2005-2011</td>
<td>Development and Implementation of the Palliative Care Pathway in all Covenant Health Continuing Care facilities and rural acute care sites. AHS rolled it out and supported the use in all Edmonton Zone Continuing Care Centers</td>
</tr>
<tr>
<td>2013</td>
<td>United Kingdom government commissioned an independent review of the LCP key recommendations to phase out LCP by July 2014. Issues of concern included: how persons were chosen and placed on the LCP; communication with patients and families; appropriateness of withholding or discontinuing hydration and/or nutrition; usage of medications causing undue sedation; and lack of an evidence based approach to care</td>
</tr>
<tr>
<td>2014</td>
<td>In response to the criticisms of the LCP, Covenant Health developed a Palliative Care Pathway Policy &amp; Procedure, and revised and rereleased the Palliative Care Pathway to align with C2 Goals of Care Designation</td>
</tr>
<tr>
<td>2015</td>
<td>Audits demonstrated that the Palliative Care Pathway was used for approximately 30% of those who died on site, and informal feedback from frontline staff indicated the Palliative Care Pathway was time consuming. Decisions made to review and revise the Palliative Care Pathway</td>
</tr>
<tr>
<td>2016</td>
<td>In collaboration, Covenant Health &amp; AHS created the End of Life (Last Hours to Days) Pathway and will begin piloting in spring 2017</td>
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</table>
Provides instruction and guidance on when to initiate and how to use the End of Life (Last Hours to Days) Pathway.
Initial Care Needs’ Assessment (Part 2 of 6)

- Identifies care and resource needs for persons identified as being in the last hours to days of life
- Initiated by the Physician, Nurse Practitioner (NP), RN, RPN, or LPN
- To be competed within 24 hours
C2 Medication and Care Orders (Part 3 of 6)

- Addresses the most common end of life symptoms and care needs
- To be completed by the MRHP (Physician/NP)
- Provides a process of communication for unmanaged symptoms
- Options for individualized care orders
Common Symptoms & Care Needs at End of Life

**Common Symptoms**
- Pain
- Dyspnea (Shortness of breath)
- Agitation
- Respiratory Secretions
- Nausea &/or Vomiting

**Care Needs**
- Hydration & nutrition
- Mouth care
- Skin integrity
- Personal care
- Bowel care
- Urinary care

**Psychosocial and Spiritual Needs**
- For the dying person
- For the family/others
• Identifies most common symptoms, care and psychosocial needs at end of life

• Includes care of the family
Symptom & Care Assessment and Documentation (Part 4 of 6)

End of Life (Last Hours to Days) Pathway

RN/RPN/LPN to assess, monitor and evaluate symptoms at least every **4 hours** in Acute Care, Facility Living and Designated Supportive Living; and a minimum of once daily in Private Supportive Living and Home Care settings.

- Circle (Y) if goal **has been met**
- Circle (N) if goal **has not been met** and document in progress notes
- Circle (NA) if the symptom is **not applicable** to the person's condition

<table>
<thead>
<tr>
<th>Day 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date: __________</td>
</tr>
<tr>
<td>Date Pathway Initiated: __________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Is the person able to communicate concerns?</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td></td>
<td></td>
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<tr>
<td></td>
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</tbody>
</table>

**Pain**

Goal: The person's pain is controlled

- Verbalized by person, if able
- Observe for non-verbal cues (facial grimacing, furrowed brow, guarding); however, these may also be present with delirium
- If pain is identified, address any contributing factors such as urinary retention, constipation, need for repositioning
- Consider use of pain assessment tool
- Educate family if patient settles quickly after repositioning, moaning may be related to person's awareness rather than discomfort
### Mouth Care

**Goal:** The person’s mouth is moist and clean

- Mouth care every two hours and as needed for comfort
- Recommend cleaning mouth at least 4 times daily with club soda
- Inspect oral cavity and mucus membranes for dryness, sores and oral candida at least once daily
- Ensure dentures are removed and cleaned once daily
- Use mouth moistening products as needed
- Educate and include family/others in mouth care if they wish to be involved
- Refer to your organization’s mouth care policy

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**RN/RPN/LPN to review End of Life (Last Hours to Days) Pathway with MRHP every 3 days to ensure appropriateness and alignment with person’s/ADM’s goals of care. RN/RPN/LPN to initial when review completed with MRHP.**

<table>
<thead>
<tr>
<th>Decision made to continue with End of Life (Last Hours to Days) Pathway</th>
<th>Yes ☐ No ☐</th>
<th>Date &amp; Time: ______________</th>
</tr>
</thead>
</table>

If no reason Pathway discontinued: ______________

Initial: ______________
Family and Healthcare Provider Communication Notes

(Part 5 of 6)

End of Life (Last Hours to Days) Pathway

Family and Healthcare Provider Communication Notes

(Part 5 of 6)

The healthcare team will have explained to you that there has been a change in your relative’s or friend’s condition. They believe that the person you care about is now dying and in the last few hours or days of life.

A personalized care plan has been created to achieve the best quality of life for the person you care about. This End of Life Pathway is a tool to ensure your relative/friend will be cared for in a manner that meets their goals and wishes. It is not unusual for a person’s health and needs to change. The healthcare team will continue to assess and change the care plan as needed. If the person is able to they and their family are included in these discussions.

Some people like to have information that they can read and that would help with end of life planning. We can provide you information on such things as: what to expect when someone is dying, a list of important phone numbers, organizations and supports and ways to help care for someone who is dying.

Caring for your relative or friend is very important to us. Please let us know how we can support and help you. We welcome your questions comments or concerns. Please use the space on the back of this page to write them down so they can be shared and addressed with the healthcare team on a regular basis. If you have any questions that need answers urgently please let your nurse know.

Important things you think we should know about the person you care about and the best way to care for them (Lifestyle, beliefs, medical history, etc).

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### Questions & Notes

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Name</th>
<th>Question/Comment/Concern</th>
<th>Addressed by a member of the healthcare team and documented in progress notes (<em>Y and N</em>)</th>
</tr>
</thead>
</table>

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**Ongoing Communication**

Goal: The family/other are able to have their questions and concerns addressed regularly

- Review Family & Healthcare Provider Communication Notes (Part 5 of 6) at least once daily addressing questions, comments and concerns. Document addressed concerns, comments, and questions in progress notes.
1. A compilation of resources that healthcare providers can utilize to support the dying person and their family
   • White Rose (not yet available)
   • Comfort Cart/Cupboard Information Sheet
   • “Caregiver Resource When Someone is Dying”
   • “What to Expect as Death Approaches” (not yet available)
   • Provincial Grief & Bereavement Package (not yet available)

2. A listing of references used to develop the End of Life Pathway
Please stop at the nursing station prior to entering.

### Resources

#### End of Life (Last Hours to Days) Pathway: Comfort Cart Ideas

<table>
<thead>
<tr>
<th>Hygiene and Comfort (Items not to be reused)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Tissues</td>
</tr>
<tr>
<td>- Soap</td>
</tr>
<tr>
<td>- Lotion</td>
</tr>
<tr>
<td>- Toothbrush</td>
</tr>
<tr>
<td>- Toothpaste</td>
</tr>
<tr>
<td>- Combs</td>
</tr>
<tr>
<td>- Hand Towels (from hospital facility)</td>
</tr>
<tr>
<td>- Hand Wipes/Cleansing products (from hospital facility)</td>
</tr>
<tr>
<td>- Chair that turns into a bedcot</td>
</tr>
<tr>
<td>- List of accommodations in the area</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Miscellaneous</th>
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</thead>
<tbody>
<tr>
<td>- Flameless candle</td>
</tr>
<tr>
<td>- Paper and pen</td>
</tr>
<tr>
<td>- Personal Memoir (butterfly, nurse, angel)</td>
</tr>
<tr>
<td>- Various craft supplies for making memories</td>
</tr>
<tr>
<td>- Handprint making tools</td>
</tr>
<tr>
<td>- Handwashing soap</td>
</tr>
<tr>
<td>- Paints</td>
</tr>
<tr>
<td>- Power Arrangements</td>
</tr>
<tr>
<td>- Night Lamps</td>
</tr>
<tr>
<td>- Power Bar</td>
</tr>
<tr>
<td>- Power strip or soft light</td>
</tr>
<tr>
<td>- Portable CD player</td>
</tr>
<tr>
<td>- CD’s: instrumental and meditational</td>
</tr>
<tr>
<td>- Sketches or videos</td>
</tr>
<tr>
<td>- Audio recorder to record personal messages</td>
</tr>
<tr>
<td>- USB: digital memory card to take pictures</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For Children (Items not to be re-used)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Crayons</td>
</tr>
<tr>
<td>- Coloring books</td>
</tr>
<tr>
<td>- Toys</td>
</tr>
<tr>
<td>- Children’s books</td>
</tr>
</tbody>
</table>

#### White Rose Program

Please stop at the nursing station prior to entering.

#### Comfort Cart

- Tissues
- Soap
- Lotion
- Toothbrush
- Toothpaste
- Combs
- Hand Towels (from hospital facility)
- Hand Wipes/Cleansing products (from hospital facility)
- Chair that turns into a bedcot
- List of accommodations in the area

#### Caregiver Resources

**Caregiver Resources When Someone Is Dying**

- **MyHealth Alberta**
  - Website: [https://myhealth.alberta.ca/palliative-care](https://myhealth.alberta.ca/palliative-care)
  - Phone: 811 (24 hours a day, 7 days a week)
  - Provides information on symptom management, what to expect in the last few days of life, videos, public education, grief and bereavement, and links to the following organizations:
    - Palliative Care (financial aid for medications and ambulance)
    - [Phone: 1-877-644-0922](tel:1-877-644-0922)
    - [Counseling Services](https://www.myhealth.alberta.ca/palliative-care/counseling-services.html)
    - [Coping with Grief](https://www.myhealth.alberta.ca/palliative-care/coping-with-grief.html)
    - [Advance Care Planning and Goals of Care Discussions](https://www.myhealth.alberta.ca/palliative-care/advance-care-planning-and-goals-of-care-discussions.html)
    - [Palliative Care Services](https://www.myhealth.alberta.ca/palliative-care/palliative-care-services.html)
    - [Virtual Palliative Care](https://www.myhealth.alberta.ca/palliative-care/virtual-palliative-care.html)
    - [Alberta Palliative Care Hospice Association](https://www.albertapalliativecare.ca)
    - [Alberta Organ and Tissue Donation Registry](https://www.myhealth.alberta.ca/palliative-care/organ-donation-registry.html)
Literature Review


• Pallium Canada. (2016). *The Pallium Palliative Pocketbook: a peer-reviewed referenced resource (2nd ed.)*. Ottawa, Canada

• All final drafts of the pilot documents were formulated in consultation with key stakeholders

• Final decisions for the pilot draft of the C2 Medication and Care Order Set were formulated by the C2 Medication Order Set Consensus Committee
Evaluation Considerations

The Question

Did the EOL Pathway make a difference in the quality of care the person received allowing for “a good death”?

• Variance Analysis?
  • Staff Satisfaction Survey
  • Family Satisfaction Survey
    • FAMCARE 2
  • Chart audit
    • Paper documentation
    • Electronic
      • Point Click Care – Point of Care

• Demographic information
  • Utilization of EOL Pathway
    • For those persons’ deceased how many had their care guided by the EOL Pathway?
End of Life Pathway Pilot Plan

- Urban Acute Care
  - Medicine
  - Emergency Department?
  - ICU/CCU?
- Rural Acute Care
- Rural Continuing Care
- Urban Continuing Care
  - St. Joseph’s Auxiliary Hospital, Edmonton
- Supportive Living
  - St. Therese Villa, Lethbridge
The End of Life Pathway as a Living Lab

- Patient & Family
- Interdisciplinary Team
- Increased performance
- Research
- Setting
- Collaboration
- Innovation
- Community
- User needs
- Real world issue

Increased performance

Patient & Family

Community

Innovation

Collaboration

Setting

Research

Interdisciplinary Team

User needs

Real world issue
Outcomes, Recommendations, Knowledge to Action

Inconsistent approach to quality end of life care

Electronic & paper documentation
Education
Standardized tools & resources
Covenant Health & AHS care settings

Check in Emerging Issues
Chart Audit
Staff Satisfaction Survey
Family Satisfaction Survey

Select, Tailor, Implement Interventions
Assess Barriers to Knowledge Use
Adapt Knowledge to Local Context

Monitor Knowledge Use
Knowledge Inquiry
Knowledge Synthesis
Knowledge Tools / Products

Identify Problem
Identify, Review, Select Knowledge

Evaluate Outcomes
Sustain Knowledge Use

Inconsistent approach to quality end of life care

http://ktclearinghouse.ca/knowledgebase/knowledgetoaction
Thank you!

Questions?
Comments?
Suggestions?