

# Walking Alongside Indigenous Peoples who are Seriously Ill: Education for Community Caregivers



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**Presenters:**

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**Date:** January 19, 2023

# Territorial Honouring



# The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

**Stay connected: [www.echopalliative.com](http://www.echopalliative.com)**

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.



# LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by CFPC and Royal College.



Learn more about the course and topics covered by visiting

[www.pallium.ca/course/leap-core](http://www.pallium.ca/course/leap-core)

# Introductions

## Host

**Stephanie Hendrickson, MSW**

Knowledge Broker, CERAH

## Presenters

**Holly Prince, MSW PhD. (Candidate)**

**Jessica Wyatt, MA, PMP**

**Kassandra Fernandes, MPH, PhD. (Candidate)**

# Conflict of Interest

## Pallium Canada

- Non-profit
- Partially funded through a contribution by Health Canada
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Pocketbook

## Host/Presenters

- Stephanie Hendrickson: None
- Holly Prince: Member of the Don Green Palliative Care Advocacy Team, Canadian Cancer Society, Consultant for the Canadian Virtual Hospice, Consultant for Healthcare Excellence Canada
- Jessica Wyatt: None
- Kassandra Fernandes: None

# Welcome and Reminders

- For comments, please use the chat function.
- For questions, please use the Q&A function, these questions will be addressed at the end of the session.
- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week.



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Aging & Health

# Walking Alongside Indigenous People who are Seriously Ill: Education for Community Caregivers





# Acknowledgements



- Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill
- Curriculum Advisory Committee

# Learning Objectives

- Understand the process undertaken by the CERAH education team to create a culturally and community appropriate caregivers' curriculum.
- Explore the newly developed caregiver curriculum and identify ways to incorporate the into practice.



# Narrative Case Story

*“In First Nations communities, there are a lot of different diseases that have no cure, and that do impact. So [we] would benefit from the palliative approach earlier on, things like diabetes and those kinds of things. Doing education around that to build capacity within the First Nations communities is key.”*

*Improving End-of-Life Care in First Nations (EOLFN) Project, 2010-2015*



# Foundational Teachings for Curriculum Development Process

“Wellness from an Indigenous perspective is a whole and healthy person expressed through a sense of balance of spirit, emotion, mind and body. Central to wellness is belief in one’s connection to language, land, beings of creation, and ancestry, supported by a caring family and environment.”

*Elder Jim Dumont, 2014*



# Foundational Teachings for Curriculum Development Process

“Life is a circle, an ‘earth walk,’ a pathway followed throughout life, striving for completeness and wholeness in growing and developing spiritually... Dying is an important part of completing the circle. It is life’s journey coming to completion and the fulfillment of our purpose. In death, the body dies. The Spirit does not die but goes to the spirit world, to a place of understanding and wisdom, returning to the Creator.”

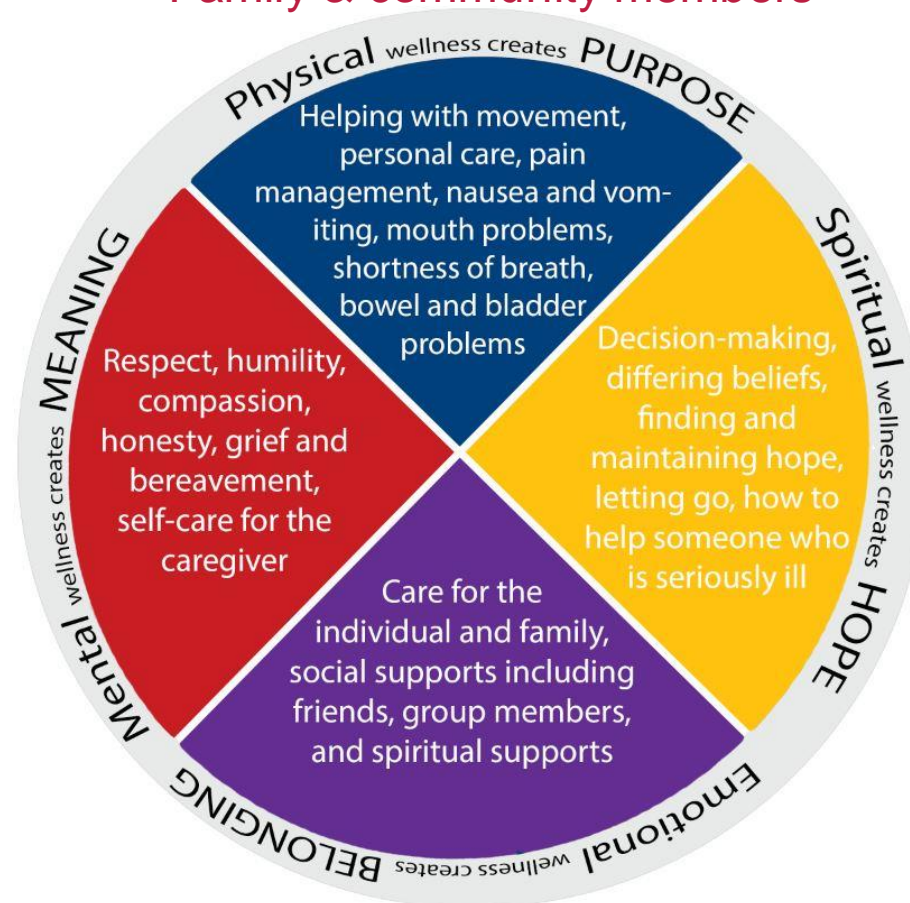
*Kinoshameg, Wikwemikong First Nation, 2017*

# Mobilizing Community Capacity

Home and Community Care, Primary Care, Public Health, Nurses, doctors, Traditional Healers

Family & community members

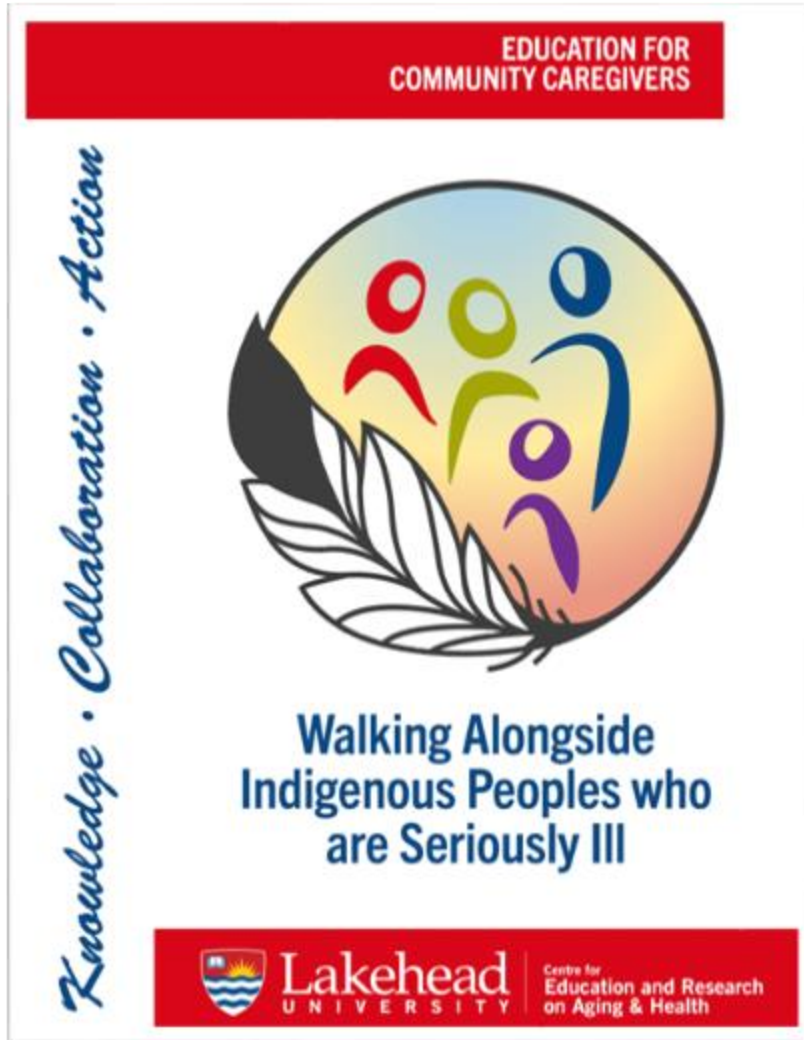
NNADAP, Crisis Intervention Programs, grief counsellors, CHR/CHE  
Family & community members



Elders, Traditional Wellness Programs  
Traditional Healers, clergy  
Family & community members

Informal caregivers, social workers, counsellors  
Family & community members

# Purpose of the Curriculum



To provide health care providers with tools & resources for delivering community-based education to families and community members caring for people who are seriously ill.

Health care providers are encouraged to have a baseline of knowledge and skills in chronic disease management.

# Palliative Care for Front-line Workers in Indigenous Communities



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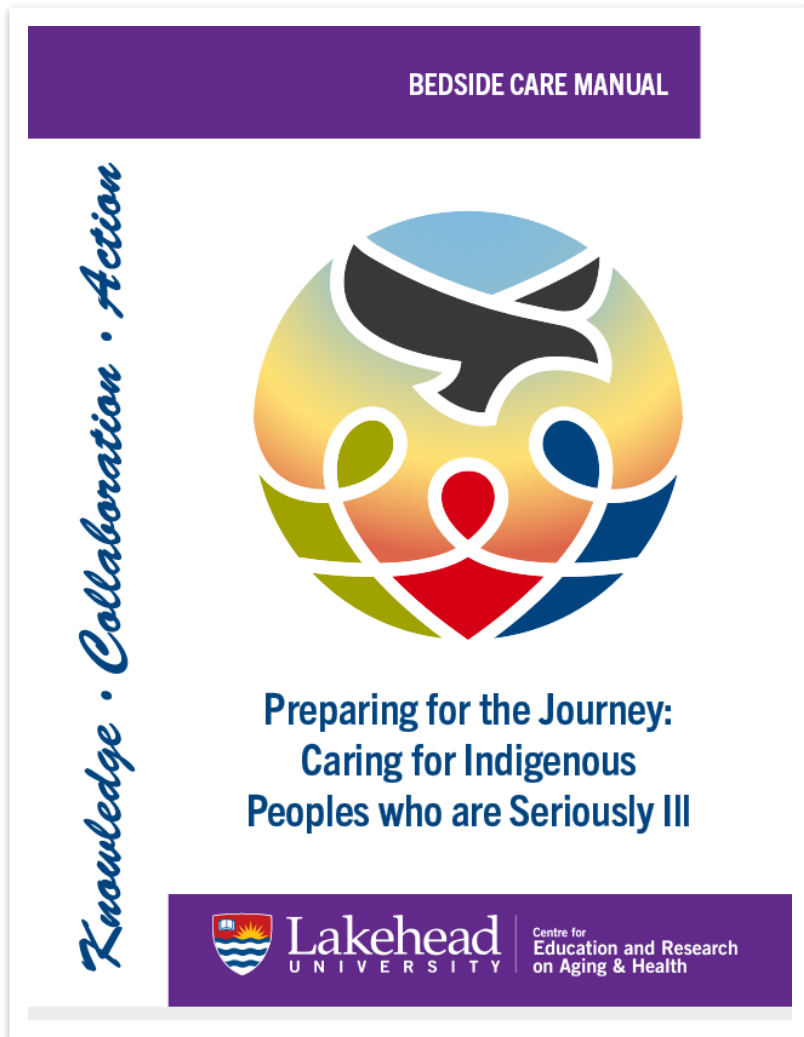
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Research on Aging & Health



# This curriculum may be of value to health care providers who:

- Want to create awareness in the community about chronic disease management;
- See an opportunity to inform more people about advance care planning and making individual wishes known;
- Have other health care providers who are new to the field or need some guidance in developing a care plan;
- Have a family or community caregiver who has questions about caregiving; and
- Have a family or community caregiver who would benefit from instruction in learning particular skills at the bedside.

# Overview of the Curriculum



*Walking Alongside* builds upon content from the *Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill* manual

*Preparing for the Journey* is based on clinical best practices. It focuses on meeting the wholistic needs of individuals and caregivers

# Overview of the Curriculum

1. The Indigenous Wellness Framework
2. Spiritual Wellness
3. Emotional Wellness
4. Mental Wellness
5. Physical Wellness
6. Making your Wishes Known
7. Developing a Care Plan
8. The Palliative Approach to Care
9. Last Weeks or Days of Life

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# Curriculum Components

- Slide Decks with Speaker Notes
- Supporting Resources
  - Videos
  - Handouts
  - Pamphlets
  - Activities



# Slide Decks (PowerPoint)

The screenshot shows a PowerPoint presentation with the following content on the main slide:

- Logo:** Lakehead University Centre for Education and Research on Aging & Health
- Title:** Managing Illnesses and Conditions: Cancer
- Subtitle:** Walking Alongside Indigenous People who are Seriously Ill: Education for Community Caregivers
- Image:** A circular logo featuring stylized human figures in red, green, and blue, with a white feather on the left.

The slide deck includes a table of contents on the left with six slides:

- Managing Illnesses and Conditions: Cancer
- This module is for nurses/registered staff to use to train non-registered staff.
- Indigenous Wellness Framework
- CARING FOR A LOVED ONE WITH CANCER
- Wholistic Approach
- What is Cancer?

The status bar at the bottom indicates: Slide 1 of 32, English (Canada), Accessibility: Investigate, 77% zoom.

## Indigenous Wellness Framework



Model adapted from the National Native Addictions Partnership Foundation, Honouring Our Strengths: Indigenous Culture as Intervention in Addictions Treatment Project - University of Saskatchewan, 2014


## Ways to Support...



- Keep people company - talk, watch movies
- Respect their need for privacy and quiet time
- Listen to them talk about their hopes, wishes, fears, regrets
- Don't give advice - help people find their own answers to problems
- Understand that "hope" may change

# Slide Decks with Speaker Notes

**Last Weeks or Days of Life – Speaker's Notes**  
*Walking Alongside Indigenous Peoples who are Seriously Ill: Developing a Care Plan*



**Other Changes at End of Life**

- Eating and drinking less
- Coolness
- Loss of control of bladder and bowels
- Congestion
- Changes in breathing patterns
- Withdrawal
- Decreased socialization
- Vision-like experiences


**Eating or drinking less:** Although this is a normal part of the dying process, it is often a difficult time for family and friends. It is important to talk about feelings and fears. Do not force the person to take food or fluids. The body prepares naturally for end of life with the organs shutting down and not working well. Feeding them may increase the person's discomfort. Keep them comfortable by giving them food and fluids they want and keeping their mouth moist with gentle mouth care.

**Coolness:** The hands, arms, feet and then legs may become cool to the touch. The face may be pale, and the feet and legs a purple-blue mottle colour. This indicates that the blood flow is decreasing to the body's extremities and is being saved for the most important organs. Keep the person warm with blankets, using just enough to keep him/her comfortable. Avoid using an electric blanket.


**Loss of control of bladder and bowels:** The person may lose control of their bladder and bowels as the muscles in these areas begin to relax when the end of life is very near. Find out about appropriate padding, and/or use of an incontinence product.

**Congestion:** There may be loud gurgling sounds coming from the person's throat or chest. This is because the person is unable to swallow saliva, and does not mean that she/he is uncomfortable. Avoid suctioning. Turn the person's head to the side and allow gravity to drain the saliva. You can wipe the mouth with a moist cloth.

**Changes in breathing patterns:** Breathing may be irregular and may stop for 10 to 30 second periods (Chayne-Stokes respirations). She/he may experience periods of rapid, shallow pant-like breathing. After someone dies there may be a "last sign" or gurgling sound. Raising the head of the bed or turning the person to the side will help. Hold the person's hand and speak softly. Note if the person is comfortable by how they look, facial expressions, and movements in the bed.

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**Spiritual Wellness – Speaker's Notes**  
*Walking Alongside Indigenous Peoples who are Seriously Ill: Developing a Care Plan*



**Leaving Gifts for Loved Ones**


There are seven things that people usually focus on as they become sicker:

1. Relationships
2. Giving Gifts
3. Meaning
4. Growing and Learning
5. Hope
6. Spirituality and Religious Belief
7. Peace

(Foley et al., 2005)

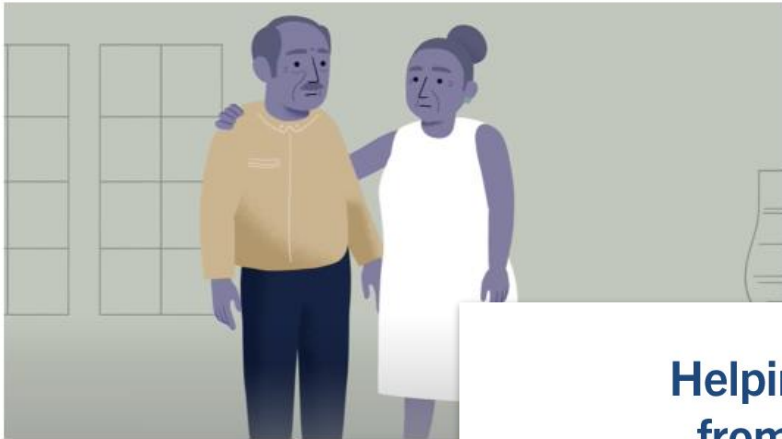
It is not unusual for people to wonder about what kind of legacy they will be leaving behind (the gifts, memories, stories, or other pieces of them that live on – the mark they leave on the world/family/community/friends).

1. Relationships: What can I do to strengthen or repair my relationships with those I care about most? Do the people who mean the most to me know how much I care about them?
2. Giving Gifts: What can I pass on to others? How can I share what I have and what I know to help and bless other people? What is the legacy I want to leave for others?
3. Meaning: What has given my life purpose and value? What gives it purpose and value now?
4. Growing and Learning: What can I learn about myself (and about life)? What opportunities does my situation (including my illness) provide for me and for others? What do I want to do with this time?
5. Hope: What specific good things can I look forward to with confidence?
6. Spirituality and Religious Belief: What is the nature of my relationship with God or a higher spiritual being? What can I do to strengthen or repair my relationship with God or the Creator?
7. Peace: How can I feel settled in my spirit? How can I be confident that, ultimately, all will be well with me?

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# Videos

What's normal?



Fear of Pain Medication



Helping Someone Move from a Bed to a Chair



# Helping Someone Change Positions in Bed

Walking Alongside Indigenous  
People with the Support of All  
Education for Community  
Change

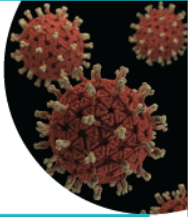
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# Handouts

**carechannel** CAREGUIDE

## Dos & Don'ts For Preventing Infection




Do	Don't
<ul style="list-style-type: none"> <li>Wash your hands often — soap is a must! See our Careguide on handwashing.</li> </ul>	<ul style="list-style-type: none"> <li>Shake hands. Simply explain you are a caregiver and no offense is intended. People will understand.</li> </ul>
<ul style="list-style-type: none"> <li>If soap and water are not available, use hand sanitizer with at least 60% alcohol.</li> </ul>	<ul style="list-style-type: none"> <li>Go to work if you don't feel well. (So you don't spread your virus to others)</li> </ul>
<ul style="list-style-type: none"> <li>Cut your finger nails! We all know to wash our hands but germs can hide just under long nails.</li> </ul>	<ul style="list-style-type: none"> <li>Touch your face.</li> </ul>
<ul style="list-style-type: none"> <li>Postpone birthdays and anniversaries. Cancel all group dining, celebrations and events.</li> </ul>	<ul style="list-style-type: none"> <li>Share towels, face cloths, cups, dishes or cutlery.</li> </ul>
<ul style="list-style-type: none"> <li>If you feel ill, avoid crowds – see our careguide on self-isolation.</li> <li>Isolate the person you are caring for to protect them from any viruses.</li> <li>In times of pandemic, limit the care recipient to contact with 2 people: yourself and the backup caregiver</li> </ul>	<ul style="list-style-type: none"> <li>Attend meetings, parties, shows or large social gatherings</li> <li>Attend any weekly club meetings (consider attending remotely, using technology, if possible.)</li> </ul>
<ul style="list-style-type: none"> <li>Actively screen yourself for symptoms of: sore throat, fever, cough, difficulty breathing, confusion, blueness in lips. See a doctor right away if you think you are sick. Phone ahead to tell them you are coming.</li> </ul>	<ul style="list-style-type: none"> <li>Wear artificial nails or nail enhancements. They are more difficult to clean and have been known to carry germs.</li> </ul>
<ul style="list-style-type: none"> <li>Cough into your elbow or a tissue. You want to avoid blowing moisture droplets into the air.</li> </ul>	<ul style="list-style-type: none"> <li>Go to a public gym. (Consider exercising at home while sick.)</li> </ul>
<ul style="list-style-type: none"> <li>Use disinfectant wipes on all touch points (Bleach &amp; water work too): TV remotes /steering wheels / door knobs / fridge door handles / light switches / counter tops / kitchen cabinet doors / cell phone / mouse and keyboard / canes / walkers / wheelchair arm rests.</li> </ul>	<ul style="list-style-type: none"> <li>Travel, in general – no planes, trains or public transit.</li> </ul>
<ul style="list-style-type: none"> <li>Reschedule wellness appointments – look ahead at your care recipient's schedule. Cancel non-essential appointments.</li> </ul>	<ul style="list-style-type: none"> <li>Have close contact with people who are sick.</li> </ul>
<ul style="list-style-type: none"> <li>If available, get the appropriate vaccine.</li> </ul>	<p><b>As a caregiver, if you are looking after someone with a weakened immune system or she or he is identified as being in a high-risk group, here are some Dos and Don'ts to help prevent infection.</b></p>
<ul style="list-style-type: none"> <li>Be aware of common touch points outside the home: shopping cart handle, door handles or glass, your steering wheel, money, gas pump. Use cashless payments if possible.</li> </ul>	
<ul style="list-style-type: none"> <li>If the person you are caring for needs to be isolated and is dependent on you, wear PPE (Personal Protective Equipment). See our video on PPE.</li> </ul>	
<ul style="list-style-type: none"> <li>Wash your hands immediately after reading magazines or papers in medical offices or waiting rooms.</li> </ul>	

Funded by Ontario Ministry of Health and Long-Term Care. Views expressed in this guide are the views of Saint Elizabeth Foundation and do not necessarily reflect those of the Province © 2020.

## Supporting Relationships & Emotional Wellness

EMOTIONAL WELLNESS HANDOUT



Page | 1 of 1

Everyone has their own reaction to finding out that someone is seriously ill. As the individual becomes sicker, everyone, including the person, their family, and community members, will go through many different losses along the way.

Some of these reactions include:

- The person who is sick may begin to accept that their death is coming and what that means for the community;
- People may become very angry or hide their emotions completely;
- People may be frustrated and want to do more to help fix a situation that cannot be fixed;
- People may feel sadness and anxiety; and
- People may feel guilty because they feel some relief when the person dies and their suffering is over.

All of these reactions are very normal and it takes time for the community to get used to having a very sick member. Some people find it helpful to talk with others about their feelings and join together to support one another.

In a palliative approach to care, the person who is sick along with their family are supported throughout the end of life journey. The family might be made up of immediate members (children, parents, siblings), or members of extended family through marriage or chosen family, like friends and pets.

Many different things can impact a family's ability to care and cope with a loved one's death, including:

- Age
- Past experiences with loss or death
- Length of the illness
- Quality of the relationship
- Presence of social supports
- The dying person's role in the family and community

**Questions you and your loved one can think about:**

- How does your loved one and the family view the illness?
- Does your loved one or the family believe the timing of illness should be controlled and that the timing and nature of death can be influenced?
- Does your loved one or the family think it is important to be able to make their own decisions, or make decisions as a family?
- What personal and/or cultural beliefs does your loved one or the family have about serious illness and death?

**For more information about Emotional Wellness, please read pages 19-20 in *Preparing for the Journey: Caring for Indigenous People who are Seriously Ill* resource manual.**

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# Pamphlets

**REMEMBER**

Whether you know it or not, all people incapable of making personal health care decisions have a **SDM**. The SDM ranking in Ontario is similar to:

- 1) A court appointed SDM
- 2) Power of attorney for personal care
- 3) Someone appointed by the Consent and Capacity Board
- 4) Spouse or common law partner
- 5) Your children or your parent
- 6) Parent with right of access
- 7) Your brothers or your sisters
- 8) Any other relative

If there is no one to fill the role of SDM then the office of the Public Guardian and Trustee will assume control. You have the right to choose someone else or someone other than those listed. You can do this using a document called a **power of attorney for personal care**. You do **NOT** need a lawyer to choose a Substitute Decision Maker.

For more information on being an SDM or advance care planning please contact:

[www.advancecareplanning.ca](http://www.advancecareplanning.ca)  
[www.fraserhealth.ca](http://www.fraserhealth.ca)  
[www.acllaw.ca](http://www.acllaw.ca)  
[www.e-laws.gov.on.ca](http://www.e-laws.gov.on.ca) (*Health Care Consent Act, Substitute Decision Act*)

This brochure was prepared for use in Ontario. People living in other provinces or territories should consult the appropriate legislation. This brochure can be adapted to your jurisdiction.

Disclaimer: This material was prepared by the Improving End-of-Life Care in First Nations Communities research project and intended to provide general information. The contents do not constitute legal advice or legal recommendations and should not be relied upon as such.

**I HAVE BEEN ASKED TO BE A SUBSTITUTE DECISION MAKER (SDM) IN ONTARIO. WHAT DOES THAT MEAN?**

[www.eolfn.lakeheadu.ca](http://www.eolfn.lakeheadu.ca)

Photo: Health Canada/First Nations, 2011

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THE WAY FORWARD / ALLER DE L'AVANT

Government of Canada / Gouvernement du Canada

Canadian Hospice Palliative Care Association / Association canadienne de soins palliatifs

Quality End-of-Life Care / Soins palliatifs de qualité

CIHR IRSC

Publication of this brochure was made possible through a grant from the Canadian Institute of Health Research (CIHR) and Government of Canada. The views expressed herein do not necessarily represent the views of the CIHR or Government of Canada.

**Who Provides Palliative Care?**

A caregiving group of family, friends, and health care providers and volunteers makes up the Palliative Care Team. The team is determined by the needs of the person that is ill and his/her family. It can include a:

- Family doctor or a doctor specializing in palliative care
- Nurse
- Community Health Representative
- Social Worker or Community Wellness Worker
- Spiritual Counsellor/Traditional Healer
- Personal Support Worker/Home Support Worker
- Community-based health provider
- Pharmacist, nutritionist, physiotherapist, occupational therapist, volunteers and anyone who can meet the ill person's needs

**Where Can I Find More Information?**

For more information, start by talking to your doctor, nurse, Home and Community Care Case Coordinator, spiritual care provider or any other health care provider. A referral to a palliative care nurse or palliative care volunteer team can be made by anyone, including the person that is ill, a family member, a spiritual care provider, a physician or any other health care provider.

You may also refer to the *Preparing for the Journey: Caring for Indigenous People who are Seriously Ill* resource manual available for free download on the CERAH website: <https://cerah.lakeheadu.ca/resources/indigenous-health/>

This brochure was originally created by: Improving End-of-Life Care in First Nations Communities (EOLFN). Additional resources available on the project website: [eolfn.lakeheadu.ca](http://eolfn.lakeheadu.ca)

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What is Palliative Care?

Action

Collaboration

Knowledge

[cerah.lakeheadu.ca](http://cerah.lakeheadu.ca)

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# Activities

## Protocols for End of Life

LAST DAYS AND HOURS ACTIVITY



Page | 1 of 1

Just as planning for your loved one's care throughout their illness is important, having protocols for knowing what happens at the end of life is also important. This will help ensure your loved one's wishes are known and respected, and it will also reduce the number of questions that need to be made right after your loved one passes.

What kind of service or ceremonies does my loved one/my family want?
Where and when will the service or ceremony take place?
Who will do the service? (Elder? Priest? Friend? Other?)
Who will be notified?
Who will do the notifying?
Will people come from out of town? Do they have a place to stay?
Does my loved one want to be buried or cremated, based on their wishes and Indigenous beliefs?
Where will the burial take place?
If cremated, where will the ashes be kept?
Who do I call when my loved one dies?

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## Thinking About Spirituality

SPIRITUAL WELLNESS ACTIVITY



Page | 1 of 3

As people become sicker, it is normal for them to wonder about what legacy they will leave behind and the impact they have had on people's lives. They may focus on relationships, giving gifts, finding meaning, growing and learning, hope, spirituality, and finding peace<sup>1</sup>.

The following questions may help your loved one think through some of these concerns using the following guide:

<b>Relationships</b>
Do the people who mean the most to me know how much I care about them?
What can I do to strengthen or repair my relationships with those I care about most?
<b>Giving Gifts</b>
What can I pass on to others?
How can I share what I have and what I know to help and bless other people?
What are the memories, stories, and gifts that I want to leave for others?
<b>Meaning</b>
What has given my life purpose and value?
What gives it purpose and value now?
<b>Growing and Learning</b>
What can I learn about myself (and about life)?

<sup>1</sup>Foley, K. M. et al. (Eds.). (2005). *When the focus is on care: Palliative care and cancer*. American Cancer Society

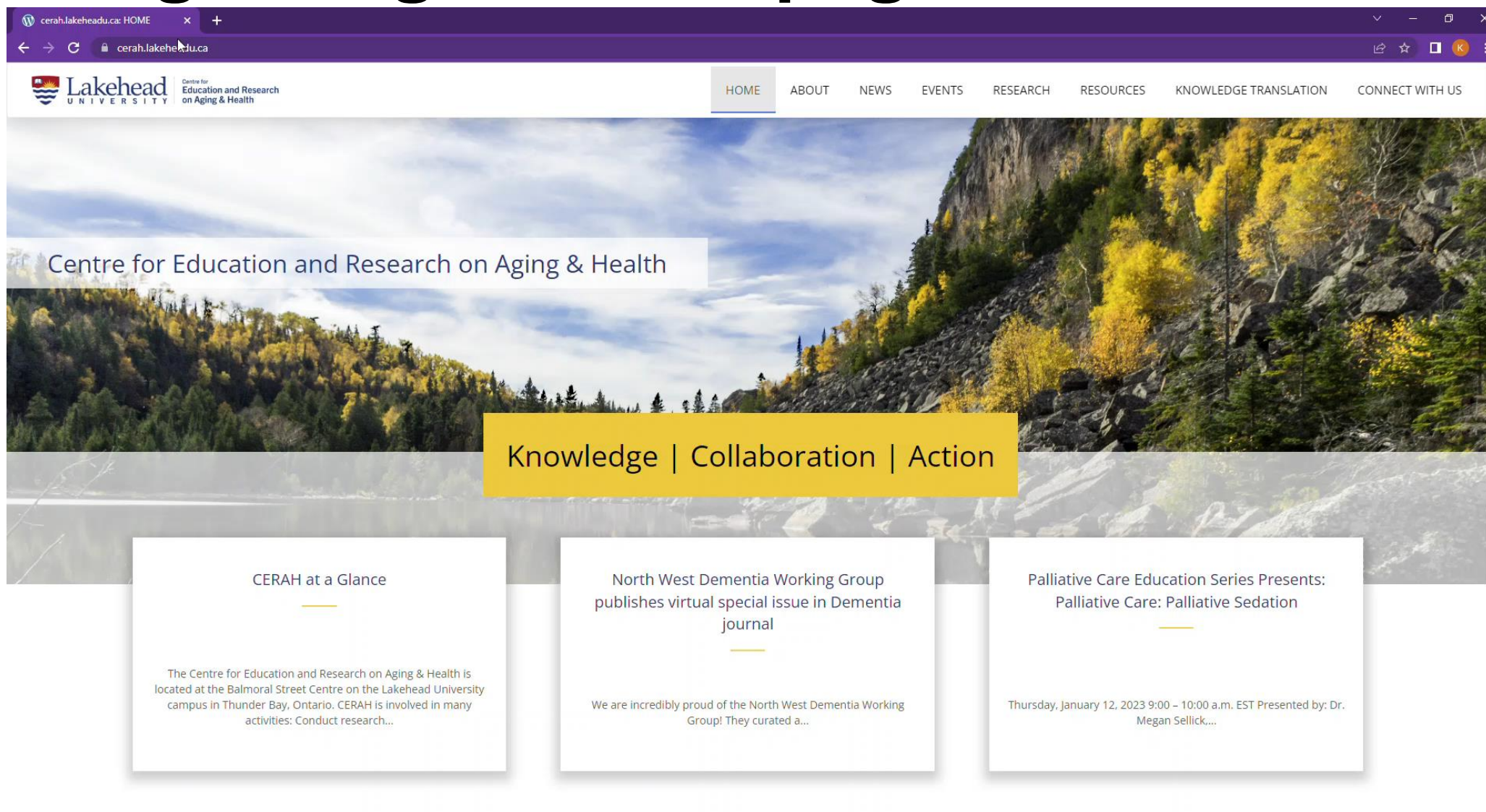
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# Walking Alongside Webpage



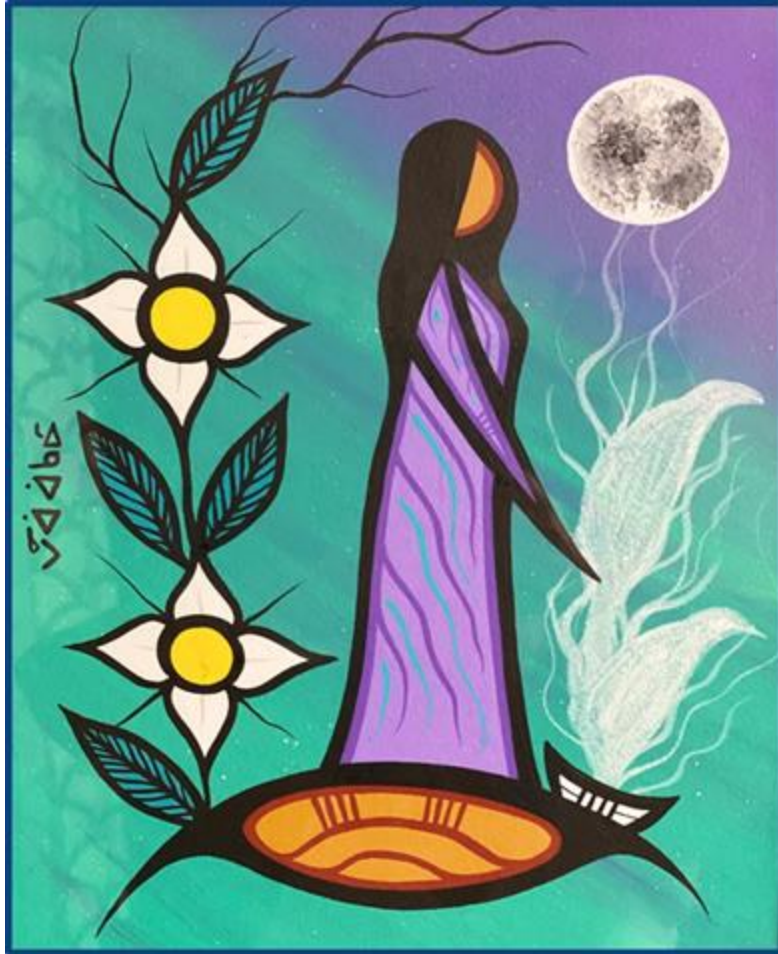
# Narrative Case Story

*“Another barrier, I think, is fear because if there’s someone’s in the hospital and they’re coming home, the family members may be fearful just because they’re not educated, and they haven’t ever dealt with something like this before.”*

*Improving End-of-Life Care in First Nations (EOLFN) Project, 2010-2015*



# Contact Information



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Q & A

# Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat.



# Thank You



**Stay Connected**  
[www.echopalliative.com](http://www.echopalliative.com)