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Walking Alongside Indigenous Peoples who are Seriously Ill



Lakehead
UNIVERSITY

Centre for
Education and Research
on Aging & Health

The ***Walking Alongside Indigenous Peoples who are Seriously Ill: Education for Community Caregivers*** curriculum is intended to provide general information only. Every effort has been made to ensure the accuracy of the information. The contents do not constitute medical advice and should not be relied upon as such. If you have questions or concerns about your health or medical issues, speak with a healthcare provider.

Individuals are encouraged to print and share any part of this curriculum. We only ask that you acknowledge the source of these materials when you use them as follows:

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For more information about this curriculum, please visit our website at www.cerah.lakeheadu.ca or contact us by email cerah@lakeheadu.ca.

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We would like to acknowledge all the individuals who contributed to the ***Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill*** manual which was developed at CERAH in 2017, upon which this curriculum is based. *Preparing for the Journey* is a resource given to workshop participants who attend CERAH's ***Palliative Care for Front-Line Workers in Indigenous Communities*** training. This resource manual provides practical guidance and support on caring for people with serious illnesses. In the development of *Preparing for the Journey*, CERAH was given permission to extract, adapt, and use material from the following existing resources:

Macmillan, K., Peden, J., Hopkinson, J., & Hycha, D. (2014). *A Caregiver's Guide: A Handbook About End-of-life Care*. The Military and Hospitaller Order of St. Lazarus of Jerusalem & The Canadian Hospice Palliative Care Association.

Linkewch, B., Potson, J., Fobister, V., & Sletmoen, W. (2003). *Caring for the Terminally Ill: Honouring the Choices of the People*. 2nd Ed.

Improving End-of-Life Care in First Nations Communities Research Team, Lakehead University. (2015). *Developing Palliative Care Programs in First Nations Communities: A Workbook, Version 1*.

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CONTENTS

PURPOSE OF THIS CURRICULUM9

Overview of the Curriculum..... 9

SECTION 1: THE INDIGENOUS WELLNESS FRAMEWORK 12

 *Handouts 13*
Indigenous Wellness and Caregiving 13

SECTION 2: SPIRITUAL WELLNESS 14

 *Slide Deck with Speaker Notes 14*
Spiritual Wellness..... 14

 *Video..... 15*
Ceremony, Tradition, and Spirituality..... 15

 *Handouts 15*
Understanding and Promoting Spiritual Wellness..... 15

 *Activity..... 15*
Thinking About Spirituality 15

SECTION 3: EMOTIONAL WELLNESS 16

 *Slide Deck with Speaker Notes 16*
Emotional Wellness 16

 *Video..... 16*
Walking Alongside for a Good Death..... 16

 *Handouts 17*
Supporting Relationships & Emotional Wellness 17

 *Pamphlet..... 17*
Supporting the Caregiver and the Family 17

SECTION 4: MENTAL WELLNESS 18

 *Slide Deck with Speaker Notes 18*
Mental Wellness 18

	<i>Videos</i>	19
	Honouring Our Loss and Grief	19
	ABCs of Self Care	19
	<i>Handouts</i>	19
	Understanding and Dealing with Grief	19
	Guidelines to Support People Who Are Grieving	19
	Good Mental Health Tips	19
	10 Tips to Avoid Burn Out	19
	Grieving Strategies	20
	<i>Pamphlets</i>	20
	Caring for Someone with a Terminal Illness: Care for the Caregiver	20
	<i>Activity</i>	20
	Personal Awareness of Loss.....	20

SECTION 5: PHYSICAL WELLNESS..... 21

HELPING PEOPLE MOVE AROUND 21

	<i>Slide Deck with Speaker Notes</i>	22
	Helping People Move Around.....	22
	<i>Videos</i>	22
	Walking	22
	Changing Bed Sheets (through repositioning in bed).....	22

PERSONAL CARE 22

	<i>Slide Deck with Speaker Notes</i>	23
	Providing Personal Care to a Person with Serious Illness.....	23
	<i>Videos</i>	23
	Bathing and Hair Care	23
	Toileting	24
	Mouth and Other Personal Care.....	24
	<i>Handouts</i>	24
	How to Maintain a Catheter	24
	Caring for Someone with Ostomy.....	24

PAIN 25

 *Slide Deck with Speaker Notes* 25
 Managing Pain 25

 *Videos* 25
 Fear of pain medication 25

 *Handouts* 25
 Creating Comfort for a Loved One in Pain 25
 Helping you feel better 25

MANAGING OTHER SYMPTOMS..... 26

 *Slide Decks with Speaker Notes*..... 26
 Managing Specific Illnesses and Conditions 26
 Infection Prevention and Clinical Skills 27

 *Videos* 27
 Shortness of Breath 27
 Infection and Waste Disposal 27
 Dealing with Wound Care at Home 27
 Understanding the Normal Aging Process..... 27

 *Handouts* 28
 Pressure Sores and Infection Control 28
 Mouth Care 28
 Infection and Waste Disposal 28
 Normal Aging Versus Possible Dementia..... 28

SECTION 6: MAKING YOUR WISHES KNOWN..... 29

 *Slide Deck with Speaker Notes* 29
 Making Your Wishes Known 29

 *Videos* 30
 The Time is Now: Advance Care Planning for First Nations People 30

 *Handouts* 30
 Coming Full Circle: Planning for Your Care 30
 Why Advance Care Plan 30

 Pamphlets	30
Advance Care Planning	30
I Have Been Asked to be a Substitute Decision Maker (SDM) What Does That Mean	30

SECTION 7: DEVELOPING A CARE PLAN 31

 Slide Deck with Speaker Notes	31
Developing a Care Plan	31
 Activities	32
Developing a Care Plan	32
Checklist for Home Passing.....	32

SECTION 8: THE PALLIATIVE APPROACH TO CARE..... 33

 Slide Deck with Speaker Notes	33
Palliative Approach to Care	33
 Videos	33
Caring for the Patient and Family	33
 Handouts	34
Introduction to the Palliative Approach to Care.....	34
Top 10 Things to Know About Palliative Care.....	34
A Patient's Story.....	34
What is Palliative Care?	34
 Pamphlets	34
What is Palliative Care?	34
Living with a Terminal Illness	34

SECTION 9: LAST DAYS AND HOURS 35

 Slide Deck with Speaker Notes	35
Last Weeks or Days of Life	35
 Handouts	36
Last Weeks or Days of Life	36
Food for Thought	36
 Pamphlets	36

What to Expect.....	36
Caring for Someone with a Terminal Illness: What to Expect	36
 <i>Activity</i>	36
Protocols for End of Life.....	36

PURPOSE OF THIS CURRICULUM

The purpose of the *Walking Alongside Indigenous Peoples who are Seriously Ill: Education for Community Caregivers* curriculum is to provide health care providers with tools and resources for delivering community-based education to families and community members caring for people who are seriously ill.

In developing the curriculum, the project team recognized that health care providers have varying levels of knowledge and skills in chronic disease management and caregiving at the end of life. Although not a prerequisite for using this curriculum, it is strongly encouraged that health care providers first take the *Palliative Care for Front-Line Workers in Indigenous Communities* training offered by CERAH. This training will help health care providers develop a baseline of knowledge and skills in caring for people who are seriously ill, which will increase their confidence when delivering community-based education.

This curriculum may be of value to you, your team, or your community if you:

- are a health care provider that wants to create awareness in the community about chronic disease management;
- have other health care providers who are newly joining your team or need some guidance in developing a care plan;
- have a family or community caregiver who has questions about caregiving for someone who is very sick or who would benefit from instruction in learning particular skills at the bedside of a loved one who is seriously ill; and/or
- see an opportunity to inform more people about advance care planning and making individual wishes known.

Overview of the Curriculum

The curriculum is based on clinical best practices. It grounds the content in a wholistic understanding of health, wellness, and balance from an Indigenous lens by situating the practical guidelines and support within the broader philosophy of the Indigenous Wellness Framework (National Native Addictions Partnership Foundation, 2014).

This curriculum is organized into nine sections and builds upon content from the *Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill* resource manual:

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

Each section of the curriculum includes the following:

- A brief overview of the section with links to the ***Preparing for the Journey*** manual. People are strongly encouraged to have a copy of *Preparing for the Journey* available to refer to for additional information. All sections and pages referenced in *Preparing for the Journey* can be photocopied from the hardcopy manual or printed from the [electronic manual located on the CERAH website](#).
- ***Slide Decks with Speaker Notes***¹: The slide decks have been developed to help health care providers teach family caregivers, community members, and other providers about important aspects of caring for someone who is seriously ill. Each slide deck includes speaker notes that explain the material on the slide, encourage discussion with participants, and refer them to other relevant resources. The slide decks can be customized (i.e. removing or skipping irrelevant slides or videos) to include only the techniques and information required for supporting the needs of a particular person who is seriously ill or to include only resources or services available in community.

Note: Some presentations have been specifically designed to be facilitated by a nurse or registered health care provider to train other health care providers (personal support workers, homemakers, health care educators, Elder support workers, respite workers). They are designed to provide health care staff with clinical skills, tools, and guidelines; therefore, they are not meant for family caregivers. These specific slide decks appear in the physical wellness section.

- ***Supporting Resources:*** For each section, there are multiple supporting resources, including videos, handouts, pamphlets, and activities. Each resource includes a brief description and is intended to support the understanding of a particular topic, skill, or strategy that caregivers and community members may find helpful when caring for someone who is seriously ill.

Although there is no "correct" way to use this curriculum, we encourage people to read through this guide in its entirety before selecting, distributing, and/or presenting material from

¹ Exception: section 1 does not have a slide deck.

specific sections as needed. Use what is necessary and supplement materials to best suit the needs and circumstances of the community and individuals needing care.

Although every effort has been made to ensure the accuracy of the information in this curriculum, the contents do not constitute medical advice, and should not be relied upon as such. If people have questions about their own health or medical issues or those of others, please speak with a healthcare provider.

SECTION 1: THE INDIGENOUS WELLNESS FRAMEWORK

“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.”² Elder Jim Dumont

This section grounds the curriculum within a wholistic understanding of health, wellness, and balance from an Indigenous lens. It also outlines a connection between the key concepts of the Indigenous Wellness Framework to that of a wholistic caregiving approach.

In *Preparing for the Journey*, the Indigenous Wellness Framework (National Native Addictions Partnership Foundation, 2014) is introduced which describes how the four aspects of self - the physical, the mental, the emotional, and the spiritual - need to be in balance to achieve health and wellness. The framework also outlines how connection and balance are needed at the individual, family, and community levels. For more information, [please refer to pages 2-3 in *Preparing for the Journey*](#).



² Elder Jim Dumont, National Native Addictions Partnership Foundation, Honouring Our Strengths: Indigenous Culture as Intervention in Addictions Treatment Project - University of Saskatchewan. (2014). Reference Guide. Bothwell, Ontario: Author. Canadian Institutes of Health Research, Funding Reference Number AHI-120535.

Suggested Audience: This section may be helpful for health care providers and community members who are beginning to make these connections and are looking for a way to understand how their values and beliefs are represented within caregiving.

Suggested Use: This handout can be given to family members who are caring for someone with a serious illness as a way to understand the care that will be provided. It can also be used as a poster in public areas within the community to create awareness and start conversations on caregiving for those with serious illnesses.

Handouts

[Indigenous Wellness and Caregiving](#) – provides a visual showing a blending of the Indigenous Wellness Framework with wholistic caregiving for people who are seriously ill.

SECTION 2: SPIRITUAL WELLNESS

The Indigenous Wellness Framework emphasizes the importance of balance in several aspects of the self, including spiritual wellness. This section recognizes the importance of respecting and supporting an individual's spiritual, cultural, and social beliefs, regardless of one's own spirituality.

In *Preparing for the Journey*, the positive effects of spirituality on an individual's wellbeing and quality of life are described. It discusses the role of spirituality as a source of meaning for many people and explains the impact of serious illness on a person's spirituality. It also explains how spirituality may influence a seriously ill person's decision making, as well as their ability to find and maintain hope. Finally, it also provides some insight into how a care provider can support an individual to leave a legacy, organize appropriate ceremonies, and otherwise be there for them in ways that align with their spirituality. For more information, [please refer to pages 15-18 in Preparing for the Journey](#).

Suggested Audience: The intended audience for this section are health and social care providers, as well as family and community members who are supporting an individual at the end of life.

Suggested Use: All of the resources can be used as stand-alone materials to provide support and education. When using the slide deck to provide education for community or health and social care providers, it is recommended to enhance the content with the other resources, including the storytelling video. Please review all the resources to determine which will best meet the needs of the audience.



Slide Deck with Speaker Notes

[Spiritual Wellness](#) – provides an overview of what spiritual wellness is within the context of chronic disease management and caregiving at the end of life care. It provides an overview of the positive effects of spirituality, as well as the spiritual needs of individuals who are seriously ill. The presentation reviews decision-making, explores the importance of maintaining hope at the end of life for the seriously ill person and their caregivers and discusses the importance of legacy work.

Estimated delivery time: 20 minutes.

[Speaker's Notes](#)

Video

[Ceremony, Tradition, and Spirituality](#) – was developed by the Canadian Virtual Hospice as part of the *Indigenous Voices - Stories of Serious Illness and Grief* project. It discusses how different the end of life experience is from person to person, and the importance of honouring the end of life rituals of the individual who is seriously ill and their family. The video emphasizes the diversity among communities and end of life practices. The video length is 21:41 minutes. After showing the video, you may want to use the following questions to begin a conversation with participants:

- *What did you think of the video “Ceremony, Tradition, and Spirituality?”*
- *Was there anything that resonated with you or that you connected with?*

Estimated delivery time (including discussion) is 30 minutes.

Handouts

[Understanding and Promoting Spiritual Wellness](#) – This handout describes the importance of spirituality for people at end of life. It provides different prompts and questions that care providers and family members may use to guide reflection and discussions with their loved one to better understand and support their spiritual beliefs, needs, and wishes for end of life.

Activity

[Thinking About Spirituality](#) – contains a fillable form with common end of life questions for a person who is seriously ill to help them reflect on their relationships, giving gifts, meaning, growing and learning, hope, spirituality and religious beliefs, and peace.

SECTION 3: EMOTIONAL WELLNESS

The Indigenous Wellness Framework emphasizes the importance of balance in several aspects of the self, including emotional wellness. This section provides some tips on how to work with and support individuals and families dealing with serious illness, loss and grief.

In *Preparing for the Journey* emotional wellness is tied to a feeling of belonging facilitated by one's connection with others. The many losses that individuals and their families experience when a loved one is seriously ill, and how a person's relations and connections with others facilitate these reactions, is explored. It recognizes that families and communities will respond differently to loss but highlights some details that can influence a family's ability to care for a loved one and cope with the losses. It concludes with some reflection questions that will help health and social care providers better understand the role that relationships, personalities, and family dynamics play in a particular situation, so they can shape their care (and care plan) accordingly. For more information, [please refer to pages 19-20 in Preparing for the Journey](#).

Suggested Audience: The intended audience for this presentation is anyone supporting an individual with a serious illness, and specifically family caregivers, who may benefit from learning about how to care for themselves when a loved one is seriously ill or at end of life.

Suggested Use: All of the resources can be used as stand-alone materials to provide support and education. When using the slide deck to provide education for community members or health care providers, it is recommended to enhance the content with the other resources, including the storytelling video. Please review all the resources to determine which will best meet the needs of the audience.



Slide Deck with Speaker Notes

[Emotional Wellness](#) – describes the emotional reactions that may occur for an individual who is seriously ill and approaching the end of life, as well as their family caregivers and/or community caregivers. It describes emotional reactions to loss and how emotions influence a family's ability to cope, as well as their relationship with their loved one.

Estimated delivery time: 20 minutes.

[Speaker's Notes](#)



Video

[Walking Alongside for a Good Death](#) – was developed by the Canadian Virtual Hospice as part of the *Indigenous Voices - Stories of Serious Illness and Grief* project. It discusses what palliative care is and what it means for Indigenous people and their families as a loved one approaches

the end of their life. The video length is 21:22 minutes. After showing the video, you may want to use the following questions to begin a conversation with participants:

- *What did you think of the video “Walking Alongside for a Good Death?”*
- *Was there anything that resonated with you or that you connected with?*

Estimated delivery time (including discussion) is 30 minutes.

Handouts

[Supporting Relationships & Emotional Wellness](#) – This handout recognizes the many losses that individuals, families, and community members are dealing with when someone they love is seriously ill. It validates their experiences of loss and recognizes many feelings as normal. It also provides families with questions that they can use to guide discussions with their loved one who is seriously ill. Health care providers can review this document to gain insight into the emotional wellbeing of the seriously ill person and see if there are ways to support them with it or give it to loved ones of the seriously ill person early in the palliative care journey to encourage reflection and discussion.

Pamphlet

[Supporting the Caregiver and the Family](#) – provides some useful suggestions for community members on how to support caregivers and their families, including how to support from afar, how to use your own time to support, and how to know which help/support is best for the caregiver and family.

SECTION 4: MENTAL WELLNESS

The Indigenous Wellness Framework emphasizes the importance of balance in several aspects of the self, including mental wellness. This section centers on recognizing and supporting the various grief and loss reactions that individuals, and their families, experience when they are seriously ill. It offers suggestions for promoting mental health, avoiding burnout, and dealing with grief. The section also provides insight into and validation of grief experiences, as well as tips to support individuals who are seriously ill and their families in coping with their grief while encouraging them to reach out for and accept the support of others. Understanding and supporting grieving children is also discussed.

Preparing for the Journey explores people’s reactions to grief and loss and the impact that this can have on their mental wellness. It also describes some common ways that people experience grief—whether physically, emotionally, mentally, or spiritually—and provides some guidelines for those supporting someone who is grieving. For more information, [please refer to pages 21-23 in Preparing for the Journey](#).

Suggested Audience: The intended audience for this presentation is health and social care providers, community members and/or family members who may be caring for someone who is seriously ill who might benefit from a stronger understanding of how this level of care impacts the self physically, mentally, emotionally, and spiritually.

Suggested Use: All of the resources can be used as stand-alone materials to provide support and education. When using the slide deck to provide education for community or health and social care providers, it is recommended to enhance the content with the other resources, including the storytelling video. Please review all the resources to determine which will best meet the needs of the audience.

Slide Deck with Speaker Notes

[Mental Wellness](#) – provides an overview of mental wellness, including how grief impacts people who are seriously ill and their caregivers. A definition of self-care is provided alongside a description of the importance of practicing self-care as a caregiver. It includes an optional short video about self-care from an Indigenous perspective (“ABCs of Self Care”), and a short individual activity to apply the learning.

Estimated delivery time: 30 minutes (including video).

[Speaker’s Notes](#)

Videos

[Honouring Our Loss and Grief](#) – was developed by the Canadian Virtual Hospice as part of the *Indigenous Voices - Stories of Serious Illness and Grief* project. It discusses different ways of honouring a loved one once they have passed on to the spirit world. Through the sharing of personal experiences, Indigenous individuals describe the ways they have paid tribute to a loved one who has passed on, and how their connections to their community influenced the different rituals and ceremonies involved in supporting their grieving. The video length is 23:07 minutes. After showing the video, you may want to use the following questions to begin a conversation with participants:

- *What did you think of the video “Honouring our Loss and Grief”?*
- *Was there anything that resonated with you or that you connected with?*

Estimated delivery time (including discussion) is 30 minutes.

[ABCs of Self Care](#) – was produced by the Indigenous Youth Wellness YouTube channel. It explains what self-care is, how to practice it, and why it is important for overall well-being. The intended audience for this presentation is anyone supporting an individual at the end of their life, and specifically family caregivers, who may benefit from practicing self-care. This video can be shared during the Mental Wellness slide deck, or as a stand-alone video presentation. The video length is 7:29 minutes.

Handouts

[Understanding and Dealing with Grief](#) – This handout defines and distinguishes between key terms often mentioned when discussing grief and palliative care: loss, bereavement, grief, and mourning. It includes a depiction of the impact grief has on the physical, mental, emotional, and spiritual aspects of self and offers some suggestions to help those experiencing grief.

[Guidelines to Support People Who Are Grieving](#) – This handout identifies some key facts about the grief experience and provides some key points to recognize and reinforce when supporting someone who is grieving. It recognizes the effort, time, and energy that goes into ‘grief work’ and explains common types of grief, anticipatory and cumulative, that Indigenous individuals and families may be experiencing. It also includes a section with information specific to supporting children and their grief.

[Good Mental Health Tips](#) – This guide developed by *SE Health* provides 12 suggestions for behavioral changes that individuals can make and instill in their daily lives to promote their mental health.

[10 Tips to Avoid Burn Out](#) – This guide developed by *SE Health* provides some actions and reflections that may be helpful for promoting mental health and preventing stress, overworking, and burnout.

[Grieving Strategies](#) – This guide developed by *SE Health* includes a description of grief as a natural response to loss and includes approachable graphics with brief tips for things to do and avoid that can help an individual cope and adapt to loss.



Pamphlets

[Caring for Someone with a Terminal Illness: Care for the Caregiver](#) – focuses on the needs of those providing care to someone who is seriously ill. It recognizes how the illness affects the caregiver and emphasizes communication and self-care to address caregiver needs, including after caregiving ends. It highlights tips for navigating the health care system, communicating with the care team, and understanding grief. It also provides some direction for accessing respite and answers to financial and legal questions.



Activity

[Personal Awareness of Loss](#) – is intended to serve as a self-reflection about one's own experiences of grief and loss. It asks participants to think about losses they have experienced and their reactions to those losses. It also asks about their hopes, fears, and wishes for their own death. This worksheet can be completed by health care providers to help them recognize their own grief experiences and in turn, help them empathize with others. It could be used as a personal check-in completed after the loss of a loved one, or as a debriefing exercise with a community care team after the loss of a community member. Regardless of the way it is used, the health care provider administering the exercise should caution participants and be prepared to offer support to those who need it as they recall past (potentially triggering) experiences.

SECTION 5: PHYSICAL WELLNESS

The Indigenous Wellness Framework emphasizes the importance of balance in several aspects of the self, including physical wellness. This section provides information for better understanding and supporting the physical wellness of someone who is seriously ill. It also offers personal and physical care activities that family and community members may be asked to provide when caring for someone who is seriously ill. For more information, [please refer to pages 24-60 in *Preparing for the Journey*](#).

This section is organized around four topic areas related to supporting physical wellness:

- 1) Helping People Move Around
- 2) Personal Care
- 3) Pain
- 4) Managing Other Symptoms

Suggested Audience: Many of the resources in this section are useful for caregivers, and family members to better understand and support people with seriously illness. Some resources however, like the slide decks are clinical in nature and intended to be delivered by registered health care providers to non-registered health care providers.

Suggested Use: The following resources provide information and guidance on how best to support the physical wellness of a seriously ill person, especially those experiencing pain, challenges with mobility, or increasing weakness. Although the slide decks are intended for health care providers, some of the videos and other resources may be helpful for family caregivers to better understand and support their loved one who is seriously ill. The documents can be revisited as the person's health and mobility declines, and they become increasingly weak and at further risk for pain and discomfort. The documents provide some key information and strategies to help caregivers in preventing illness and injury and supporting the well-being of the person who is seriously ill. There is also information included for recognizing changes and supporting the cognitive well-being of someone who is seriously ill. Some of these documents may also be useful as posters in waiting rooms, community health centre bulletin boards, or strategically placed as reminders where caregiving is taking place.

HELPING PEOPLE MOVE AROUND

When a person is seriously ill, they may need support with getting in or out of, or repositioning in a chair or bed, or walking around their home. Caregivers may also need to help their loved one with toileting and getting to and from the bathroom. The material in this section provides practical considerations, tips, tools, and demonstrations for caregivers to safely and effectively support someone with their mobility. For more information, [please refer to pages 25-35 in *Preparing for the Journey*](#).



Slide Deck with Speaker Notes

[Helping People Move Around](#) – provides guidance around the proper techniques and motions to help someone who is seriously ill move around safely. It includes strategies for lifting someone, moving someone in or out of, or repositioning them in a chair or bed, and walking. There are also tips for using tools like draw sheets to make moving someone easier.

[Speaker's Notes](#)



Videos

People who are seriously ill have varying amounts of mobility that can change as their illness progresses, so it is important to know how to safely and effectively help them move around – even repositioning in bed. The following videos guide caregivers through detailed demonstrations to support someone who is seriously ill with their walking, as well as how to reposition them in bed to change their bedsheets.

[Walking](#) – The following videos by *SE Health* demonstrate how you can support the person you are caring for to use a walker, a cane, or crutches safely:

- [How to Assist Someone with a Walker](#) (Video – 2:22mins)
- [How to Assist Someone with a Cane](#) (Video – 2:54mins)
- [How to Assist Someone Using Crutches](#) (Video – 3:24mins)

[Changing Bed Sheets \(through repositioning in bed\)](#) – Changing bed sheets is an important task for supporting the physical wellness of a person who is seriously ill, but it may be challenging or painful to get them in and out of bed when performing this task. This short video from *SE Health*, provides a demonstration of how to reposition your loved one in bed so that you can change their bed sheets without them having to leave the bed.

- [How to Change Bed Sheets with Someone in the Bed](#) (Video - 2:53 secs)

PERSONAL CARE

Caregivers at the bedside can support a seriously ill person's wellbeing by providing personal care. The material in this section provides practical considerations to help with bathing a loved one who is seriously ill, as well as providing mouth care with recipes for mouthwash and tips for effective toothbrushing and denture care. It also includes important information about changes in food and fluid consumption among people who are seriously ill, and how to manage reduced fluid intake and giving help with eating as the person gets weaker. For more information, [please refer to pages 36-45 in *Preparing for the Journey*](#).



Slide Deck with Speaker Notes

[Providing Personal Care to a Person with Serious Illness](#) – explains what personal care is, why it is important, and provides detailed explanations and video demonstrations of tasks, techniques, and strategies for providing personal care (including bathing, toileting, and mouthcare) at the bedside for someone who is seriously ill. The videos referenced in the slides are also available and described below.

[Speaker's Notes](#)

Please note: these slides have been specifically designed to be facilitated by a nurse or registered health care provider to train other health care providers (personal support workers, homemakers, health care educators, Elder support workers, respite workers, etc.). They are designed to provide health care staff with clinical skills, tools, and guidelines; therefore, they are not meant for family caregivers.



Videos

The following videos provide detailed demonstrations of personal care that caregivers, family members, and support workers may be expected to provide when caring for someone who is seriously ill. The videos have been organized into the following categories: *bathing and hair care, toileting, and mouth and other personal care.*

[Bathing and Hair Care](#) – The following videos by *SE Health* provide detailed instructions and demonstrations important for safely, effectively, and respectfully bathing a person who is seriously ill. Recognizing the discomfort and unease that may be involved with providing some personal care tasks, like bathing, *How to Manage Awkward Tasks* offers suggestions to reduce the stress and make supporting people who are seriously ill in these ways more pleasant for all involved. There are also videos focusing on washing a person's private areas - the most important part of bathing someone - and providing menstrual support. These videos are geared toward family caregivers who may be feeling awkward about providing personal care for their loved one, but they could also help the person who is seriously ill to prepare for bathing and know that there are ways to make it a more comfortable experience for them.

- [How to Manage Awkward Tasks](#) (Animated Video – 2:52mins)
- [How to Give a Bed Bath](#) (Video – 4:36mins)
- [How to Wash Someone's Genitals](#) (Video – 4:44mins)
- [How to Care for Someone on their Menstrual Cycle](#) (Video 4:22mins)
- [Preventing Falls \[in the bathroom\]](#) (Video – 0:30-1:20mins)

[Toileting](#) – Depending on the seriously ill person’s condition or mobility, they may not be able to get up and out of bed to use the bathroom. The following videos from *SE Health* provide demonstrations to help support a loved one who is seriously ill to use a commode or bedpan. They also provide some guidance around changing an adult brief and an ostomy bag.

- [How to Help with a Commode Chair/Urinal](#) (Video - 3:01 secs)
- [How to Use a Bedpan](#) (Video - 3:55 secs)
- [How to Change an Adult Brief](#) (Video – 3:30 secs)
- [How to Empty and Change an Ostomy Bag](#) (Video 5:12 secs)

[Mouth and Other Personal Care](#) – The following videos developed by *SE Health* provide detailed information and demonstrations about providing mouth care, including toothbrushing, flossing, and denture care for an individual who is seriously ill. Depending on their mobility, pain, or other symptoms of their condition, they may also need help with some of the personal care tasks involved with getting ready. The following videos demonstrates how to help someone shave, as well as how to dress someone in bed including tips for adapting their clothing to make the dressing process easier.

- [How to Help with Tooth Brushing](#) (Video – 2:51mins)
- [How to Care for Someone’s Dentures](#) (Video – 2:13mins)
- [How to Help Someone Get Dressed in Bed](#) (Video – 3:12mins)
- [How to Help Shave Someone](#) (Video – 3:32mins)

Handouts

[How to Maintain a Catheter](#) – This care guide developed by *SE Health* describes and shows what a catheter looks like, what to look out for, and where to place the tubing and drainage bag. It does not provide information for catheter insertion or removal, as those activities should only be performed by a healthcare professional. It may be helpful to keep this document visible near the seriously ill person so that helping people know what to observe and to reach out for help from a healthcare provider quickly if needed.

[Caring for Someone with Ostomy](#) – This care guide developed by *SE Health* explains what an ostomy is and what it looks like, highlighting key information about what to look out for, and how to keep the area clean. It also provides suggestions for foods to avoid and tips for skin care around the area and during pouch changes. It may be helpful to keep this document visible near the seriously ill person so that helping people know what to observe and to reach out for help from a healthcare provider quickly if needed.

PAIN

This section contains valuable information to help understand, support, and help manage a seriously ill person's pain. This section discusses the signs of pain as they occur and provides information about how caregivers can go about understanding and helping manage the different elements of a seriously ill person's total pain experience. This section also provides information about what to look out for in terms of side effects of pain medications and distinguishes between addiction, physical dependence, and tolerance. Some non-pharmacological ways to help with pain are also included. For more information, [please refer to pages 24-25, 45-51 in *Preparing for the Journey*](#).



Slide Deck with Speaker Notes

[Managing Pain](#) – explains the total pain experience and provides examples of signs of pain and strategies for communicating with people who are seriously ill to better understand their pain. It also includes tips for managing pain and describes side effects of pain medications to document and when to seek assistance. Please note that pain is also briefly discussed in the *Infection Prevention and Clinical Skills* slide deck in the **Managing Other Symptoms** section.

[Speaker's Notes](#)



Videos

[Fear of pain medication](#) – was developed by the Canadian Virtual Hospice. It recognizes that some people are worried about the side effects of pain medications and provides some ways to address their concerns, especially sleepiness and addiction, in a supportive way. The video clip length is 01:55 minutes.



Handouts

[Creating Comfort for a Loved One in Pain](#) – This handout focuses on non-pharmacological ways to support a loved one who is seriously ill and experiencing pain. The handout suggests ways that caregivers can help their loved one feel more comfortable, including reminiscing on and making new memories with them, making changes to the space they are in, incorporating spiritual or traditional practices, seeking out supplemental non-drug therapies, and/or helping them leave a legacy.

[Helping you feel better](#) – This handout was developed by the Canadian Virtual Hospice as part of the *Indigenous Voices - Living with Serious Illness and Grief* project. It provides information for helping people to understand and help relieve symptoms of pain and other causes of discomfort that someone who is seriously ill may experience. It includes a symptom scale and guides people through the important process of keeping a symptom diary - a detailed record of

symptoms and medicines. The seriously ill person may need support tracking and recording their symptoms and experiences with medicines as their illness progresses.

MANAGING OTHER SYMPTOMS

This section provides information to help understand and manage many of the other symptoms that people who are seriously ill may experience. It covers things to consider, what to watch for, and what to do about some of the other symptoms that people who are seriously ill may experience, including: mouth problems, bowel and bladder problems, shortness of breath, skin problems, trouble sleeping, swelling and confusion. For more information, [please refer to pages 50-60 in *Preparing for the Journey*](#).

Slide Decks with Speaker Notes

The following slide decks can be used in presentations, including training sessions, lunch and learns, and workshops to educate new care providers or provide a refresher to experienced care providers about the specific needs of people who are seriously ill who are also dealing with these particular illnesses and conditions. The slide decks are intended to be part of a facilitation process, with clear explanations and opportunities for questions answered by a registered health care provider with experience in the area.

Please note: these slides have been specifically designed to be facilitated by a nurse or registered health care provider to train other health care providers (personal support workers, homemakers, health care educators, Elder support workers, respite workers, etc.). They are designed to provide health care staff with clinical skills, tools, and guidelines; therefore, they are not meant for family caregivers.

[Managing Specific Illnesses and Conditions](#) – The following slide decks contain information and considerations specific to providing care for people with Diabetes, COPD, Cancer, and Hypertension. Each slide deck explains what the illness is, signs/symptoms and causes associated with the disease, common issues that may arise from the illness and different ways to manage it. They also include information and opportunities to discuss western medications and alternative therapies and traditional medicines specific to each illness.

- [Managing Illnesses and Conditions: Diabetes](#)
[Speaker's Notes](#)
- [Managing Illnesses and Conditions: COPD](#)
[Speaker's Notes](#)
- [Managing Illnesses and Conditions: Cancer](#)
[Speaker's Notes](#)

- [Managing Illnesses and Conditions: Hypertension](#)

[Speaker's Notes](#)

[Infection Prevention and Clinical Skills](#) – introduces what an infection is, including ways to prevent, identify, and address infections. It also explains the different types of wounds and offers some advice for managing them at the bedside. The last section explains how to measure and assess vital signs including temperature, pulse rate, breathing rate, blood pressure, and pain. It includes links to instructional videos demonstrating effective handwashing and wound care, as well as one outlining the difference between changes, signs and symptoms associated with normal aging from those that may be more serious and require more support from a health care provider.

[Speaker's Notes](#)

Videos

[Shortness of Breath](#) – Depending on their condition and how they are progressing on their journey with serious illness, some people may need support with breathing. The videos below provide demonstrations and important information to know to help safely and effectively set up and take care of oxygen treatment. Some people may use an inhaler (puffer) to deliver the medication they need to help them breathe. One of the videos shows two different types of inhalers and demonstrates the process of administering them, as well as tips to keep them clean.

- [How to Help with Oxygen Therapy](#) (Video – 3:11mins)
- [How to Help Someone with a Puffer](#) (Video – 2:38mins)

[Infection and Waste Disposal](#) – The following short video from *SE Health* provides information about how to properly identify and safely manage and dispose of medical waste to minimize any possible health risks.

- [How to Safely Dispose of Medical Waste](#) (Video – 2:30mins)

[Dealing with Wound Care at Home](#) – The following video from *SE Health* describes the types of medical supplies you should have on hand if caring for someone who is seriously ill with a wound. A health care provider on the community care team should provide most of the wound care and will be able to offer specific instructions for applying dressings, however this video demonstrates how to manage the wound to prevent infection in the case that a dressing falls off or gets soiled before the next scheduled change.

- [How to Manage Wound Care at Home](#) (Video – 2:51mins)

[Understanding the Normal Aging Process](#) – The changes a body goes through as it ages sometimes cause increase risk for illness and may affect measurements of physical health and wellbeing, including the monitoring and managing of pain and vital signs. This animated video

by *SE Health* describes normal age-related changes and how to differentiate them from signs and symptoms of other serious illnesses and conditions.

- [Understanding the Normal Aging Process](#) (Video – 3:20mins)

Handouts

[Pressure Sores and Infection Control](#) – This handout explains what pressure sores (bed sores) are, what makes them worse, as well as what to watch for and do to prevent them. It also highlights the role of handwashing and waste disposal in infection control.

[Mouth Care](#) – This handout emphasizes the importance of maintaining a clean, healthy mouth on a person's quality of life. It also offers some guidance around how to provide mouth care and outlines three recipes for making your own mouthwash.

[Infection and Waste Disposal](#) – The following care guides, developed by *SE Health*, provide information related to preventing infection through proper waste management, cleaning, and hygiene.

- Handling Needles
- How to Dispose of Medical Waste
- Disposal of Sharps
- Dos and Don'ts for Preventing Infection
- How to Wash Your Hands

[Normal Aging Versus Possible Dementia](#) – This care guide, developed by *SE Health*, provides valuable information comparing the signs and symptoms of normal aging to those more commonly associated with dementia. It includes descriptions of 11 early signs of dementia to help caregivers distinguish them from normal aging and advises individuals to contact a health care provider if symptoms accumulate and begin to affect daily life.

SECTION 6: MAKING YOUR WISHES KNOWN

This section provides information and resources on advance care planning, including making your wishes known and planning for your future health and social care. It covers the goals and benefits of advance care planning, defines and discusses the role of substitute decision makers in this process, and provides information on how to start talking about your wishes.

In *Preparing for the Journey*, the importance of advance care planning is discussed. People are encouraged to plan ahead for their care, to be fully informed about their illness and treatment options, and to have someone who knows their wishes for care who can advocate and make decisions if the person is unable to do that for themselves. Advance care planning is for all ages and encourages people to talk about their wishes when they are healthy. It focuses on everyday conversations where people talk about their values, beliefs, and what they would like to see happen if they get sick. For more information, [please refer to pages 7-10 in Preparing for the Journey](#).

Suggested Audience: The intended audience for this section are health and social care providers and community members (regardless of health status or relation to someone who is seriously ill) who have not previously participated in any advance care planning conversations.

Suggested Use: All of the resources can be used as stand-alone materials to provide support and education. There are booklets which can help guide people's decision making while they are healthy and to determine who would be their spokesperson/spokespeople. The poster can be displayed in community centres, bulletin boards in waiting rooms, health and social care offices, and anywhere the community gathers and can serve as a prompt for care providers to start conversations about advance care planning with clients. When using the slide deck to provide education for community or health and social care providers, it is recommended to enhance the content with the other resources, including the video. Please review all the resources to determine which will best meet the needs of the audience.



Slide Deck with Speaker Notes

[Making Your Wishes Known](#) – discusses advance care planning and substitute decision makers and explores the importance of planning for your care. It also includes a video, *The Time is Now: Advance Care Planning for First Nations People*, and some prompts for encouraging these discussions with individuals and their families.

Estimated delivery time: 30 minutes.

[Speaker's Notes](#)

Videos

[The Time is Now: Advance Care Planning for First Nations People](#) – explains advance care planning and discusses the importance of having these discussions early. It explains substitute decision making and what it means to be someone’s substitute decision maker. This video can be shown on its own, or as part of the Making Your Wishes Known slide deck to further explain the process of advance care planning. The video length is 7:24 minutes.

Handouts

[Coming Full Circle: Planning for Your Care](#) – This booklet was developed by the Canadian Virtual Hospice as part of the *Indigenous Voices - Stories of Serious Illness and Grief* project. It is a tool to help individuals reflect on and document their values, beliefs, and wishes and as well as help them select someone they trust to make decisions for them if they become unable to do so themselves. This document contains many questions and prompts to help people think and begin to make decisions about their wants and needs when it comes to their care. It can help family members, health care providers, and substitute decision makers understand what is most important to the individual. Working through this booklet can help guide an individual’s conversations about their care with health care providers or loved ones so that they can be sure to act and support the individual in ways that the individual would have if the individual were capable to make their own decisions.

[Why Advance Care Plan](#) – This poster provides brief points about the benefits of advance care planning and stresses the importance of advance care planning before an individual gets seriously ill.

Pamphlets

[Advance Care Planning](#) – provides individuals with a brief explanation of advance care planning and discusses the benefits of having these conversations early. It answers common questions that community members may have about advance care planning like “what do I need to know?” and “I want to talk about my wishes...now what?” It also reminds individuals of some of their rights when it comes to advance care planning and provides links to websites that provide further information.

[I Have Been Asked to be a Substitute Decision Maker \(SDM\) What Does That Mean](#) – explains what a substitute decision maker is, their duties, rights, and responsibilities. It also provides links to resources that provide more information on being a substitute decision maker and advance care planning.

SECTION 7: DEVELOPING A CARE PLAN

This section focuses on the importance of planning and working together with community care teams in the delivery of wholistic care. The material in this section helps people work together with the person who is seriously ill, their family members, and the health and social care providers to develop a care plan to best support the seriously ill person's needs.

In *Preparing for the Journey*, the important aspects of developing a care plan include an explanation of what a community care team is, who is involved, and the important role it has in ensuring that a person's needs are being met as discussed. It also provides some details and questions to consider when organizing and developing a care plan that will provide some guidance to everyone in the community care team, particularly in the case where the person who is seriously ill is returning to their home from hospital. It emphasizes the importance of having a plan for care, steps to follow in case of emergency, and protocols in place for when death occurs. For more information, [please refer to pages 11-14 in Preparing for the Journey](#).

Suggested Audience: The intended audience for this section are health and social care providers as well as community members as the intention is to bring people together to develop and deliver the care plan as a team. The supporting documents can help guide the process of developing the care plan and support the family and caregivers when the person is at end of life.

Suggested Use: All of the resources can be used as stand-alone materials to provide support and education. A health care provider, care coordinator, or case manager involved in the seriously ill person's community care team can use the handouts or activities to have conversations with the person who is seriously ill and/or their substitute decision maker(s). The individual may be given this in advance of a meeting or discussion with the health care provider to reflect on their wishes. The community care team should be consulted and informed about the decisions made on the form, and any changes or updates that happen should be recorded and communicated to the whole team. When using the slide deck to provide education for community or health and social care providers, it is recommended to enhance the content with the other resources. Please review all the resources to determine which will best meet the needs of the audience.



Slide Deck with Speaker Notes

[Developing a Care Plan](#) – provides an overview of the purpose and process of developing a care plan when someone has been diagnosed with a life-limiting illness. It explains who the members of the Community Care Team are, and why this team is important at the end of life. It provides a series of guiding questions to support that organizing and planning of care. Finally, this presentation reviews the protocol for Expected Death in the Home which is important to review prior to supporting someone who is planning to die at home.

Estimated delivery time: 20 minutes.

[Speaker's Notes](#)

Activities

[Developing a Care Plan](#) – explains what a care plan is, who can be involved in a community care team, and provides some structure for developing a care plan with a community care team. There are several questions to consider when developing a care plan, including: Where does the person want to receive care? What treatments or services would they like or not like to receive? And, who would they like to provide this care? The second page of this document is a fillable form where the responses to some important questions can be recorded.

Hearing about the seriously ill person's feelings and probing about the community and familial capacity for home care is important. Knowing who the person has to support them in their care and their contact information is important to document. These questions can help direct conversation and ultimately guide the development of the care plan.

[Checklist for Home Passing](#) – provides a series of questions for the person who is seriously ill and/or their family to consider when an individual has expressed their wish to die at home. The questions should be reflected upon and then answered, and anything that is unclear, or any further action required based on the answers to these questions, should be addressed. There is a section at the bottom of the checklist to indicate who completed the checklist and the date. These checklists should continue to be reviewed and can be revised as the patient's needs and/or the availability and accessibility of community resources change.

SECTION 8: THE PALLIATIVE APPROACH TO CARE

This section introduces the palliative approach to care and provides an overview of how palliative care can be supported in Indigenous communities.

In *Preparing for the Journey*, palliative care is described as whole-person health care which focuses on the mind, body, and spirit. The goal is to relieve suffering and improve the quality of life for persons who have a serious illness. During a palliative approach to care, the seriously ill person and their family are a part of the "unit of care." Support is therefore provided to both the individual who is sick and their family. Palliative care begins at the time of diagnosis and continues on after the person passes with grief and bereavement support to family and loved ones. Palliative care is for any individual who has been diagnosed with a serious illness, including (but not limited to) cancer, end-stage heart/lung/kidney diseases, AIDS, and diabetes. It also helps to meet a person's needs towards end of life, including pain management, safety, dignity, and respect. For more information, [please refer to pages 4-6 in Preparing for the Journey](#).

Suggested Audience: The intended audience for this section is health care providers, community members and/or family members who are not familiar with the palliative approach to care and who may be caring for someone who would benefit from this approach.

Suggested Use: All of the resources can be used as stand-alone materials to provide support and education. When using the slide deck, it is recommended to enhance the content with the other resources, including the storytelling video. Please review all the resources to determine which will best meet the needs of the audience.

Slide Deck with Speaker Notes

[Palliative Approach to Care](#) – provides an overview of palliative care and offers ways to support people who are very sick. This slide deck can be presented at health fairs and public meetings to provide education for community members, as well as lunch and learns/education sessions for health care provider education.

Estimated delivery time: 30 minutes.

[Speaker's Notes](#)

Videos

[Caring for the Patient and Family](#) – was developed by the Canadian Virtual Hospice as part of the *Indigenous Voices - Stories of Serious Illness and Grief* project. It discusses what palliative care is and what it means for Indigenous people and their families as a loved one approaches

the end of their life. The video length is 16:50 minutes. After showing the video, you may want to use the following questions to begin a conversation with participants:

- *What did you think of the video “Caring for the Patient and the Family?”*
- *Was there anything that resonated with you or that you connected with?*

Estimated delivery time (including discussion) is 30 minutes.

Handouts

[Introduction to the Palliative Approach to Care](#) – connects understandings about wholistic wellness and caregiving to explain what the palliative approach to care is, when it begins, and what is involved.

[Top 10 Things to Know About Palliative Care](#) – provides important information about palliative care in a brief, easy-to-read, one-page document. It addresses the questions and debunks common myths that people often have about palliative care.

[A Patient's Story](#) – is written from the perspective of someone who is seriously ill. The purpose of the story is to help people better understand how the seriously ill person is feeling and empathize with them, recognizing that not every seriously ill person’s experience is the same or unchanging.

[What is Palliative Care?](#) – was developed by the Canadian Virtual Hospice as part of the *Indigenous Voices - Stories of Serious Illness and Grief* project. It discusses some misunderstandings about palliative care through a series of myths and facts that help clear confusion.

Pamphlets

[What is Palliative Care?](#) – talks about palliative care in the home, hospital, and/or long-term care facility. It includes information about pain and symptom management, social and emotional support, spiritual support, caregiver support, volunteer support, bereavement support, and links to resources.

[Living with a Terminal Illness](#) – provides quick facts about diagnosis, symptoms, pain (both physical and soul), emotions, as well as what to expect and other needs a person living with a serious (or terminal) illness may have at this stage in their journey.

SECTION 9: LAST DAYS AND HOURS

This section includes information about how to know and what to do when death has happened. It concludes with some self-care support for caregivers.

In *Preparing for the Journey*, information that is important to know when death is near is explored. Although we recognize that the experience of dying is different for every individual and impacts families and communities differently, information is provided that may help care providers support a seriously ill person, the family, and themselves during this final stage. It lists some general signs that can be expected as a person's condition begins to worsen as they approach end of life and provides some things health and social care providers can do to identify and support individuals as these changes occur. It also includes protocols for end of life and provides some guiding questions to help with arranging end of life plans and ceremonies that are aligned with their values, beliefs, and wishes. Please refer to [pages 61-66 in *Preparing for the Journey* for more information.](#)

Suggested Audience: This material is intended for health care providers, particularly those who have not provided care at the bedside to someone at end of life before. The information in this section might be useful to help family members better understand what to expect as their loved one approaches the end of life.

Suggested Use: All of the resources can be used as stand-alone materials to provide support and education. Health care providers may want to begin to discuss the protocols for end of life with the person who is seriously ill (and any specified family members) early on in their journey, to ensure necessary conversations with loved ones are had and the individual's end of life wishes are respected. The resources in this section can be handed out to families and caregivers of someone who is seriously ill. When using the slide deck to provide education for community or health and social care providers, it is recommended to enhance the content with the other resources. Please review all the resources to determine which will best meet the needs of the audience.



Slide Deck with Speaker Notes

[Last Weeks or Days of Life](#) – describes what happens during the last weeks and days of life for a person who is seriously ill and their family. It describes the signs that the end of life is approaching, it explains some of the protocols for end of life and offers opportunity for group discussion, and it also reviews what to do when death occurs and how to care for oneself.

Estimated delivery time: 20 minutes.

[Speaker's Notes](#)

Handouts

[Last Weeks or Days of Life](#) – This handout outlines the changes that someone who is seriously ill may experience when death is near. It contains suggestions for what to do and not do once the expected death occurs. This information can help individuals and families more easily recognize end of life changes in their loved ones, support them, and plan accordingly.

[Food for Thought](#) – The content of this handout was developed by the Palliative Pain and Symptom Management Program in Thunder Bay, Ontario and adapted by CERAH. It addresses the benefits, concerns, and considerations involved when the seriously ill person loses their appetite and ability to eat. This resource recognizes the discomfort caregivers may encounter and offers suggestions for ways to help themselves and support their loved one during this difficult time.

Pamphlets

[What to Expect](#) – was developed by the Canadian Virtual Hospice as part of *Indigenous Voices - Living with Serious Illness and Grief* project. It explains what can be expected to occur and what you can do to support a loved one when they are diagnosed with a serious illness, in their final days, and in the last day or two.

[Caring for Someone with a Terminal Illness: What to Expect](#) – provides an overview of care needs when a loved one is diagnosed with a serious (or terminal) illness, including ways to help the loved one feel more comfortable. It also describes pain, and how to recognize signs that the end is near.

Activity

[Protocols for End of Life](#) – This activity guides individuals and families through a series of reflection questions to help them plan for end of life in ways that are respectful of the seriously ill person's wishes. It offers questions to promote reflection and discussion between the person who is seriously ill, their families and caregivers, with space to record responses.

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