

# Creating Culturally Safe-r Palliative Care Education for Indigenous Communities



**Host:** Diana Vincze, Palliative Care ECHO Project Manager

**Presenters:**

Holly Prince, Project Manager, HBSW, MSW, (PhD. Cand.)

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**Date:** April 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:

**Diana Vincze**, Palliative Care ECHO Project Manager, Pallium Canada

## 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

- Diana Vincze: nothing to disclose
- 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

- Please introduce yourselves using 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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# Creating Culturally Safe- Palliative Care Education for Indigenous Communities





# Learning Objectives

At the conclusion of this activity, participants will be able to:

1. Articulate the process undertaken by the education team to develop culturally safe-r palliative care education for health and social care providers working in Indigenous communities;
2. Incorporate new culturally relevant tools and resources developed within the education into practice.



“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 Project, 2010-2015





# Innovative Strategies to Support Capacity in Indigenous Communities



# Palliative Care for Front-Line Workers in Indigenous Communities

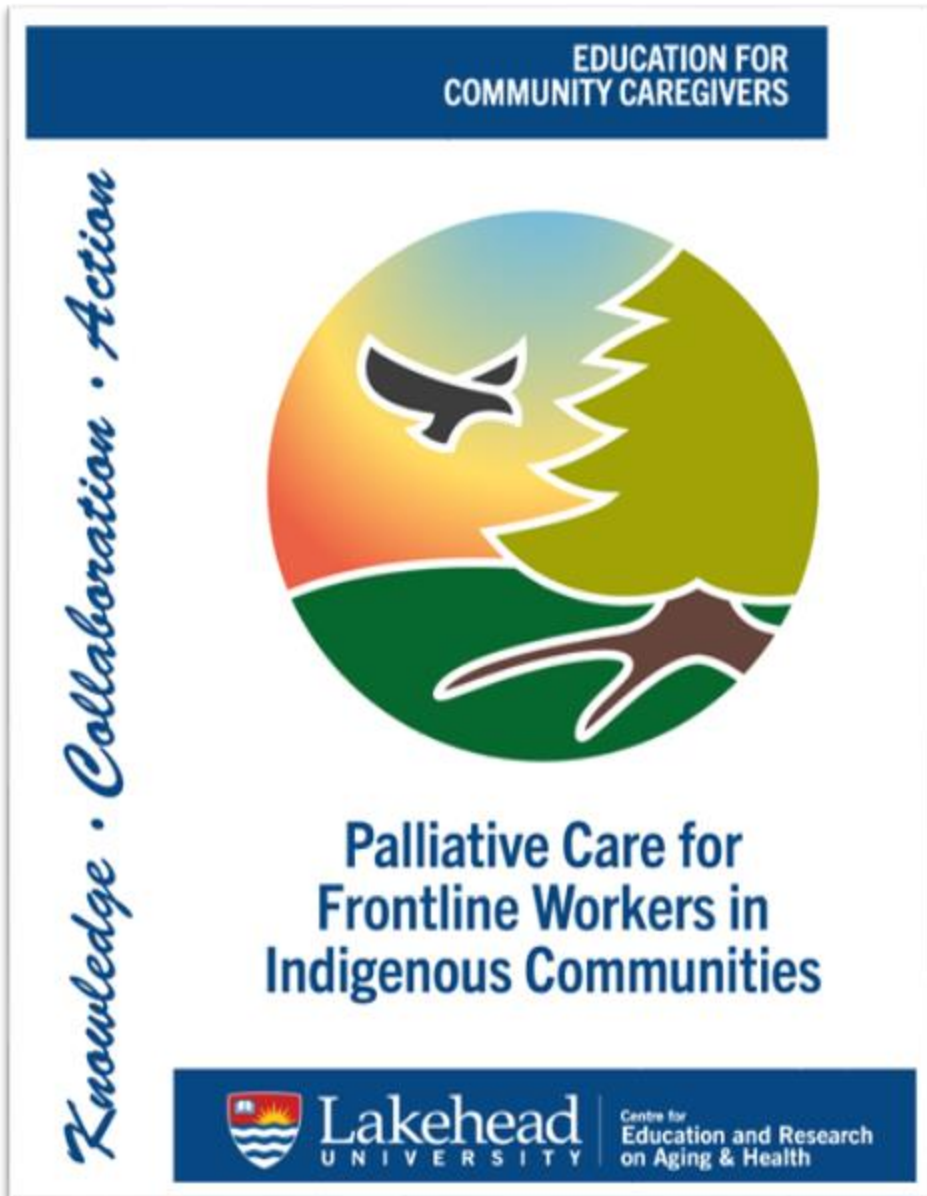
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An introduction to the palliative approach to care for  
healthcare providers working in Indigenous communities



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Introduces the palliative approach to care, tools and resources.

The curriculum consists of 8 modules delivered:

- In-person: 15-hour workshop in community, delivered over two days
- Online: 12-hour workshop through Zoom, 4 x 3-hour weekly sessions

*Learn more* ➔



# Foundational Principles of Indigenous Worldviews

- The Spirit
- The Circle
- Harmony and balance
- All my relations
- Kindness, caring and respect
- Earth connection
- Path of life continuum
- Language



## Communication Support Frameworks

### N-U-R-S-E-S

A framework for understanding and attending to desires

Working with families to often involve your efforts to discern what the person's desires are. When patients express strong opinions, it is helpful to actively listen more often than to respond for them.

**Notice** — Acknowledge the emotion. (A sign, colour, or symbol) to avoid like you are frustrated/lost/overwhelmed.

**Understand** — Is there logic to the emotion or situation. (The client of "I understand how you feel" for example, "I can't agree with you because going through," or "This helps me understand what you are thinking.")

**Respect** — Expressions of praise or gratitude about things the patient has said or done. "I really appreciate what you have been working hard to follow the instructions," or "You have been so strong throughout this difficult time."

**Support** — Express support and affirm your involvement. "We will do our best to do it in support of you through this process" or "I will do my best to make sure you have what you need."

**Empower** — Asking a patient question that is placed on what they can do. "What do you think you would like to do about this?"

**Listen** — Listening about how best to show presence.

### WISH-WORRY-WONDER

A framework for exploring the patient's wishes

Wish... / worry... / wonder statements

KEY TO USE

"I wish" allows for aligning with the patient's hopes

"I worry" allows for being mindful of what is feared

"I wonder" is a subtle way to take a recommendation

Align with patient hopes, acknowledge concerns, and then propose a way to move forward

"I wish we could slow down or stop the growth of your cancer and I wonder that I will continue to look for options that could work for you. I worry that you and your family won't have space if things don't go as we hope. I wonder if there is a chance of a different place to go."

### ASK-TELL-ASK

A framework for assessing the understanding of information

**ASK** What they know and what they want to know (i.e. "What is your understanding of...?")

**TELL** Provide information about outcomes and options in a way that is clear (i.e. "Here's what the facts show...")

**ASK** How to repeat back what you just explained in their own words (i.e. "If you were to go forward with this decision, how would you describe it?")

ONCE AGAIN (2012) © PHARMACIA

Palliative Care for First-Line Workers: Indigenous Communities

### Dorothy's Story



Dorothy does not want to feel like a burden to her grandchildren; she already feels they do so much. She is worried about her 17-year-old and 15-year-old grandchildren as she does not know who will take care of them should something happen to her.

If we consider the family an essential component of the unit of care, let's take a minute to think about them...

Dorothy's grandchildren are scared and unsure of what is happening. Her eldest granddaughter Karen feels that it is up to her to take care of her grandmother because "You are also alone, not even her own children." She is angry at her family for their lack of support and for having to take this on all by herself. She was planning on leaving to go to college but will not be able to do that now. She loves her grandmother.

There are issues with substance use and mental health in the family. Two of Dorothy's sons, Frankie and Max, are heavy drinkers and do not get along with the rest of the family. They have been arrested several times for assault.

Dorothy's daughter MaryAnn, who lives in the city, is considering moving back home to take care of her mother; however, she is hesitant due to her brother's substance use.

Dorothy's extended family wants to help out as much as they can.

When Dorothy was taken by ambulance out of her community, her eldest granddaughter Karen travelled with her as her medical escort. Her daughter MaryAnn was waiting at the hospital upon her arrival. Both Dorothy's granddaughter Karen and daughter MaryAnn were there when she received the news that her cancer is not curable.

Let's think of Dorothy and her needs first...

Dorothy has many questions about her illness and doesn't know who to talk to about it. She doesn't want to bring it up with her family as she doesn't want to worry them. She's pretty sure she heard something about surgery but can't remember if the doctor said she would get one or not. It was all pretty confusing for her. Once she heard the word "cancer," the rest of the conversation was a blur.

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### REMEMBER

Whether you are it or not, all people incapable of making personal health care decisions have a SOM. The SOM ruling in Ontario is similar to:

- 1) Adult appointed SOM
- 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 brother or your sister
- 8) Any other relative

If there is no one to fill the role of SOM 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 SOM or advance care planning, please contact:

[www.advancecareplanning.ca](http://www.advancecareplanning.ca)

[www.1800health.ca](http://www.1800health.ca)

[www.ont.ca/health](http://www.ont.ca/health)

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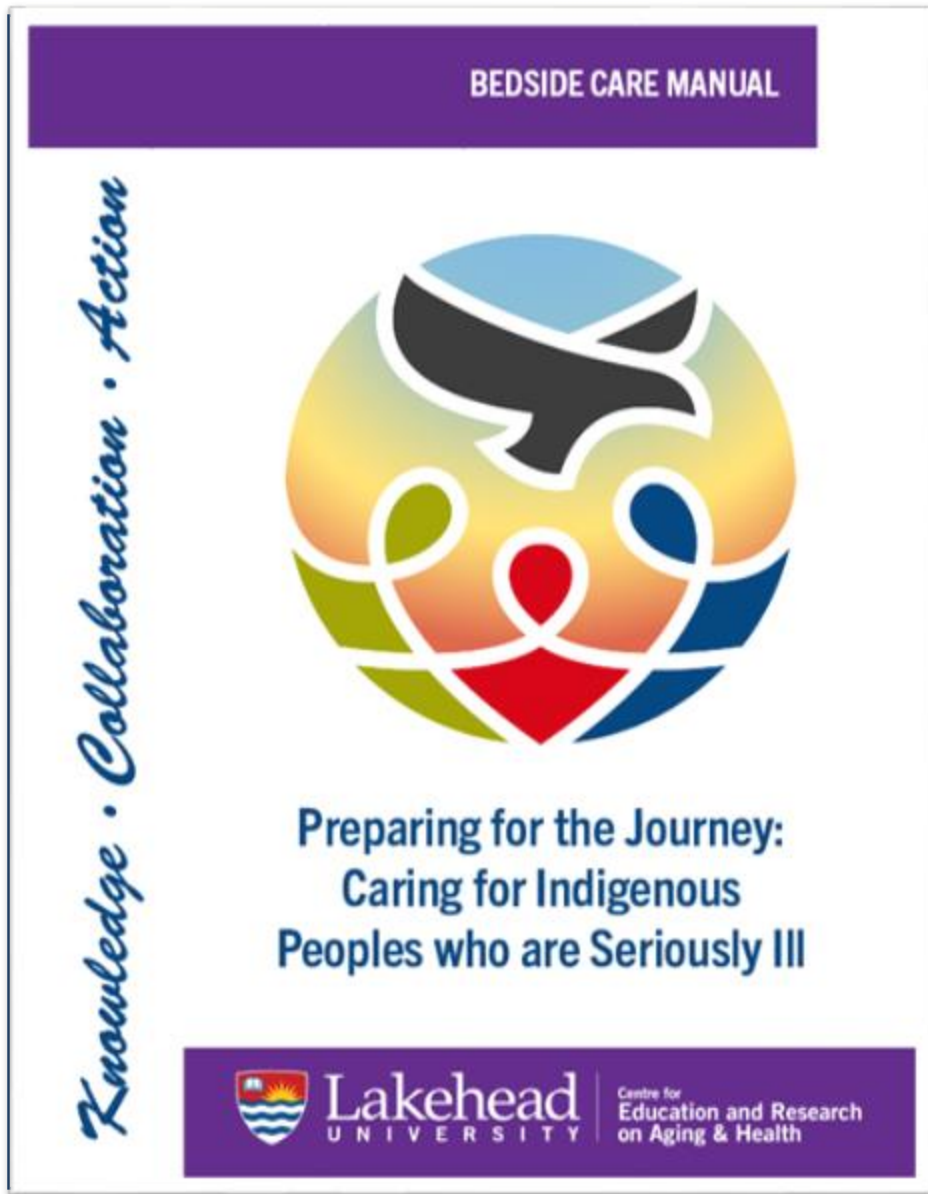
[www.ont.ca/health](http://www.ont.ca/health)

[www.ont.ca/health](http://www.ont.ca/health)

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



[www.ont.ca/health](http://www.ont.ca/health)



Resource manual to accompany and enhance the front-line worker curriculum

Gives health care providers, family and community members practical guidance and support

Based on clinical best practices

Focuses on meeting the wholistic needs of individuals and caregivers

*FREE download here* →



Preparing for the Journey

container when it is full and tape it shut so the needles will not fall out and stick anyone. Clearly label the container with an alert as to what it contains. Ask your home care nurse how it is done in your community.

### Helping People Move Around

When people are seriously ill, they may need help getting in or out of bed, walking around their home, or getting to the bathroom.

Care providers need to focus on how they position themselves and understand the proper motions and techniques (body mechanics) during lifting or bending.

A member of your Community Care Team can show you how to help people move safely either on your own or using equipment or aids such as transfer boards, transfer belts, poles, arm rests, and side rails, if available.

Things to remember:

- Your center of gravity is located at the middle of your body, at about your hips.
- Your line of balance is an imaginary line, from head to foot, that divides your body into two equal parts (See Figure 1).
- The base of support is the space between your feet that bears the weight of your body.
- When moving or lifting anything heavy, reduce the strain on your back by keeping your line of balance close to your center of gravity. Bend your knee keep from leaning forward or backward.
- Open the distance between your feet to broaden your base of the extra weight you are bearing or lifting and reduces strain on your back.
- Get close to the object or person you are moving. Make sure you are close as possible.
- Use your arm and leg muscles, not your back, to do the work. Keep the load close to your body. Your greatest lift power comes pulling.
- Look at where you are and where you want to go. Think through your procedure.
- The closer you are to the person or object you are lifting, the less strain on your back.
- Make sure the area you will be lifting or walking in does not have children's toys, throw rugs and that it is not slippery.

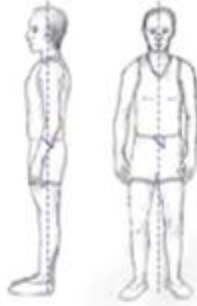


Figure 1

#### 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 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-our-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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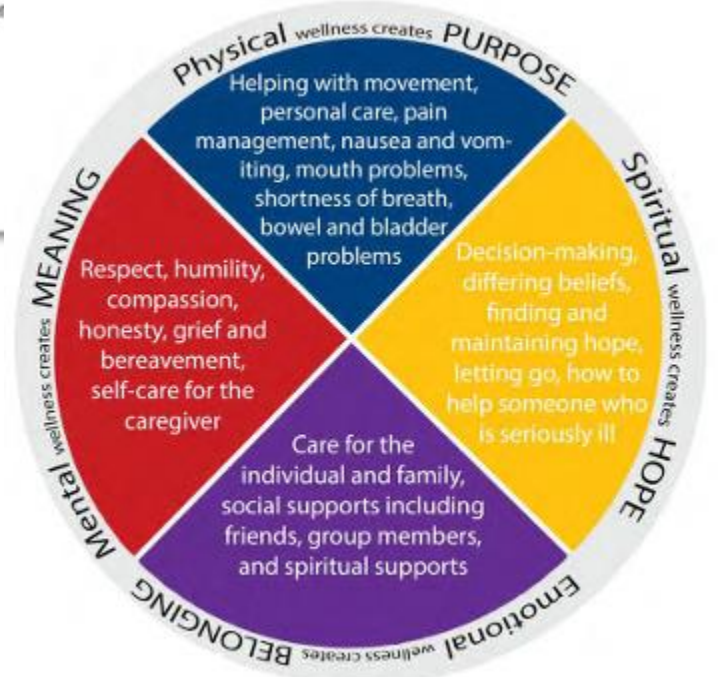
### PROGRAM CHECKLIST FOR HOME PASSING

- \_\_\_ Client is assessed using PPS PPS score \_\_\_\_\_ Date \_\_\_\_\_
- \_\_\_ Family caregivers are identified and committed
- \_\_\_ DNAR order written on in-home chart, signed and dated
- \_\_\_ DNR confirmation form signed and on in-home chart
- \_\_\_ Spiritual support person has been identified family has contact information
- \_\_\_ Family educated on what to expect at time of passing
- \_\_\_ Family knows who to call for crisis management
- \_\_\_ Family knows who to call when passing occurs
- \_\_\_ Plan for pronouncement is in place
- \_\_\_ Funeral home is identified and notified; Name and contact number \_\_\_\_\_
- \_\_\_ Certification has been arranged between Nurse Practitioner or Physician and Funeral Home
- \_\_\_ Physician has sent letter to Police, notifying of expected passing
- \_\_\_ Local Police detachment notified of expected passing and/or presence of narcotics in home
- \_\_\_ Local EMS is aware of expected passing and presence of DNR confirmation form in chart



# Coming full circle


Planning for your care  
Ensure your wishes are heard and respected.






EDUCATION FOR  
COMMUNITY CAREGIVERS

*Knowledge · Collaboration · Action*



**Walking Alongside  
Indigenous Peoples who  
are Seriously Ill**

 **Lakehead**  
UNIVERSITY | Centre for  
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Free web-based curriculum where healthcare providers can access over 90 unique tools and resources for educating family and community members caring for people who are seriously ill

Based on clinical best practices

Focuses on meeting the holistic needs of individuals and caregivers

*FREE download here* →



## Spiritual Wellness – Speaker's Notes

Walking Alongside Indigenous Peoples who are Seriously Ill: Developing a Care Plan

### Spiritual Wellness

- Spirituality is a source of meaning for many people which helps them to understand the significance of life.
- An individual's spirituality may be expressed through organized religion or can be expressed through love of nature and celebrated through meditation or reflection.
- A person does not have to be a part of a church to be spiritual.

- Spirituality is a source of meaning for many people which helps them to understand the significance of life.
- It is important to recognize that everyone is an individual with their own spiritual, cultural and social beliefs, values, and practices which need to be respected by all who provide care to them. As care providers we are not there to judge, but rather to support people in their own journey.
- We can be helpful by ensuring that people's spiritual and cultural needs are being met by those individuals that have similar values and beliefs. This might include bringing in a local Elder, Traditional Knowledge Carrier, pastor or minister, or any combination of these to provide ceremonies, teachings, or prayers.

## 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 Peoples who are Seriously Ill* resource manual.

The content of this document was adapted from *Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill*. © Copyright Holly Prince, Lakehead University, 2002

## Indigenous Voices: Living with serious illness and grief



## Helping you feel better

Some people may live through an illness without pain or other common symptoms such as shortness of breath, nausea, vomiting, confusion (delirium), constipation, or anxiety. If you have symptoms, make sure you get help to relieve them.

### Things to know

- Your healthcare team needs to know about your symptoms so they can help you feel as well as possible. Your illness may not be curable, but you can still expect your symptoms to be controlled.
- Your doctor and nurses can help you sort out the best way to relieve your symptoms. This may include medications, complementary approaches, and traditional medicines.
- Pain medications taken known as "opioid" medications such as morphine may help relieve pain or shortness of breath during a serious illness.
- Opioids, prescribed in the right dose do not cause addiction or make you die sooner.

"People don't want to suffer. They don't want their families to see them suffer."

Dr. Amy Mambour  
1st Minister of the Grand Stair, Ontario

### Here are some other ways to relieve symptoms

Pain	Applying warm or cold compresses, Repositioning the person, Gentle massage or movement, & distraction such as thinking or talking about other things.
Shortness of breath	Air movement from a fan or open window. Sitting up or raising head of bed.
Nausea and vomiting	Small snacks rather than big meals, Respecting food preferences, Avoiding spicy or heavy foods, Preventing constipation.
Constipation	A calm environment with familiar things and people.
Anxiety	Regular laughter, Increased fluids, Movement, Privacy and sitting up for loved ones.
	Relaxation/Visualization exercises, Talking to others, Asking questions.

For more information go to [VirtualHospice.ca](http://VirtualHospice.ca)

## Caring for Someone With Ostomy



# Centre for Education and Research on Aging & Health

Knowledge | Collaboration | Action

### CERAH at a Glance

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The Centre for Education and Research on Aging & Health is located at the Balmoral Street Centre on the Lakehead University campus in Thunder Bay, Ontario. CERAH is involved in many activities: Conduct research...

### North West Dementia Working Group publishes virtual special issue in Dementia journal

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We are incredibly proud of the North West Dementia Working Group! They curated a...

### Palliative Care Education Series Presents: Palliative Care: Palliative Sedation

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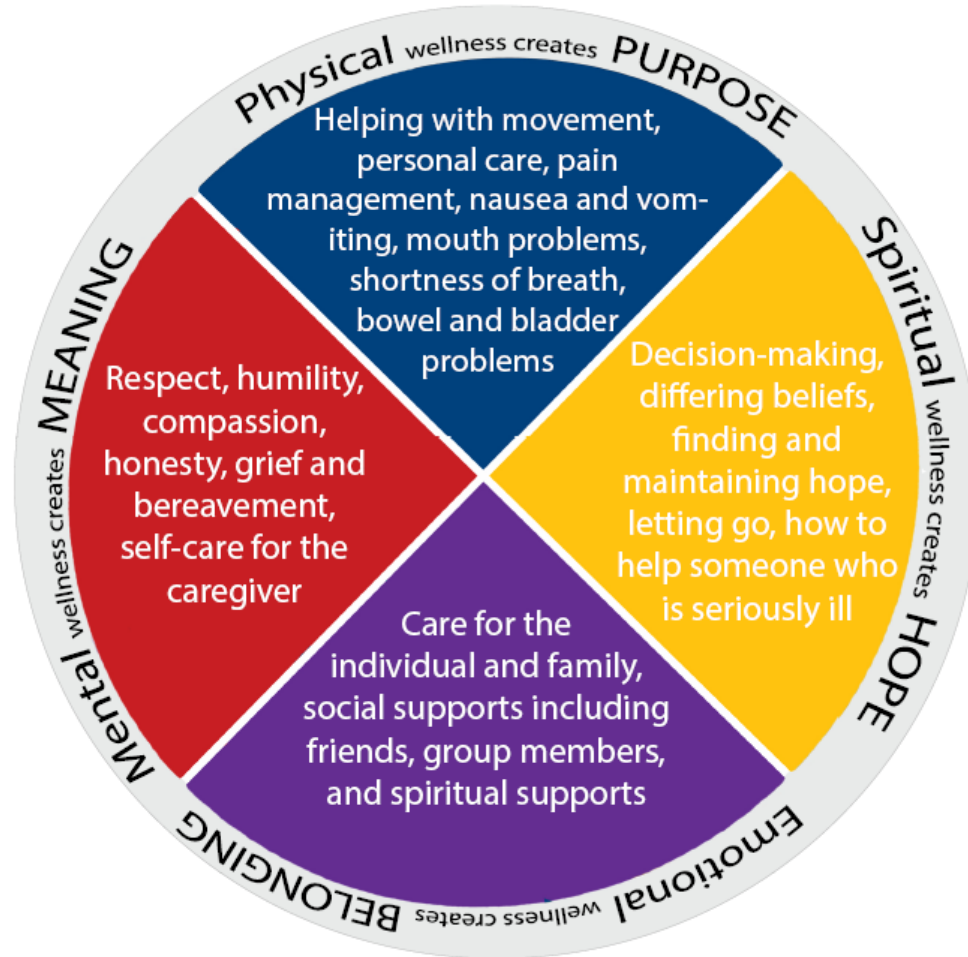
Thursday, January 12, 2023 9:00 - 10:00 a.m. EST Presented by: Dr. Megan Sellick...

# Keys to Success

- Indigenous-led, designed, and implemented educational initiative
- Guided by Elders and Knowledge Carriers as active facilitators
- Community engagement
- Responds to actual community needs based on “here and now”
- Process is flexible and responsive



- Recognizes and respects cultural diversity of Indigenous communities



## Indigenous Wellness Framework & Palliative Care

Adapted from Elder Jim Dumont, National Native Addictions Partnership Foundation, Honouring Our Strengths: Indigenous Culture as Intervention in Addictions Treatment Project – University of Saskatchewan: Author. Canadian Institutes of Health Research, Funding Reference Number AHI-120535

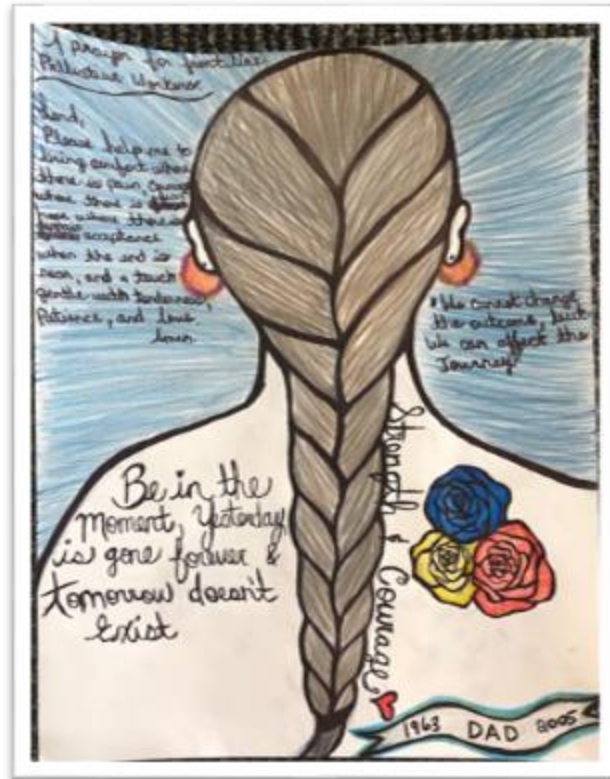
- Culturally relevant and community-specific content
- Mentorship embedded in the process
- On-going evaluation of content and delivery process of workshops
  - post-delivery team debrief sessions
  - quarterly curriculum review
  - participant feedback (written evaluation, poster activity, Circle, post-workshop questionnaire)

# Evaluation

“Information was very culturally appropriate for our communities and care. The training was very interactive between presenters and the participants.”

“These workshops are very rare in local level communities. That is where it is needed the most in terms of resourcing versus receiving services.”

“This was literally the best example of how to run a workshop. Pacing was great. All sections: use of videos, guides, speakers, breaks, small groups.... was literally the best I've been in. Maybe it's the sincerity in which the workshop was provided. And the genuine feedback from the presenters and the participants. I left fulfilled - but wanting more.”



# Miigwetch...Baamaapii

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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



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