



# Walking Alongside Indigenous Peoples Who Are Seriously Ill



## CAREGIVER PATHWAY GUIDE

A guide to help family and community caregivers understand what to expect, what questions to ask, and how to seek and provide support through serious illness



The *Walking Alongside Indigenous Peoples who are Seriously Ill Pathway* document 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 health care provider.

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# INTRODUCTION

The *Walking Alongside Indigenous Peoples who are Seriously Ill: Caregiver's Pathway Guide* is for anyone caring for an Indigenous person with a life-changing illness. Caregivers can be family, friends, community helpers, and health or social care providers.

This resource guides caregivers right from the moment they learn about the diagnosis, guiding them through every step. The goal is to help caregivers feel supported, guided, and empowered in their role. The guide covers many helpful topics, including:

- Sharing wishes and planning care
- Providing daily care
- Caring for your own well-being
- Preparing for the end of life

This pathway looks at well-being in a wholistic way. We look at how all parts of a person and their relationships are connected. We base this guide on the teachings of the Indigenous Wellness Framework<sup>1</sup>. This framework teaches us that true wellness comes from balancing four parts of our being:

- **Spiritual wellness** – our connection to Spirit, identity, Creation, and purpose.
- **Emotional wellness** – comes from our ties to family, community, Land, and All Our Relations.
- **Mental wellness** – our thoughts and feelings. It also includes what we learn, our intuition, and understanding our place in the world.
- **Physical wellness** – caring for our body and living out our purpose each day.



When these four parts are in balance, they bring hope, belonging, meaning, and purpose. Those four parts are at the heart of Indigenous wellness.

We bring together the teachings of the Indigenous Wellness Framework and the palliative approach to care. This approach can be seen in the model below<sup>2</sup>. Palliative care is a type of support that focuses on comfort and quality of life for people with serious and life-changing illness. Even though these two systems are different, they work well together to support a person's well-being.

Both approaches share these beliefs:

- Wholeness involves the body, mind, and Spirit
- We must balance our physical, emotional, spiritual, and social selves
- Connecting with family, caregivers, and communities is foundational
- Healing must happen on three levels: physical, spiritual, and emotional
- Wellness affects the individual, their family, and their community.



# 1

## UNDERSTANDING ILLNESS

Someone you are caring for has been diagnosed with a life-changing illness. Now what?

**Purpose:** To help caregivers understand what a life-changing illness means. This also helps them start preparing.

**Contents:**

- Understanding what a “life-changing illness” means
- Recognizing how illnesses change over time
- Introducing the palliative approach to care

**Reflection questions to think about as you go through this section on Understanding Illness:**

- What do I know and understand about the person’s illness?
- Is this illness curable, or is it something they will live with for the rest of their life?
- How might this illness affect their daily life (physically, emotionally, mentally, or spiritually)?
- What changes have I noticed that show me how this illness is progressing?
- What cultural or family teachings can help guide how we make sense of this diagnosis?



A life-changing illness is a health condition that impacts a person’s daily life. These illnesses often are described as chronic, advanced, incurable, progressive, life-limiting, or terminal. While these illnesses cannot be cured, they can be managed with care. They affect not only physical health but also mental and emotional well-being. These illnesses can change how people connect with their families and communities. Many people live with these illnesses for months or years. With the right support, people can still live well and find purpose in their lives.

Here are some life-changing illnesses that often affect First Nations, Inuit, and Métis communities:

- Diabetes and its complications
- Cancers
- Organ failure – such as kidney, liver, or heart problems
- Progressive neurological conditions – brain and nerve conditions like Parkinson’s, ALS, or dementia

Every person’s experience is different, but many face similar challenges. Sometimes, even children are affected by conditions that have no cure.

## Understanding how illness changes over time

Illnesses can change in different ways, which we call “trajectories” or illness journeys. Knowing how these changes happen can help you prepare for what might come next. This understanding helps you plan better, make smart choices, and know when to ask for more help.

Research<sup>3,4</sup> shows us four common patterns or paths that people may experience with these types of illnesses:

- 1 Fast Change or Rapid Decline:** This pattern is often seen in people with advanced or late-stage cancer. At first, people may feel okay for a long time, but then their health quickly worsens. Emotions often run high during key times, such as getting a diagnosis, after treatment, or when they notice new symptoms.

**Tip for Caregivers:** Plan ahead because illnesses can change quickly. Talk early about changes and symptom management. Discuss key priorities and support before the person gets very sick.

- 2 “Up and Down”:** This pattern is often seen with organ failure, like heart or lung problems, or other long-term, chronic conditions. Symptoms can suddenly get much worse, then get better, then get worse again. The person may go in and out of the hospital. Over time, they may have more bad days (crises), and recovery takes longer. Sudden changes can lead to anxiety and uncertainty about what to expect.

**Tip for Caregivers:** Watch for signs of change and have a plan for what to do if symptoms worsen. Know who to call for support on bad days.

- 3 Slow Change or Gradual Decline:** This path is often seen with conditions like frailty and dementia. It can also happen with brain and nerve conditions, like after a stroke. Changes happen slowly over months or years. The person might slowly lose strength, memory, or independence. They may also feel sad or worry as their abilities change.

**Tip for Caregivers:** Get the person involved in planning. Let them make decisions and choose activities they enjoy. This keeps their dignity and purpose. It also helps them feel connected to family.

- 4 Living with Multiple Illnesses:** Some people may face more than one serious health condition at the same time. For example, having diabetes along with heart, lung, or kidney disease, or dementia. This situation can be challenging and unpredictable. Because many illnesses share similar symptoms, it can be hard to identify which is the cause of a certain problem.

**Tip for Caregivers:** Symptoms can mix together and look like normal signs of aging, but they are not. It is important to have open conversations with the person you are caring for. Ask them how they feel and what “living well” means to them. By focusing on what matters most to them, you can better understand their needs.

Many Indigenous people face health issues at an earlier age, a reality rooted in the ongoing effects of colonization. Racism in the health system and lack of access to healthcare services can also be factors. First Nations, Inuit, and Métis people often face a higher “burden” of disease.<sup>5</sup> This means they may get sick earlier and have more severe symptoms. In Indigenous communities, it is common to see multiple illnesses affecting people at the same time.

## Returning to Balance

The Indigenous Wellness Framework teaches us that wellness is about balance. It includes our spiritual, emotional, mental, and physical selves. A serious illness affects all these parts, creating an imbalance. A physical illness affects other parts of a person’s being.

Here is how these connections affect a person:

- If someone is in physical pain, they may feel hopeless spiritually.
- Mentally and emotionally, they might feel sad, angry, or overwhelmed by hard choices, which can cause stress or tension with family members.
- This connection also works in a positive way. When we support a person spiritually, it helps their physical, mental, and emotional well-being. Ways to offer spiritual support include connecting with their identity, the Land, or Ceremony.

From this wholistic view, wellness means being a whole and healthy person, even in the face of illness.

When an illness cannot be cured, we can still move toward balance, belonging, and connection. We can help support a good quality of life through the end of life. This is where the palliative approach comes in.

## Introducing the palliative approach to care

The palliative approach to care looks at the whole person, rather than just the physical illness. Palliative care focuses on comfort. It helps reduce suffering. It also aims to deeply understand a person's needs.

Palliative care is not just for the final weeks, days, or hours of life. It is person-centred care for people living with a life-changing illness. The goal is to promote living well, not just dying well. This approach brings physical comfort by managing pain and treating other symptoms. It also gives spiritual, emotional, and mental support. This help is for both the person and their family. Starting palliative care can help to find balance and promote healing. It also protects a person's dignity throughout the journey.



### Questions to ask a health care provider or to bring to your next appointment:

- Is this illness curable, or will it keep getting worse over time?
- Are the treatments meant to cure the illness, slow it down, or just provide comfort and symptom relief?
- When would a palliative approach be helpful, and how will we know when that time has come?
- Who can help us understand changes in their condition? What signs should we look for that show we need more support?
- If things change suddenly, who should we call, and what should we do first?



For more information and additional tools, resources, and examples to support you in *Understanding Illness*, visit the resource website at [www.walkingalongside.lakeheadu.ca](http://www.walkingalongside.lakeheadu.ca).

## 2

# MAKING WISHES KNOWN

What's next? Think ahead to what matters most to you or the person you are caring for.

**Purpose:** This section helps people and their caregivers reflect on their values, priorities, and care wishes.

**Contents:**

- Why planning early matters
- Understanding what advance care planning is
- Consider your values, beliefs, and wishes as a whole — including your spiritual, emotional, mental, and physical well-being
- How your wishes can help guide future treatments and care goals
- Making your wishes known to care providers

**Reflection questions to think about as you go through this section on Making Wishes Known:**

- What matters most to the person I am caring for (in how they live, receive care, and are supported)?
- Do I understand their wishes about comfort, pain management, and decision-making?
- Who do they want nearby during this time? Are there any spiritual practices that are important to them?
- Am I the right person to lead these talks, or should I bring in someone else? This could be an Elder, another family member, a helper, or a health care provider.
- Am I strong enough to help my loved one? What supports do I need?
- What worries or uncertainties do I have about talking about wishes? What supports might help me feel more prepared?
- Where would they feel most at peace receiving care (e.g., home, hospital, hospice, long-term care)? Are they comfortable travelling for care? What would we need to make these wishes possible?
- What stories, teachings, or values guide how they want care decisions to be made?



When you are caring for someone with a life-changing illness, it can be hard to talk about the future. But having these conversations early is one of the best ways to support them.

Talking about values, needs, and wishes is key. It helps caregivers and the care team to provide care that truly reflects the individual and what matters most to them. Planning early is not about giving up hope; it is about preparing to live well. For you as a caregiver, this can help ease the pressure and confusion of guessing what you think they might want. It helps you know how to support them if their health changes, which reduces stress for everyone.



### **The caregiver's role in planning ahead**

Planning ahead is sometimes called Advance Care Planning (ACP). This process helps the person you care for think about their wishes and share them with others. People often need support to think about their care needs. They should consider goals and what they might want in the future, or as things change.

It may not be something they have ever thought of. Maybe they have, but they have not mentioned it to anyone. Either way, they need to think and plan ahead. It is important for you as a caregiver, too. This is especially true if there comes a time when they cannot speak for themselves.

Having these conversations and planning ahead can feel hard or uncomfortable. However, it is much better than leaving decisions to others who may not know what the person would want.

When helping someone plan ahead, you get to know and understand the person you are caring for. You learn what *living well* means to them. This helps you do your best to support care that aligns with their values, beliefs, and goals.

As a caregiver, you can help someone think about and plan for their care by:

- Listening to their feelings, beliefs, and concerns. These concerns include their thoughts about comfort, quality of life, traditions, spirituality, getting sicker, and dying.
- Encouraging them to share what matters to them. This may include asking what comfort or quality of life means to them.
- Helping them make their wishes known, so that family, friends, care providers, and anyone who may be involved in their circle of care are aware.
- Helping them pick someone they trust to make health decisions if they get too sick to speak for themselves. This person is sometimes called a “substitute decision-maker” or “proxy”.

In some provinces and territories, these wishes or preferences can be written down and recorded through legal forms. These forms include Advance Directives, Powers of Attorney for Personal Care, or Goals of Care documents. However, planning does not always have to be so formal. Sometimes friends, family, Elders, or spiritual leaders share these wishes through casual conversations or written notes. No matter how it is done, the goal is the same. It is about making sure the person’s wishes are honoured and preventing confusion or conflict when it is time to make choices.

## Thinking holistically

Planning ahead is most meaningful when it reflects the whole person. To help the person you are caring for think and talk about their wishes, you can use the Indigenous Wellness Framework as a guide.

Try asking questions about these four areas:

- **Spiritual:** Are there ceremonies, songs, teachings, or practices that are important to include in your care? What brings you meaning or helps you feel hopeful?
- **Mental:** What information do you need to feel calmer or less stressed? Who do you trust to best understand your illness or care options?
- **Emotional:** Who do you like to spend time with? Who do you want by your side for support? What brings you joy or helps you feel at peace?
- **Physical:** What brings your body comfort? How do you want pain and symptoms to be managed?



## Where is the best place for care?

A very important topic to talk about is where your loved one feels most at peace and where they would like to receive care.

- Many people want to stay home in their communities with loved ones nearby.
- Others prefer a hospital or care home, where more medical help is close by.

There is no right answer. What matters is respecting the person's wishes. Keep in mind that some treatments, procedures, or therapies may not be available at home or in the community. Receiving these treatments might require travel or moving away. Hospitals and health care centres should support traditional and spiritual ceremonies and practices. They should also accommodate Indigenous medicines and culturally safe supports. The person you are caring for may need your help advocating for these wishes with the health care team. Talk together about what is available, what is possible, and what supports they would need to make their wishes happen.

It is common for people to say they want to go to a hospital because they do not want to be a “burden”. If this happens, try bringing family, friends, and community together. You can ask: “How can we work together to support their wish to stay at home?” Often, sharing the work helps the person feel more at ease.



## Helping make their wishes known

Once you have had these talks, the next step is sharing the information. You can help the person you are caring for connect with:

- family or friends
- an Elder, Knowledge Carrier, or spiritual leader
- a health care provider (such as a doctor, nurse, or social worker)

It helps to write these wishes down or to have them record them in their own words. You can use tools like *Coming Full Circle: Planning for Your Care* to help guide the conversation. This document is available on the *Walking Alongside* resource website.

## Plans can change, and that is okay

A person's wishes can change even if they are written down or recorded. As a person journeys throughout their illness, they may change their mind about what they want. This is natural and very common.

What felt right at the beginning of the journey might not feel right later on. For example:

- Someone who did not follow a traditional path early on. As time passes, they want to include more Ceremony or traditional practices.
- Someone who wants to keep certain family members away might fix old conflicts. Then, they may welcome those people back later.
- Someone who was determined to travel for medical care may eventually grow tired of the journey. Then, deciding they would rather stay in the comfort of their own home.

Because feelings can shift, it is important to keep checking in. Review the Coming Full Circle: Planning for Your Care resource again, or ask: "Is this still what feels right to you?" Whenever a wish changes, try to update your notes or records. It is important to share the most up-to-date information with the family, doctors, and the care team. This makes sure everyone is on the same page. Keeping these conversations going is very helpful. It ensures the person you are caring for feels heard and supported along their journey.



### Questions to ask a health care provider or to bring to your next appointment:

- Can an Elder, community health worker, nurse, or doctor help guide our conversations about care wishes if we do not know how to begin?
- What care, treatments, or supports are available in our community? What would require us to travel outside the community?
- How can we clearly write down and share the person's wishes, so the care team honours them if the person cannot speak for themselves?
- What should we consider when choosing or confirming a substitute decision-maker? Who needs a copy of it, and who needs to be informed?
- What signs or changes might tell us that it is time to revisit or update these conversations?



For more information and additional tools, resources, and examples to support you in *Making Wishes Known*, visit the resource website at [www.walkingalongside.lakeheadu.ca](http://www.walkingalongside.lakeheadu.ca).

# 3

## CREATING A CARE PLAN

Bringing wishes and needs into action.

**Purpose:** To help caregivers know the person's wishes and priorities. This ensures that they are part of the care plan and supports the person in navigating the health care system.

**Contents:**

- What is a care plan, what goes into it, and why does it matter?
- Recognizing and recording changes
- Understanding who is who in your care team
- Navigating the health system and advocating for care

**Reflection questions to think about as you go through this section on Creating a Care Plan:**

- What parts of the care plan do I feel confident about, and where might I need teaching, guidance, or support?
- Who in our family or friend circle is willing and able to help with care, and what roles or tasks make sense for each person?
- What changes in symptoms, behaviour, or daily routines have I noticed? How am I keeping track of them? Do I have a plan for tracking these changes that is easy for other family members to follow?
- What cultural, spiritual, language, or communication needs should be included in the plan?
- What supports or services do I think we might need now, soon, or later? This could include home care, equipment, respite, or transportation. Are any of these likely to have a waitlist or take time to bring in?

### What is a care plan, and why does it matter?

A care plan is a shared guide that brings together the person's goals, values, and needs in one place. It helps everyone involved, like family, community members, Elders, and health care providers, to work together. This way, they can support the person in a coordinated and effective way. A care plan outlines what matters most, who will help, and how those supports will work together.

A care plan can be thought of as a “living document”. It is not a one-time list. You can and should update it during the person’s illness journey. Their needs, treatments, and illness can change often. Use this tool to schedule visits, record medications and appointments, and clarify responsibilities. A good care plan keeps the focus on the whole person, not just their illness.

## Keeping track

Families and caregivers know the person best. Keep an eye on any changes you notice in the person you are caring for. Record them in a consistent place. It is hard to keep track of everything with the stresses of caregiving. Changes, whether good or bad, can be easily forgotten.

You can write the following in a notebook, journal, or chart to document the person’s journey:

- Medications – name, strength or dosage, and the date and name of the prescriber
- Appointments – date, provider name, type of appointment, and contact information
- Treatments – type, start and end dates, and notes on whether symptoms improved or worsened
- Care Team Members – provider name, role, and contact information

You can also write down changes in a person’s pain or symptoms:

- Physical symptoms: changes in pain, appetite, sleep, or breathing
- Mood: feeling more sad, anxious, or frustrated than usual
- Energy: feeling extra tired, or having brain fog
- Medications: time it was taken or skipped

These symptoms do not always have to be “bad” reactions. You can record notes on improvements in symptoms, moments of clarity, or pain relief. Also include details about food or drink consumed, such as the amount and type.

It is very helpful to keep a document in a safe, easy-to-find place. This document should include all current care, medications, medicines, and treatments. It should also list all names and contact information for the members of the care team. This includes family, health and social care providers, and other community care providers involved.

How you decide to keep track and how many details you would like to include, or share, is up to you. If you do not know where to start, visit the *Walking Alongside Indigenous Peoples who are Seriously Ill* resource website for helpful examples.



## When to reach out for extra help

Write down new or worsening symptoms, changes, or reactions. This can help you notice signs that lead to a crisis or symptom flare-up in the person you are caring for. Sharing these notes with the care team can help them notice patterns and decide if the care plan needs to change.

Recognizing signs or changes early and informing the care team can help prevent crises or emergencies. Changes in illness paths often occur slowly, with ups and downs. Sudden changes are always a concern and should be reported to a member of the health care team as soon as possible. Call your nurse or doctor if you notice a sudden change in pain, breathing, confusion or memory, or the ability to get out of bed or eat.

As a person's main caregiver, you know this person you are caring for very well. If you feel like something is wrong or may be an emergency, trust your gut and seek help right away. Know the contact information of the nearest emergency health service provider and reach out as soon as possible.



## Advocating: speaking up for the person you care for

Advocacy means speaking up for the needs of the person you are caring for. Families and caregivers are encouraged to ask questions. They should clarify roles. It is important that their wishes are respected and their concerns are heard. You can help amplify their voice. To feel more confident during appointments, you can:

- Make a list: Look at your tracking notebook and write down your questions before you go.
- Take notes: It is always a good idea to take notes during appointments. You can ask someone else to take notes so you can remember what was said later. If you cannot do this, ask the health care provider for a short summary. These notes can help you share updates with family members and other caregivers.
- Bring a friend: Ask a trusted family member, a translator, or a Patient Navigator to come with you for support.
- Ask “Why?”: You might not understand what a care provider said, or what a medication is for. If a treatment does not seem to match the person's wishes, ask for an explanation.

## Understanding who is who in your circle of care

Write down new or worsening symptoms, changes, or reactions. This can help you notice signs that lead to a crisis or symptom flare-up in the person you are caring for. Sharing these notes with many different people in different roles may be involved in care. Together, they form a circle of care around the person who is ill, their family, and you as the caregiver. You do not need everyone on this list at once, and the team may change over time.

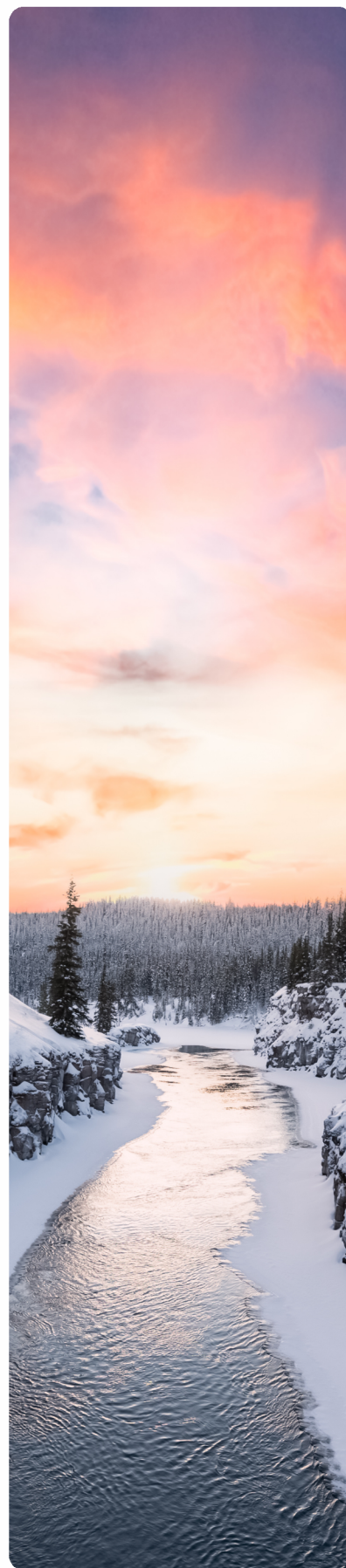
The team may include:

- **Primary Care Providers** – This is usually a family doctor or nurse practitioner. They monitor a person’s overall health, prescribe medications, and help set up medical care with other health workers.
- **Specialists** – These are medical doctors who focus on a specific illness or area of the body. They find out exactly what is wrong. This is called a diagnosis. Specialists order tests and prescribe treatments. Your healthcare team might include a few different types of specialists. You could see a cardiologist (a heart doctor) or an internist (an internal medicine doctor). If you need cancer care, you will work with an oncologist. A radiologist is the doctor who handles your X-rays, and a gastroenterologist focuses on your digestive tract.
  - **Palliative Care Specialist** – These are doctors with specialized training in palliative care. This care focuses on comfort for people living with life-changing illnesses. They help manage complex pain and other symptoms. Palliative care specialists work with the care team to reduce suffering and promote quality of life for both the person who is ill and their family. This support is from early in illness through to the end of life and bereavement.
- **Home-Care Nurses and Personal/Home Support Workers** – also called health care aides or continuing care assistants. They help with medications, bathing, mobility, and comfort at home or in care settings.
- **Community Health Representatives (CHRs) and Home-Care Coordinators** – connect families with programs, equipment, and transportation.



- Social Workers – offer help with grief and emotional support. They can help with understanding and completing paperwork related to personal care, financial planning, benefits, and housing.
- Elders, Knowledge Carriers, Traditional Healers, Spiritual Leaders – offer spiritual guidance and Ceremony. They can provide traditional medicine and cultural teachings. These practices build wholistic well-being, balance, and strength.
- Volunteers, family, and friends – provide company. They give caregivers short rest. This rest is called respite. They also can help with transportation, everyday tasks, errands, and meals.
- Health System Navigators & Indigenous Patient Navigators – are usually based in hospitals or special care units. Their job is to help you understand your options, advocate for your needs. They guide you through health and social care services and can offer translation or interpretation services. They can connect you with spiritual care or help with hospital admissions, discharge planning, and coordinating care between different locations.
- Dieticians – support nutrition and hydration. They help plan meals that meet a person’s health needs and help them eat or drink comfortably.
- Physio and Massage Therapists – support movement, comfort, and circulation through exercises, positioning, and hands-on therapies. This can help support strength, ease stiffness, and relieve pain.
- Occupational Therapists – assess how a person manages activities of daily living and recommend equipment or adaptations to support safety and independence. This may include help with eating, dressing, bathing, moving around, and continuing other meaningful activities.
- Pharmacists – give expert advice on medications. They help with getting your prescriptions and explain how to use them safely. They can also answer questions about side effects, allergies, and how to store your medicine at home.
- Others (could vary depending on your needs and available organizations, services, and agencies in your area)

Not everyone will need all these supports. The care team may also change over time. If you are not sure who should be involved, ask a health care provider what supports are available and how to get them. Feel free to ask about any of these roles, even if they have not been offered yet.



## **Could this person benefit from a palliative approach to care?** ***Let us ask a specialist!***

Palliative care specialists are doctors trained in palliative care. Their goal is to support people living with serious and life-changing illnesses. They support the whole person in four ways: physically, emotionally, spiritually, and mentally. They also offer support to families and caregivers.

These specialists are highly skilled at managing complex pain and other challenging symptoms. They help reduce distress and improve quality of life. Palliative care specialists work closely with the rest of a person's care team. This ensures that care stays focused on the person and matches their needs, values, and wishes.

A palliative approach to care is most helpful when it starts early in the illness journey. However, these specialists are not always brought in as soon as they could be. This often happens because people mistakenly think palliative care is only for death or the final days of life. Palliative care does NOT mean giving up on treatment or that someone is going to die right away.

This type of care can happen at the same time as other treatments. For example, it can be used with chemotherapy, which is a medication for cancer treatment. It can also work with dialysis, which is a treatment that cleans blood when the kidneys fail. A palliative care specialist does not replace other doctors or stop treatments that keep the person alive. Instead, they work with other doctors to provide the best care possible.

Palliative care specialists help organize care and adjust plans as illness changes. They do their best to make sure symptoms are well managed, whether care is provided in a hospital, at home, or in the community. Having them on your team means having another team member to connect with you and speak up for your needs. Having a palliative care specialist involved often means:

- better control of pain and symptoms,
- clearer communication and planning that focuses on the person's goals,
- more consideration and support with mental, emotional, and spiritual well-being
- a care plan that adapts as needs change over time.

If you think the person you are caring for could benefit from this kind of support, it is important to talk with them about it. Sometimes, patients or families need to ask directly for a palliative care or pain and symptom management meeting. You can start by speaking with your primary care provider or another member of the care team. Ask them if a referral to palliative care or a meeting with a palliative care specialist is right for you. Do not be afraid to be very clear and direct: "We have decided we would like a palliative care consult".

The palliative approach to care is about living as well as possible for as long as possible. It focuses on comfort, dignity, and support. Getting help from a palliative care team focused on these goals can be an important part of supporting someone throughout their illness journey.

## Navigating the health system

Navigating the health system can feel overwhelming. This is especially true when a person's care needs are changing. A good place to start is knowing who to ask and when to ask. If you are feeling lost, look for a navigator. Navigators can include home-care coordinators, Community Health Representatives (CHRs), health system navigators, or Indigenous Patient Navigators. They can help guide you through services such as:

- Palliative care – an approach focused on comfort and well-being
- Equipment loans
- Transportation
- Home support
- Respite – short rest breaks for caregivers

Indigenous Patient Navigators are there to speak up for you and the person you are caring for. They may also provide culturally relevant information and support communication with care teams. They help with hospital admissions or creating a plan for going home, and help connect you with spiritual care or Ceremony. Indigenous Patient Navigators may also be able to offer translation services or connect you to people who can. While navigators are sometimes assigned to specific areas (such as cancer care, renal services, diabetes, or mental health), they can also support people in other parts of the system upon request. If you feel you need help understanding or coordinating care, ask if navigation support is available, even if it has not been offered.

**Don't wait to be offered help.** If the person needs a ride to an appointment, a hospital bed for the home, or someone to help explain a diagnosis, ask for help. You can ask the CHR, nurse, or local Friendship Centre what is available in your area. Do not hesitate to contact local health or community centres. They can tell you what other services, supports, or resources are available in the area or at a distance. Examples of helpful services include:

- Meal services
- Respite care
- Telehealth lines – phone or video health support
- Tele-visitation – virtual visits
- Transportation programs

Write down the contacts you make and the suggestions for resources, supports, and services you get. Even if the person does not need them right now, it may be helpful to look back on these notes later.

Remember that support is not just about medical care and medications. Things that bring comfort are just as important. This includes Ceremony, traditional practices, music, visits with grandchildren, or time on the Land. Your care team should support these needs and make these things happen, too.





**Questions to ask a health care provider or to bring to your next appointment:**

- What signs or symptoms should tell us it is time to seek more help, and who do we call first when something changes?
- Who are the key members of our care team, and how can each of them support us (Elder, doctor, nurse, Community Health Representative, Traditional Healer, home care, social worker, etc.)?
- Is there an Indigenous Patient Navigator or cultural support worker available, and how can we connect with them?
- How can we get help with translation, cultural practices, or spiritual wellness when needed?
- What community programs, equipment, or home care supports are available to help us provide care safely and comfortably at home?



For more information and additional tools, resources, and examples to support you in *Making Wishes Known*, visit the resource website at [www.walkingalongside.lakeheadu.ca](http://www.walkingalongside.lakeheadu.ca).

# 4

## PROVIDING CARE

Supporting the whole person; mind, body, and Spirit.

**Purpose:** To support caregivers in providing wholistic care day-to-day that promotes physical, mental, emotional, and spiritual well-being.

**Contents:**

4.1 Spiritual wellness

- Creating supportive environments that consider and honour a person's identity

4.2 Mental wellness

- Supporting the mental weight involved with illness, grief, and loss

4.3 Emotional wellness

- Helping foster connection to family and friends as roles and relationships change

4.4 Physical wellness

- Providing comfort care to support a person's pain and other symptoms and adapting care as illness progresses

**Reflection questions to think about as you go through this section on Providing Care:**

- What do I know about the care needs of the person I am supporting right now (physical, emotional, mental, spiritual)? Where do I feel confident or unsure?
- How comfortable am I providing hands-on care, and what skills or support might help me feel more prepared?
- How do I notice when they are in discomfort, pain, or distress, and what helps me respond in a calm, supportive way?
- What routines, practices, or settings help their overall wellness? How can I add more of these into their daily life?
- Who in our family or community can help me provide care? Sharing this support helps keep things balanced. It also honours our shared cultural values, needs, and traditions.
- Who else is available or capable of learning how to provide support? Is there someone I can depend on when I am not there?

Caring for someone who is seriously ill means looking after the whole person, including their spiritual, emotional, mental, and physical health. The Indigenous Wellness Framework reminds us that wellness is a balance of these four parts. When one part of the circle hurts, the other parts feel it too.

As a caregiver, walking alongside the person means honouring that balance. It means caring for the whole person, not just the illness.

The next sections explain what to think about when giving care for each aspect of wellness. For step-by-step guides, demonstrations, and examples, visit the Walking Alongside Indigenous Peoples who are Seriously Ill resource website. There you will find videos, handouts, and activities to support you in providing care at home and in the community.

## 4.1 Spiritual wellness

Spiritual wellness is an essential part of health. It connects people to meaning, hope, and belonging. It also connects them to family, ancestors, Land, and the Creator. Supporting someone's spiritual wellness means honouring their beliefs. You can do this even if their beliefs are different from yours.

How you can help as a caregiver:

- Create a peaceful space: Make a quiet spot for Ceremony, prayer, or song.
- Bring in comfort: Light a candle, hold ceremonies, or place meaningful items. Do whatever brings comfort and connection.
- Invite spiritual leaders: You can ask Elders, Traditional Healers, or faith leaders to visit if the person wants that.
- Listen to stories: Offer to help them record their life stories or leave messages for the family. This can be a way of celebrating their legacy.



**Note:** Sometimes illness causes spiritual distress (a sense of loss, fear, or questioning). Simple things like gentle conversation, spending time outdoors, or listening to traditional teachings can help. Cultural and spiritual practices can help when someone feels lost or disconnected. These practices can help restore balance and meaning in life.



## **4.2 Mental wellness**

Mental wellness is about the part of us that thinks, learns, decides, and makes meaning. When someone is very sick, they may feel confused, worried, sad, frustrated, or afraid.

How you can help as a caregiver:

- **Speak gently and simply:** Give information in small, gentle steps. Invite questions. Repeat things as many times as needed. Do your best to answer questions or find someone who can. Keep them informed to prevent confusion.
- **Keep them involved:** Include the person in decision-making whenever possible. Even small choices can help them feel in control and respected.
- **Keep a routine:** Sometimes the person may feel restless, forgetful, or not like themselves. Keeping their daily routine the same can help. For example, try eating at similar times or turning on their usual TV or radio programs. Reading aloud, playing their favourite music, or sharing stories and teachings can also calm the mind.
- **Support them through grief:** Grief is a natural part of a serious and life-changing illness. Many of us are already carrying grief and loss from the past. A life-changing diagnosis can add to this grief as their health, roles, and abilities change.
- **Listen and reassure:** People may feel calm one day and very worried or frustrated the next. Encourage them to talk about their feelings with you or someone else they trust. Reassure them that these feelings are normal. If you do not know what to say, just being there and listening is more helpful than you think.

### 4.3 Emotional wellness

Emotional wellness comes from feeling connected to family and friends, to the Land, and to the community. When someone is sick, those connections can shift. For example, a mother might now be the one receiving care, or a daughter might take on the role of the main helper. As these roles and responsibilities in the family change, relationships can be affected. Supporting emotional well-being helps families stay close. It also helps them understand each other through the changes that illness brings.

How you can help as a caregiver:

- Encourage communication with family: Encourage family members to talk openly and share their fears and hopes. Some people will want to talk, while others may want to sit in silence. Either way is okay.
- Share moments, make memories: Share a meal, tell a funny story, or take part in Ceremony. Keep doing things together. The activities might change, but it is important to keep having fun and experiencing joy together. Talk about the past (photos, stories) or create new memories. These small acts can make big differences.
- Value every role: Everyone in the family circle has a job or role to play in care. Whether they are the cook, the storyteller, the one who prays, the singer or drummer, the jokester, the organizer, the informer, or the listener. When everyone is seen, the whole family feels stronger.
- Ask for support: If there is tension or a misunderstanding in the family, talk to a trusted Elder or respected community member. You can also reach out to a social care provider for help. Talking things out can help. It can make it easier to understand the emotions behind the conflicts. These emotions include worry, exhaustion, and fear.



## 4.4 Physical wellness

Providing care that promotes physical wellness is about making sure the person is comfortable, rested, and safe. When someone is sick, they may need help with everyday activities like getting around, bathing, dressing, or eating. Providing these acts of care helps preserve a person's dignity and shows love.

How you can help as a caregiver:

- Offer small comforts: Clean clothes and sheets, a gentle touch, and keeping their mouth clean and hydrated can make a huge difference in how they feel. If they style their hair or trim their facial hair a certain way, help them with that. If they have a favourite piece of clothing (like a ball cap, sweater, or pair of slippers) that they are most comfortable in, support them with this too.
- Food and drink: As they get sicker, they may not want to eat much. Offer small amounts of favourite foods or traditional soups and teas. Sometimes the smells or the rituals around preparing food or making and warming teas can be comforting.
- Manage pain: In most cases, pain can be managed well by medication. Watch for signs of discomfort, such as a change in facial expression, tense muscles, balled fists, sighing, or heavy breathing. Also watch for signs of confusion.
  - Work with the nurse or doctor to adjust medication if needed. You can also use your circle of care to see how other treatments, medicines, or comfort measures can be used safely. This may include massage, heat, music, or Ceremony.
  - If you notice the person you are caring for has trouble moving, you may need to help them shift positions or offer pillows to prevent soreness. Ask your care team to figure out the best way to do this so you do not get hurt and the person does not feel more pain.
- Find joy: Think about what they love, what they enjoy watching, listening to, or what they liked to do when they could. Listening to the sounds of nature, or their favourite television show or sports game, can bring comfort. Tuning in to the local radio bingo can also help them relax.



**Remember:** As the person's care needs grow, you might feel like you can never leave their side. It is easy to miss chances to rest when they need near-constant support. To avoid getting overstretched and "burnt out", you must plan for breaks. Reach out to family, friends, or home-care workers early to create a visiting schedule. Do this much earlier than you think you need to.

See if there is a caregiving task they could help with. Talk to them about how you are keeping track of changes, and leave the list of who to call just in case. You are not in this alone. There are often people more willing to help than you think, and there are also people whose job it is to help! They are just waiting for the call. Plan ahead and take time to rest. Taking care of yourself helps you stay strong so you can keep caring for them.

On the Resource website: [walkingalongside.lakeheadu.ca](http://walkingalongside.lakeheadu.ca), you will find helpful resources to support someone's physical health. These include step-by-step videos, instructional "how-to" guides, and more, all organized into 4 sections:

- Helping People Move Around: Ways to help someone sit up, move around, and reposition safely.
- Personal Care: Tips for helping with bathing, hygiene, mouth care, and supporting nutrition and hydration.
- Pain: Noticing and responding to pain, including the use of medication and other ways to bring comfort.
- Managing Other Symptoms: Noticing and responding to other symptoms people with life-changing illnesses can face, like issues with breathing, digestion, infections, and wounds.



**Questions to ask a health care provider or to bring to your next appointment:**

- What daily actions can I take to ensure the comfort and well-being of the person I am caring for?
- What symptoms or changes should I watch for that would mean they need more help or a change in their care plan?
- Can you show me how to safely support with personal care or moving around at home? If not, can you put me in touch with someone who can teach me?
- How can we integrate cultural or spiritual practices into the care we provide in ways that are supported and safe in this setting (e.g., home, hospital, long-term care)?
- Who can I contact and when if I have questions about pain, symptoms, emotional changes, or mobility issues?



For more information and additional tools, resources, and examples to support you in Providing Care, along with info about spiritual, mental, emotional and physical wellness, visit the resource website at [www.walkingalongside.lakeheadu.ca](http://www.walkingalongside.lakeheadu.ca).

# 5

## HONOURING THE CAREGIVER

You can't give what you don't have.

**Purpose:** To remind caregivers to think about and attend to their own well-being, self-awareness, and self-compassion, including their grief throughout and after the caregiving journey.

**Contents:**

- Recognizing signs of stress, exhaustion, and burnout
- Checking in and self-reflection
- Supporting your own grief
- Looking for and accepting support from others

**Reflection questions to think about as you go through this section on Honouring the Caregiver:**

- What signs tell me that I am becoming tired, overwhelmed, or stretched too thin? Reflect on how you feel spiritually, emotionally, mentally, and physically.
- What practices, ceremonies, or activities help me feel grounded, restored, or connected to myself and my community?
- Who in my circle can I ask for help, and what kinds of support would make the biggest difference for me right now?
- What grief or mixed emotions am I carrying as I walk this caregiving journey, and how am I honouring them?
- What teachings, traditions, or cultural supports might help me navigate this time in a good way?



Caring for someone with a life-changing illness can be rewarding, but it can also take a toll on your body, mind, Spirit, and emotions. You might feel a mix of things: love and pride, but also anger, guilt, or a deep sense of being “empty”, all while trying to stay strong for others. It is important to remember that caring for yourself is not selfish. It is the only way you can continue supporting the person you are caring for.



## **Recognizing when you are burnt out**

Sometimes we are so busy looking after others that we do not notice our own “warning lights” flashing. Your body and Spirit will tell you when they need rest. Watch for signs like:

- Feeling tired all the time, even after sleeping
- Getting angry or upset easily
- Having trouble focusing or making simple choices
- Feeling like you just do not care as much as you used to (compassion fatigue)

If you notice these things, it is time to pause. Caregivers need to rest, eat well, take breaks, and have fun and experience joy, too. Taking time for yourself is important. Even a few minutes of quiet, a laugh with a friend, or a short walk can help. Short moments of stillness, laughter, or connection with friends can help restore balance.

## **Checking in on yourself**

Reflection is an important part of caring for yourself. Taking time to pause and ask, “How am I doing?” helps you notice what you are carrying, what you might need, or what you are struggling with. Before you reach burnout (feeling like you can not go on or do this anymore), talk with an Elder, counsellor, or friend. Have these supportive conversations early and often. Writing down your thoughts in a notebook can help you name and make sense of heavy feelings. Be kind to yourself. Caregivers need to notice their own feelings, assumptions, and limits with compassion rather than judgment.

## **Creating your own personal wellness**

Just like the person you are caring for, you are also a whole person, with wholistic needs. Consider the following:

- **Spiritual:** Take part in ceremonies, songs, or other practices that bring you meaning and hope.
- **Emotional:** Share your feelings honestly with people you trust. Laughter, storytelling, or spending time on the Land can be healing.
- **Mental:** Take quiet time for yourself. Try journaling, reading, and reflecting on teachings or prayer. It can calm the mind.
- **Physical:** Ensure you are eating well and staying active. Stretch, walk, and rest when you can. Also, make sure you are seeing your own care team when you need to. Do not skip medical or other health and wellness appointments.

## **Asking for and accepting help**

Many caregivers try to do everything themselves, but you do not have to. Caregivers often refuse help or are afraid to ask. They worry about burdening others, appearing unable to handle it, or looking uncommitted to supporting the person they are caring for. Accepting help is a sign of strength, not weakness.

Friends, family, and community often want to help, but do not know how. So, when someone asks, “If there is anything I can do”, be ready and specific! Think about some things that you think would make a difference and tell them. Some things could include:

- Bringing over a hot meal or some groceries
- Sitting and visiting with the person you are caring for so you can take a shower, nap, or go for a walk
- Helping with errands like laundry, cleaning the yard, or shovelling snow

Think about the many different people and roles in your circle of care. Health and social care providers are there to help people with life-changing illnesses and their families. As their caregiver, you have these supports, too. Community Health Representatives, social workers, respite and home support workers, and volunteers can provide practical and emotional support. You can also reach out to Elders, Knowledge Carriers, Healers, and other trusted spiritual leaders for support. Reach out to them.



## Caring for your own grief

Grief is a natural part of caregiving, and it begins long before the person you are caring for dies. Indigenous Peoples often carry grief from past losses and experiences. This is especially true for those taking on helping roles. On top of this, you can feel something called “anticipatory grief”. This is a type of sadness that can happen when the person is first diagnosed with a serious and life-changing illness. It happens when you start thinking about the hard changes and losses that will come up as they get sicker. As their health changes, you might feel sad, frustrated, or even a sense of relief and guilt at the same time. These mixed emotions are normal and do not mean you care any less.

Grief may change over time, but it never truly goes away. It just changes how you carry their love, teachings, and memories forward. To manage your grief, it is important to find ways to tend to your heart. This means allowing yourself to rest, seek connection, and find comfort in community and Ceremony:

- Use spiritual or traditional practices that bring you comfort. Spend time in Ceremony, light a candle, or say a prayer.
- Spend time with family and friends, sharing memories and storytelling.
- Find a Land-based activity like fishing, berry-picking, or gathering medicines. Or, try a creative, arts-based activity like drawing, beading, crafting, drumming, or singing. These can be ways to manage your feelings and honour the care and love you gave.
- Participate in community events, like feasts, fires, and celebrations. It can be easy to retreat, stay inside, and keep away from people. But getting out and being around others can be helpful.

Think about what brings you joy and comfort. *Are there any traditions or ceremonies you would like to take part in that would be meaningful to you?*

When your time as a caregiver ends, you might feel lost or like you have lost your purpose. This is a natural part of the change. Give yourself permission to feel whatever comes up, whether that is sadness, pride, relief, or gratitude. And be sure to take time to rest. By listening to your own needs, seeking support, and finding moments of rest and renewal, you honour both yourself and the person you care for.





**Questions to ask a health care provider or to bring to your next appointment:**

- What supports are available locally (or virtually) to help caregivers manage stress, burnout, or grief?
- Are there Elders, counsellors, social workers, Indigenous Patient Navigators, or spiritual care providers who can support my family or me?
- How can I get help with respite, home care, or community programs if I am becoming overwhelmed?
- What resources or tools can help me better understand my role, set healthy boundaries, and recognize when I need rest?
- Are there ceremonies, cultural practices, or community services you can help connect me with after the person I am caring for dies?



For more information and additional tools, resources, and examples to support you in *Honouring the Caregiver* visit the resource website at [www.walkingalongside.lakeheadu.ca](http://www.walkingalongside.lakeheadu.ca).

# 6

## SUPPORTING THE JOURNEY TO THE SPIRIT WORLD

Walking alongside someone in the last days and hours of their journey into the Spirit world.

**Purpose:** To prepare caregivers to recognize and support the final stage of the journey.

**Contents:**

- Noticing signs when someone is nearing the end of life
- Supporting someone in their final days and hours
- Offering care and support after death
- Remembering and honouring their legacy, memory, and Spirit

**Reflection questions to think about as you go through this section on Supporting the Journey to the Spirit World:**

- What changes am I noticing in their breathing, eating, sleeping, or alertness, and what might these changes be telling me?
- What helps the person I am caring for feel most at peace (spiritually, emotionally, and physically)? Are there ways we can bring that into their space?
- Are there ceremonies, teachings, songs, or cultural practices that they would want as they prepare for their journey to the Spirit world?
- Who should be informed when this person is nearing death? Who needs to be there: family, friends, Elders, spiritual leaders?
- What support might I need (emotionally or spiritually) as I walk with them through this time?
- What have I learned from this experience? What was done well? Were there people, acts, or supports that I appreciated? What do I wish could have gone differently? Am I able to help someone else in the future?

The last stage of life is a unique journey for everyone. While it can be a heavy time, there are shared patterns that help us know when the transition is coming. Recognizing these signs helps you stay calm and provide the best comfort possible.

## **Recognizing the signs when someone is nearing the end of life**

As the body prepares to let go, it naturally slows down. You may notice the person:

- Sleeps more, especially during the day, and spends less time awake. It can be hard to wake them up.
- Eats and drinks less because the body does not need as much energy. They may lose interest in food and not feel hungry at all.
- Has changes in their breathing. Their breathing may become shallow, or they might have long pauses between breaths. It might sound like a gargle at times.
- Talks much less or seems to withdraw from conversation. It might seem like they are drifting away, in and out of sleep or a dream.
- Has changes in skin temperature. Their hands and feet might feel cool to the touch, or their skin colour may change to be paler or bluer.

Remember: Hearing is often the last sense to fade. Even if the person you are caring for cannot speak or open their eyes, they can likely still hear you. Speaking softly, sharing kind words, or playing gentle music can bring them comfort. This is not a sign of suffering; it is the body's way of preparing for its natural transition.

## **Providing comfort in the final days**

At this stage, care is all about peace and presence. You do not need to “do” very much; simply being there and being present is the best medicine.

As a caregiver, you can help in these moments by:

- Keeping the room calm, warm, and quiet. Turn down overly harsh or bright lighting.
- Providing mouth care. Use a small sponge or a clean, damp cloth to moisten the mouth and lips. Ask a member of the care team whether there are mouth rinses you can offer, or if they can provide tools, tips, or more support for good mouth care.
- Helping them reposition for comfort. They may need more help repositioning as they sleep more, become weaker and are unable to shift themselves. In these moments, make sure your movements are very gentle. Work with your care team provider to review your pain medication schedule and timing before moving.
- Using gentle touch. Holding their hand, gently rubbing their back or arm, brushing their hair, or offering a gentle massage can help them feel connected and comforted.
- Making sure the bedding is kept clean and dry. Keep dark towels nearby for cleanup.
- Continue gentle touch, music, or prayer.
- Speak calmly and share words of gratitude.
- Share memories, tell stories, offer words of thanks, and listen to soft music together. Even just sitting in a good, peaceful silence together can help.

## Creating a sacred space

Caring for the Spirit is just as important as caring for the body. You can help create a sacred space for this transition, whether you are at home, in a hospital, or in a care home.

- **Ceremony:** This might include singing or playing music, drumming, lighting a candle, saying specific prayers, or sharing teachings that honour them on their journey.
- **Meaningful Items:** Place photos of family, medicines, symbols, or comfort items, like favourite blankets, near them.
- **Guidance:** Invite Elders, Knowledge Carriers, Traditional Healers, or spiritual leaders to take the lead. They can offer support and comfort to the family and loved ones. Each community's ways are unique. But what matters most is that care respects tradition and brings balance and harmony.

Make sure these practices align with their wishes and the conversations you had with them and the family along this journey.



## Caring and support after death

When the person's journey ends, your role as a caregiver shifts to tending to your own heart and the family's grief. In the first few hours and days, allow yourself time for tears, silence, and prayer. There is no rush.

Many people find comfort in traditional cleansing or honouring practices. These may include ceremonies led by Elders or spiritual leaders. Some may wish to gather to eat, share stories, reflect on memories, and laugh together. Allow space for people to grieve in their own ways. The love for this person does not end with their death.

## Keeping their legacy alive

You can keep the connection to the person who has passed alive in whatever ways feel right to you. Some examples include sharing stories, songs, and photos with others. Doing acts of kindness in the person's name. Visiting the Land, water, or other places they loved.

Remembering is part of healing; it transforms loss into legacy. These continuing bonds can help transform the loss into a legacy. The love, teachings, and what they gave you become a part of who you are and how you live moving forward.



**Questions to ask a health care provider or to bring to your next appointment:**

- What signs should I look for that tell us the person I am caring for is nearing the end of life, and when should I reach out for help?
- What can I do at home (or in the care setting) to keep them comfortable in their final days?
- How can we include cultural or spiritual practices safely (smudging, drumming, prayer, medicines) in this space?
- Who can guide us in caring for the body (and Spirit) after death, and what steps should we follow based on our traditions, values, spirituality?
- Are there grief supports, Elders, counsellors, or Indigenous navigators available for our family once our loved one has passed?



For more information and additional tools, resources, and examples to support you in *Supporting the Journey to the Spirit World*, visit the resource website at [www.walkingalongside.lakeheadu.ca](http://www.walkingalongside.lakeheadu.ca).

# CLOSING REFLECTION

As you walk alongside someone who is living with a serious or life-changing illness, remember that this is part of a sacred journey. This journey is guided by ancestors, the Land, Ceremony, and story. Caring in this space means listening, learning, and speaking up for the person you are caring for. It means making space for what they need and supporting them in their journey to the Spirit world. It also means trusting and honouring their wishes.

May this experience remind you to move gently. Caregiving can be meaningful and rewarding, but it can also be hard. Be kind to yourself as you navigate this path.

Thank you for walking alongside someone who is seriously ill and for the care you provide. We hope this resource supports both you and the person you are caring for, and helps guide you along the way. Feel free to share these resources with others so they can be supported on their journey as well.

## **Acknowledgements**

We would like to recognize the Indigenous Peoples' Health and Aging Division education team for developing these resources, as well as the members of the Indigenous Guidance Circle who contributed to the manual's creation.





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

To access the Resource Website that holds all supplementary resources and multimedia, scan the QR code or visit:

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



**Footnotes**

<sup>1</sup> Thunderbird Partnership Foundation. (2020). Indigenous wellness framework reference guide. National Native Addictions Partnership Foundation. <https://www.thunderbirdpf.org/IWF>

<sup>2</sup> Model adapted from the Indigenous Wellness Framework and Outcomes - Indigenous Wellness Framework-Thunderbird Partnership Foundation. (2015). Indigenous Wellness Framework. National Native Addictions Thunderbird Partnership Foundation (NNAPF Inc.). <https://www.thunderbirdpf.org/IWF>

<sup>3</sup> Murray, S. A., Kendall, M., Mitchell, G., Moine, S., Amblas-Novellas, J., & Boyd, K. (2017). Palliative care from diagnosis to death. *BMJ*, 356. <https://doi.org/10.1136/bmj.j878>

<sup>4</sup> Murray, S. A., Boyd, K., Moine, S., Kendall, M., Macpherson, S., Mitchell, G., & Amblas-Novellas, J. (2024). Using illness trajectories to inform person centred, advance care planning. *BMJ*, 384. <https://www.bmj.com/content/384/bmj-2021-067896>

<sup>5</sup> Hurd, K., & Barnabe, C. (2018). Mortality causes and outcomes in Indigenous populations of Canada, the United States, and Australia with rheumatic disease: A systematic review. *Seminars in arthritis and rheumatism*, 47(4), 586-592.



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