BEDSIDE CARE MANUAL

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PREPARING FOR THE JOURNEY: CARING FOR INDIGENOUS PEOPLES WHO ARE SERIOUSLY ILL

REVISED 2025

Lakehead UNIVERSITY
Centre for Education and Research on Aging & Health

The *Preparing for the Journey: Caring for Indigenous Peoples Who Are Seriously Ill* resource manual 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.

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

Prince, H. (2025). *Preparing for the Journey: Caring for Indigenous Peoples Who Are Seriously Ill*, Version 2: Centre for Education and Research on Aging & Health, Lakehead University, Thunder Bay, ON.

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

ACKNOWLEDGEMENTS

The *Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill* manual was developed at the Centre for Education and Research on Aging & Health (CERAH), Lakehead University, Thunder Bay, Ontario. It helps build and enhance Indigenous communities' capacity to care for community members who are seriously ill.

When developing the contents for the manual, the development team acknowledged the cultural diversity of Indigenous communities' experiences, knowledge, and teachings regarding caring for people who are sick. As a result, the content is not grounded in any one community's specific traditions, values, and beliefs. Rather, the manual uses the wholistic teaching concepts of the Indigenous Wellness Framework[1] that focuses on health and balance, which is then combined with the wholistic focus of palliative care.

Foundational in the development of this manual was the *Improving End-of-Life Care in First Nations Communities* research project (EOLFN), funded by the Canadian Institutes of Health Research and led by Dr. Mary Lou Kelley and Holly Prince. Through the EOLFN project, education for health care providers, family members, and community members was recognized as a key to building and sustaining a successful palliative care program. As such, the First Nations communities involved in the project developed numerous educational, administrative, and clinical tools and resources included in this manual.

Preparing for the Journey is an original document developed at CERAH, which draws heavily upon existing resources. The project team would like to acknowledge and thank the following organizations, individuals, and projects for granting us permission to extract, adapt, and use material from the following documents:

Macmillan, K., Peden, J., Hopkinson, J., & Hycha, D. (2014). A *Caregiver's Guide: A Handbook About End-of-life Care.* Ottawa, ON: 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.). Thunder Bay, ON.

Improving End-of-Life Care in First Nations Communities Research Team, Lakehead University. (2015). *Developing Palliative Care Programs in First Nations Communities: A Workbook*. Retrieved from www.eolfn.lakeheadu.ca.

Canadian Virtual Hospice. (2016-present). LivingMyCulture.ca. https://livingmyculture.ca/culture/

We would also like to recognize the following individuals who contributed to the creation of the manual:

- The development team was led by Holly Prince, Project Manager, and consisted of Jessica Wyatt, Knowledge Broker, and Kassandra Fernandes, Curriculum Developer. The team was supported by Dr. Kathy Kortes-Miller, School of Social Work, and Dr. Elaine Wiersma, Department of Health Sciences at Lakehead University.
- An Advisory Committee reviewed Version 1 (2017) of the resource manual and provided feedback on palliative care best practices: Robin Cano, Verna Fruch, Ruby Jacobs, Dr. Mary Lou Kelley, Jill Marcella, and Marg Poling.
- Indigenous Services Canada, Ontario Region provided funding for this initiative to CERAH through an education contract.

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

CONTENTS

PURPOSE OF THIS MANUAL

> **"I think a big part is talking to them, the families, and educating them ahead of time what to expect as well, because it can be scary, frightening for families especially when we see them dying you know, or in pain or struggling and, just providing that knowledge and support ahead of time instead of in the moment when they're stressed, or anxious about what's going on, and just preparing them gradually before it gets to that point is very important."[2]**

Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill provides Indigenous health and social care providers, family, and community members with practical guidance and support on caring for people with serious illnesses. The manual is based on clinical best practices within the palliative approach to care and focuses on meeting the wholistic needs of individuals and their caregivers.

When developing the contents for the manual, the development team acknowledged that there are many different values, beliefs, and practices across and within Indigenous communities regarding care for people who are very sick. To respect this diversity, the team situated the practical guidelines and support within the broader philosophy of the Indigenous Wellness Framework. The Indigenous Wellness Framework provides readers with a shared foundation for understanding health and balance while being inclusive of diverse cultural and spiritual practices. This manual provides a foundation for individuals, families, and communities to build on by taking the teachings provided and adapting the practices to suit their beliefs and circumstances.

Individuals are encouraged to photocopy and share any part of this resource manual and use the information in any way that is helpful to them. Numerous resources are also referred to throughout the manual, which may be useful to community members.

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[2] Improving End of Life Care in First Nations Communities Research Team, Lakehead University. (2015). *Developing Palliative Care Programs in First Nations Communities: A Workbook*. Retrieved from https://eolfn.lakeheadu.ca

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.”[3]**

The Indigenous Wellness Framework was developed as part of the Honouring Our Strengths: Culture as Intervention in Addictions Treatment project.[4-5] It describes how the four aspects of self, the physical, the mental, the emotional, and the spiritual being, need to be in balance in order to achieve health and wellness. This connection and balance are needed at the individual, family, and community level. All four areas are interrelated and dependent on each other.

The development of the framework was influenced by many Indigenous teachings across Canada. No directions (North, South, East, West) are attached to the Indigenous Wellness Framework as their meanings and teachings differ across the country.

The Indigenous Wellness Framework describes wellbeing as coming from a balance of four kinds of wellness. Each kind of wellness creates a key outcome[4-5]:

- Spiritual wellness creates hope, and is facilitated when we are connected to beliefs, identity, and values.
- Emotional wellness creates a sense of belonging and is facilitated through attitude, relationships, and connections to community and family.
- Mental wellness creates meaning and is facilitated through intuition, understanding, and rationale.
- Physical wellness creates purpose and is expressed through wholeness, a way of being, and a way of doing.

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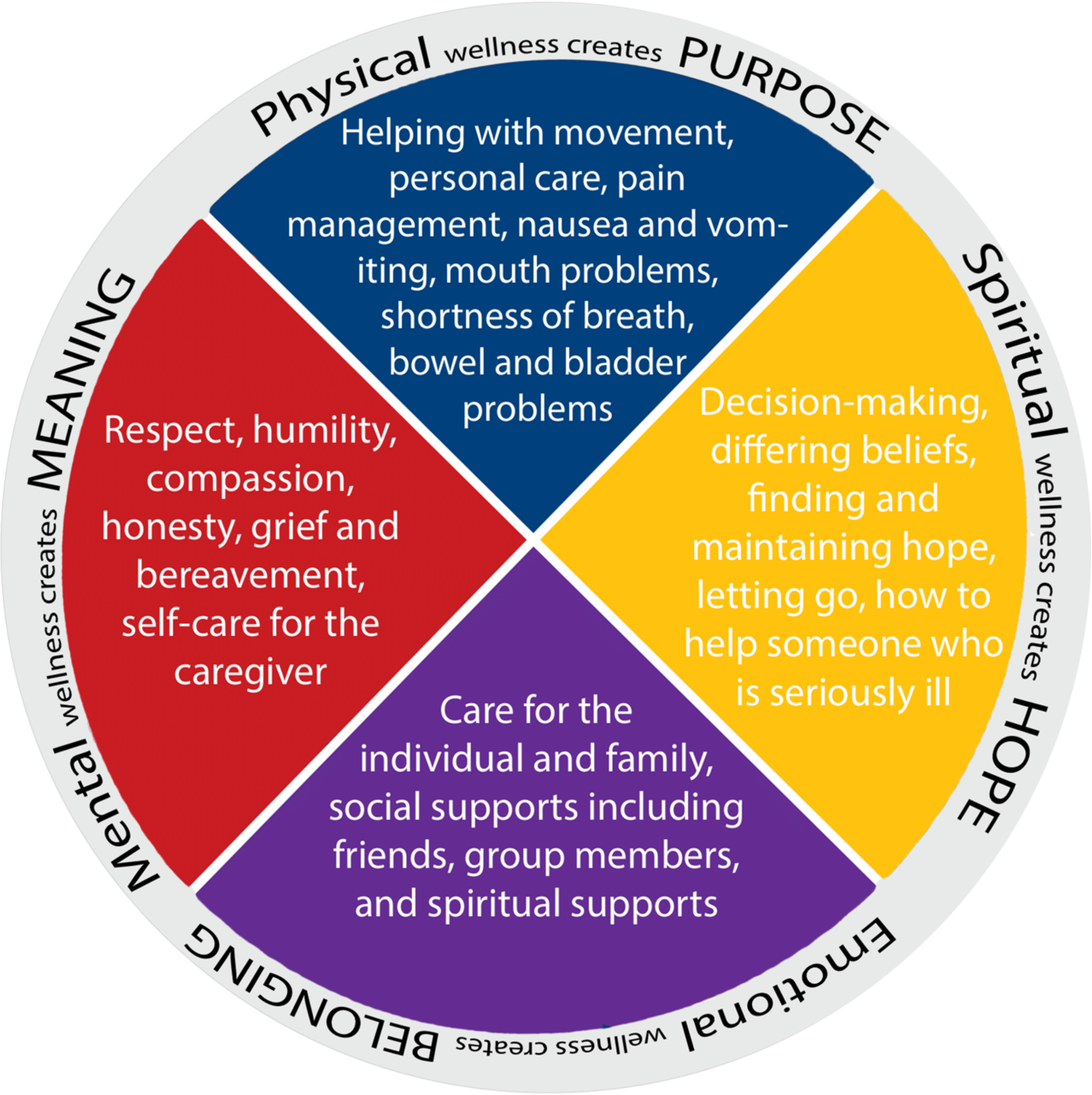
[3] Elder Jim Dumont, National Native Addictions Partnership Foundation, Honouring Our Strengths: Indigenous Culture as Intervention in Addictions Treatment Project. (2014). University of Saskatchewan. Bothwell, Ontario: Author. Canadian Institutes of Health Research, Funding Reference Number AHI-120535.

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

[5] Thunderbird Partnership Foundation. (2020). *Indigenous wellness framework reference guide.* National Native Addictions Partnership Foundation. Retrieved from: https://www.thunderbirdpf.org/IWF

Although this framework was developed within the addictions field, the key concepts of the framework reflect the same philosophy as the palliative approach to care. The palliative approach to care emphasizes the relationships between the body, mind, and spirit and the need for care to address these different areas of self in order to achieve wellness. The palliative approach to care honours the connections and relationships that people have with family members, community members, and care providers, and views the family as the unit of care. The palliative approach to care also focuses on wellness and healing through physical healing, spiritual healing, and the healing of families through grief work.

The following is an adaptation of the Indigenous Wellness Framework model[6], re-designed to reflect a palliative approach to care:



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[6] Thunderbird Partnership Foundation. (2015). *Indigenous Wellness Framework.* Thunderbird Partnership Foundation (NNAPF Inc.). Retrieved from: https://www.thunderbirdpf.org/IWF

THE PALLIATIVE APPROACH TO CARE

> **"First Nations communities are willing and able to support community members and their families to receive a palliative approach to care and to die at home if that is their choice."** [7]

What is the Palliative Approach to Care?

- Is WHOLE – person health care, meaning it is care that focuses on the body, mind, and spirit.
- The goal is to relieve suffering and improve quality of life until the end of life, for persons who have a serious illness.
- Focuses on the highest quality of living possible, until the person dies.
- Provides services not only to the person who has a serious illness, but also to their family.
- Begins at time of diagnosis and continues after the person passes with grief and bereavement support to family and loved ones.

Guiding Principles of the Palliative Approach to Care

- Views the family as the "unit of care" and not solely the individual who is dying.
- Views life and death as a normal process.
- Does not speed up nor postpone death.
- Provides relief from pain and other distressing symptoms.
- Believes in the right of people to participate in informed discussions about health care options and supports them to choose the best possible options based on that information.
- Offers support to help people live as actively as possible until death.
- Offers support to help family cope during the individual's illness and in their own bereavement.

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[7] Improving End of Life Care in First Nations Communities Research Team, Lakehead University. (2015). *Developing Palliative Care Programs in First Nations Communities*: *A Workbook.* Retrieved from https://eolfn.lakeheadu.ca

Who Benefits from the Palliative Approach to Care?

Anyone with a serious illness can benefit from a palliative approach to care. This includes:

- Any person who has been diagnosed with a life-limiting illness.
- Any person about whom you can say: "If they died within the next year, I would not be surprised."
- Any person with an incurable, progressive disease.
- Any person who elects a palliative or comfort-care approach and has symptom management issues.

Additional Resources in the Section Appendix

* *What is Palliative Care?* Pamphlet
* *Living with a Serious Illness* Pamphlet
* *Caring for Someone with a Serious Illness: Care for the Caregiver* Pamphlet
* *Caring for Someone with a Serious Illness: What to Expect* Pamphlet
* *Supporting the Caregiver and the Family* Pamphlet

Some examples of life-limiting illnesses include:

- Cancer
- End-stage heart, lung, and renal (kidney) diseases
- Motor neuron disease/Amyotrophic Lateral Sclerosis (ALS)
- AIDS
- Diabetes

Needs of People with Serious Illnesses

A person living with a serious illness may have needs related to their physical health and care, their sense of safety, security, and belonging, as well their need to feel loved, understood, and accepted. The following are some things that people may want or need:

- To be pain free.
- To be alert and aware of what is happening.
- To feel safe and secure.
- To not feel like a burden.
- To have love, affection, and contact.
- To have the opportunity to talk about concerns and fears.
- To have an explanation about their illness and symptoms.
- To be accepted as the person they always were.
- To be involved in their decision making and make choices about their care.

Section Appendix

Who Provides Palliative Care?

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

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

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

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

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

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What is Palliative Care?

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Palliative Care is a special type of healthcare that provides care, comfort and support to individuals and families who are living with a life threatening illness.

- It is for people of all ages
- Its focus is on the person and not the disease
- It is about improving the quality of life at a time when the goal is not to cure

Palliative care involves a wide range of services that can be personalized to meet the needs of the person living with a serious illness and their family. These services may vary from place to place, but generally, include:

Pain and symptom management

Family doctors or doctors who specialize in palliative care can help with pain and symptoms such as nausea, loss of appetite, vomiting, constipation, shortness of breath, fatigue, difficulty sleeping, etc. Home visits by a nurse may also be available.

Social and emotional support

Support can be made available to help deal with feelings, such as fear and grief or concerns about the illness.

Spiritual support

Arrangements for spiritual support can be made whether the person is at home, in hospital, or in along-term care facility.

Caregiver support (including family and community care providers)

Support and advice can be provided to family caregivers, as well as community-based care providers on making the person that is ill feel more comfortable.

Volunteer support

Volunteers may be available to provide support services such as companionship, provide relief for the caregiver and offer transportation.

Bereavement support

Grief support is available to help the family work through emotions and grief regarding the illness and death of a loved one.

Links to resources

Other programs may be available to the person receiving palliative care depending on what services are present in your area. For example, home care provides a variety of services to help take care of the family and home; ‘Meals on Wheels’ programs provide nutritious meals that can be delivered right to the home.

Where is Palliative Care Provided?

Palliative care may be provided in a variety of settings:

Home

Home is where most people prefer to live when they have a terminal illness. Home provides a comfortable, private, informal setting that is familiar for the person who is ill, and allows the caregivers, family members and friends to visit as often as they like.

Hospitals

Hospitals may provide a sense of security to the person requiring palliative care as they are able to provide direct access to doctors, nurses and other health care providers. Some hospitals may even have a palliative care unit.

Long-term care facilities

Long-term care facilities, such as nursing homes, may be used for short periods of time to help control pain and symptoms or to provide respite to the caregiver.

You deserve to:

- Be treated as a living human being;
- Be part of decisions concerning your care, and to have your choices and wishes respected and followed;
- Be treated with openness and honesty;
- Live free of pain;
- Receive good medical and nursing care;
- Be cared for by caring, sensitive, knowledgeable people who will try to understand and meet your needs;
- Have help for you and your family in accepting your death;
- Live and die in peace and with dignity.

Where Can I Find More Information?

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

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Living with a Serious Illness

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Facing a terminal illness (an illness with no cure) can be a frightening time and it may be difficult to make sense of what is happening to you, but you should know that you are not alone.

My feelings

When you hear about your illness,

- It can bring on feelings of fear, sadness, anger, worry
- It may result in hopelessness and depression
- You may feel numb and be in a state of shock, disbelief or panic

People face their illness and experience this phase of their life in an entirely personal and individual way. Whatever feelings you experience, know that they are normal. There is no set way that you 'should' behave or emotions that you 'should' feel.

My diagnosis

You may have many questions about your illness and may have difficulty in finding the right words. To help, you might want to:

- Keep a notebook handy and write down questions as you think of them. Take this list to your doctor's visit.
- Have a family member, friend or caregiver attend your medical appointments with you to take notes.
- Start talking with your family or people who will be providing care to you so that they are always aware of your concerns and wishes.

My symptoms

Physical pain is the pain that can be felt in your body. This kind of pain may be eased with the careful use of medication and other treatments.

Soul pain is the pain felt in the heart such as grief or sorrow. This kind of pain may be worked through by talking to a counselor, a traditional healer, Elder, your spiritual care provider, or others close to you.

Symptoms can include lack of appetite, skin problems, shortness of breath, weakness, loss of movement, fatigue, confusion, nausea and vomiting. It is important that you communicate symptoms to your caregivers (family, doctor and/or nurse).

Some symptoms may also be the result of medications taken. It is important that you let your doctor or health care provider know about any side effects that you are having.
What can I expect?

Experienced members of your palliative care team can discuss with you your questions about what may happen next. They will try to respond gently but directly to anything you want to know.

Some things you may want to know:

- Although the journey of dying is different for every person, there is a common final pathway that most people dying from a serious illness experience.
- With good palliative care, the time before death is generally peaceful.

There is often a gentle winding down that can take several days. A person may spend a lot of time sleeping. Breathing may change, and may be shallow, possibly with short periods of no breathing. Sometimes fluid in the lungs may make a bubbling noise. Often hands, feet and legs may be cool to the touch and skin colour may change, which shows that circulation of the blood is slowing down.

Closeness and touch from people you love may be comforting for you and may be just as important for them. Even though it may seems to others that you are unaware of their presence, the sound of voices will probably still be heard because hearing is one of the last senses to be lost.

Your family can continue to be with you until the very end. This is a time when those closest to you often give their greatest support by expressing their love and their feelings openly and saying their goodbyes.

My needs

In order to make your needs known to your family and health care team, you may want to make a list of your needs:

- Physical needs such as medication, aids such as railings or special seats, or assistance to do certain tasks
- Emotional needs such as understanding and help in dealing with emotions/feelings.
- Social needs such as outings and maintaining contact with family and friends
- Cultural needs such as customs, beliefs or traditions that you wish to continue
- Spiritual needs such as religious and/or traditional practices

8 Tips for Caregivers

1. You are the person’s primary supporter.
2. If you try to provide care at home, try to find a doctor who will visit you there.
3. Make a list of questions you want to ask and give a copy of this list to your doctor or nurse.
4. Take notes during appointments so that you can refer to them later.
5. Arrange for someone to attend doctor’s appointments with the person if you or your family cannot. Prepare them questions to ask the doctor and have them take notes for you.
6. Keep a journal of all care and treatments. Include in it details of the medications, appointments, names and numbers of the health care team.
7. You may notice changes and symptoms that other members of the health care team do not. Inform other members of the team.
8. After appointments, ask for a summary of what was talked about if you find it helpful.

After Caregiving Ends

As a caregiver, there can be a natural sense of loss when our caregiving is over. We face the double sorrow of losing the person and our purpose or role in their lives. It can be a very difficult time that leaves us feeling lost, lonely, and useless. The first step is to allow and accept our feelings. It is possible that we may feel relief that we don’t have to work so hard any longer, and then feel a sense of guilt for feeling such relief. We may be angry with ourselves or someone else for letting us down. All of these are natural reactions. It is important to express our sadness, anger, loneliness and whatever else we may feel.

Where Can I Find More Information?

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

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Caring for Someone with a Serious Illness: Care for the Caregiver

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Taking Care of Yourself

Understand how this illness affects you

You may struggle with anger, guilt, anxiety, or sadness. You may feel tired and may feel a sense of emptiness wondering why your loved one is suffering or dying and why you are reacting the way you are.

Practice self care

Eat well, exercise, and get enough rest. Take care of your mental health. This will help your overall health and will also help you provide better care to the person. Ask your family and friends for support. They want to help, but may not know how they can help.

Communicate your needs

It is easy to forget about your own needs when caregiving, such as personal chores, errands, etc.

It is important to talk with your family and friends about ways they can help and ask your doctor or health care provider about available resources.

Know your Caregiving Needs

Providing care to someone who is sick can be a complex and challenging process. Here are a few points to keep in mind.

Navigating the system

Know who does what and how to access services in the health care system.

Communicating with the care team

When caregiving for an ill person at home, you might feel like your home is “invaded” by a series of strangers who are also providing care. You may feel you are no longer “at home” in your own house.

- Get to know the members of the care team
- Know what each member’s job is
- Ask to have the same care providers in the home so that you are not always getting used to new faces or having to explain your situation over and over again
- Ask to be informed about who will be coming into your home (if the person is in a facility, ask about the roles of the various health care providers).

Respite is a service for when you need a break in order to re-energize and be able to continue caregiving. Use it when you need to attend to other things in your life such as child care, shopping, your own health care, etc.

Learn all the aspects of providing care

Operating equipment such as a hospital bed, turning the person from side to side, giving fluids, food or medications, or transferring the person from a bed to a chair are activities that can add to your stress if you are unsure of how to do them properly. Talk to your health care provider about these things so you feel confident in doing these tasks.

Financial questions

If you are in the work force, you may need to take time off from work in the form of a vacation or a leave of absence. The Employment Insurance Compassionate Leave plan allows for up to six weeks of partial coverage of earnings. Social work can also assist with financial concerns.

Legal questions

Talk to your doctor or a legal representative for information on wills, advance care planning, or a power of attorney and when these should be used if the person can no longer make their own decisions.

Understanding Grief

Grief is a natural reaction to illness and loss and is a process of coping. It affects us socially, physically, mentally, emotionally and spiritually. It is a journey which should proceed gently and not be rushed through. While some people grieve privately, others are more open about their grief. The process can last a short time for some, and for others, it can go on for months to years. Grieving may begin before the death actually occurs. Grief is a uniquely personal experience and can be viewed as involving:

- Accepting the reality of the loss
- Working through the pain of grief
- Adjusting to life without the person
- Emotionally letting go of the person and moving on with life

Eating and drinking decreases as the body is preparing to die. This is one of the hardest things for the family to accept. Assist, but do not force the person to take food or fluids.

Withdrawing is normal. There is less of a need to communicate. The person may have no interest in newspapers or television, begin to withdraw from people and may want to be with just a few people or only one person. It is important that this not be taken personally. The person who is sick may just want as little stimulation as possible.

Levels of awareness and sensory changes are not unusual. The person may:

- not remember things or recognize familiar faces or objects
- be easily distracted and unable to follow simple directions
- be fully awake but non-responsive at times
- speak or claim to have spoken to a person already dead, or claim to see people/places not visible to you

Accept what the person is saying. Avoid explaining or arguing. The experience is real to them. It is normal and common.

Coma - Often before death, people will go into a deep state of unconsciousness called a coma. They may still hear what is said even if they no longer respond. Never assume that your voice cannot be heard.
Hearing is the last sense to be lost.

Where Can I Find More Information?

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

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The individual's personal care needs may change. You may be able to help them with:

- Getting in and out of bed, walking around the home
- Personal care (assisting them in going to the bathroom, helping with bathing and personal grooming)
- Feeding and nutrition

Some things that may make the person more comfortable:

- Keep hair clean and combed
- Gently rub the back and skin with lotion to increase blood circulation. Keep skin folds and creases clean and dry
- Adapt clothing to make care easier for the person who is sick and for others
- Keep the mouth moist with water, ice chips, popsicles or mouth swabs. Moisten lips with petroleum jelly (Vaseline®) to avoid dryness and cracking
- Change the person's position in bed and use pillows and extra padding on the bed to avoid bed sores
- Keep the bed clean, dry and comfortable and use fitted bottom sheets

Understanding Pain

Pain is a common experience for people facing a terminal illness. It can be recognized in things like tensing muscles, sweating or facial expressions, or it can appear to be nonexistent. It may come and go or it may be constant and unlikely to go away. As you care for the person, keep the following in mind:

- Visit with them first before you provide care. Recall the day's events to establish a caring relationship.
- Be sensitive to what they are feeling.
- Offer reassurance and encouragement. Loss of independence can be upsetting for them.
- Ask how you can help with bathing or grooming.
- Involve them in decisions about their care.
- Ensure privacy by closing the door.
- Remove used bed pans from sight when not in use.
- Provide them with a bell, chimes or something else to tap on so that they can call you to help if they need to.

No matter what type illness, there are common signs present when someone is nearing death. For some, this process may take weeks; for others, only a few days or hours.

Activity decreases. They may speak and move less, may spend more time sleeping and may be harder to wake. Help by sitting with the person, holding their hand and speaking softly and naturally.

Losing control of urine and bowel movements can be a problem when death is very near. The amount of urine will decrease and the urine become darker as death nears. Absorbent pads can be placed under the person for more comfort and cleanliness, or a urinary catheter may be required.

Bodily changes may occur such as:

Body temperature may go down so they may feel cold to the touch.

Blood pressure may gradually lower and blood flow to the hands and feet will decrease.

Skin color and fingernail beds may change from normal pinkish to a duller, darker, greyish tone.

Breathing rate may change to several rapid breaths followed by short periods of no breathing.

Coughing may increase as the body's fluids begin to build up in the lungs. This can cause **congestion** and a gurgling sound that may be upsetting to others, but it is not an indication that the person is in pain or suffering.

How you can help me:

BE HONEST WITH ME. I can tell when your feelings or actions are insincere.

LAUGH WITH ME, CRY WITH ME. Allow me to express intense emotions.

DON'T FEEL SORRY FOR ME. Your understanding helps preserve my dignity and pride.

LET ME TALK ABOUT MY ILLNESS IF I WANT TO. Talking helps me work through my feelings.

LET ME BE SILENT IF I WANT TO. Sometimes I don't have much energy and I just may want your silent companionship. Your presence alone can be comforting.

SPACE YOUR VISITS AND CALLS. Consistent support is very helpful.

OFFER TO BABYSIT. The children need a break and private times with my spouse are treasured.

SUPPORT MY FAMILY. I may be caregiving, but they too are suffering. Let them express their grieve.

OFFER TO HELP ME WITH THE SIMPLE CHORES. Routine jobs are often difficult to accomplish.

CONTINUE TO BE MY FRIEND. Don't let my illness overshadow all the good times we've shared together. I know this is hard for you too.

Where Can I Find More Information?

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

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

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

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Action

Collaboration

Knowledge

Supporting the Caregiver and the Family

cerah.lakeheadu.ca

Lakehead UNIVERSITY | Centre for Education and Research on Aging & Health

Challenges brought on by illness or loss affect not only the person who is experiencing it, but also the caregiver, family members, friends, and coworkers.

A person may feel powerless and helpless, and not know what to say. It is common to feel overwhelmed or be scared to say the ‘wrong’ thing.

These conflicting feelings may lead to avoiding the person or caregivers and begin a terrible cycle of guilt or assumptions.

“I haven't called or said anything in so long, she'll be upset with me if I do it now.”

Supporting the Caregiver

Caring from a long distance

Sometimes you may not live close enough to provide care or support. Ways on how you can help from a distance are:

- Arrange for neighbours or friends to drop off dinner, mow the lawn or shovel the snow
- Create and contribute to a ‘petty cash’ fund for hidden costs associated with caregiving
- Talk with the caregiver or family members about other ways to help

Volunteering your Time

Often the best way you can help is to be specific about what you will do. We may mean well when we ask “Is there anything I can do?”, but the person caring for someone may be too stressed to consider how you might help.

Volunteer to do specific things, such as:

- Cooking dinner or taking it over
- Babysitting
- Helping with chores or running errands
- Assisting in caregiving

Follow their Lead

When entering their home, be respectful of the family and their routine. When in doubt, ask how you can best help.

Caregivers may need to talk about their experience and at other times may need to avoid it. Talking “normally” is what they may prefer at that moment.

Give them that space to explore their thoughts, feelings, or decisions they must make. Avoid being judgmental. Share advice when asked, but mostly listen.

Supporting the Family

Family members give and need support at the same time. They may experience several issues both during the person's illness and after the individual has died.

- Health changes - chronic illnesses may worsen; there is an increased risk of illness due to a lower immune system; and people may have difficulty concentrating and sleeping.
- Psychological issues - people may experience feelings of loss, isolation, depression and anxiety.
- Physical care demands - family members may need to assume duties such as providing transportation to treatments and appointments, child care, work demands.
- Costs of caring - Often there are extensive costs with providing care (e.g., renovations, transportation, medical equipment and medications, special meals, taking time off from work).

MAKING YOUR WISHES KNOWN

> **"I think the thing that's more comforting to people too is if you say to them, this is just for today. It might happen and we can have this discussion again tomorrow if you change your mind, it's just not written in stone just because we talked about it. It's a process, it's ongoing, but if you can't speak for yourself tomorrow what do you want to have happen to you tomorrow? 'Cause if you can't talk for yourself somebody needs to know what your wishes are…"** [8]

It is helpful for care providers to know what a person's wishes are including knowing where the person with a serious illness would like to receive care, what health care treatments they want or don't want, who will speak for them in the event that they cannot speak for themselves, and what the process is on how decisions will be made. Individuals must decide what is important to them and talk with their family, community, and care providers to develop a plan. This is called **Advance Care Planning**.

Advance care planning requires a person to think about and talk with their close family and friends about **health care treatments** that they **want or don't want** in the event that they get very sick and are unable to make those decisions for themselves.

Advance care planning is about how people want to live their life, about controlling what care they receive, maintaining control of their body in the event that they are unable to speak for themselves, and ensuring that the decisions/choices they want can be followed. Advance care planning:

- Is for people of all ages – any age would benefit from letting people know what their wishes are.
- Encourages people to talk about their wishes when they are healthy.
- Does not have to be a "formal meeting or conversation" – it can be everyday conversations where people talk about their values, beliefs, and what they would like to see happen if they got sick.
- Is not about "planning for your death" – rather it encourages people to talk about what is important to them in the event that they got very sick and were unable to speak for themselves (i.e., if they were in a car accident and were in a coma for a few weeks).
- Is not the same as a will – wills are a written document which outlines what will happen to people's material items after a person passes.
- Does not need to be written down – it is all about **having conversations.**

---

[8] Improving End of Life Care in First Nations Communities Research Team, Lakehead University. (2015). *Developing Palliative Care Programs in First Nations Communities: A Workbook*. Retrieved from http://eolfn.lakeheadu.ca

Benefits of Advance Care Planning

- Provides peace of mind for people and those who may be making decisions for them in the event they cannot make decisions for themselves.
- People are reassured that their wishes are known.
- People's wishes help their family and those making decisions know what to do.
- People have a say in who provides care to them and who doesn't provide care to them.

Goals of Advance Care Planning

- If people are not able to make decisions for themselves, advance care planning helps guide their spokesperson.
- It reduces unwanted health treatments, care, and/or healings.
- It can lessen the family's and community's stress, anxiety, and guilt.
- It can lessen conflict or arguments.
- It provides a person with the opportunity to choose their spokesperson/spokespeople.
- It can aid in navigating western medicine.

Having a Spokesperson

If a person is not capable of making decisions for themselves, another person(s) will be asked by health care providers to give consent for health care treatments. This person(s) will become the spokesperson/spokespeople.

Having a spokesperson is important especially when health care providers, such as doctors or nurses, need someone to make decisions regarding a person's care if they are unable to speak for themselves.

A person can have more than one spokesperson. Where there are multiple spokespeople, everyone will be included in the decision-making conversations.

Everyone has the right to choose their spokesperson. If a person does not choose someone, then the law has a list of people who will be asked to be their spokesperson. To learn more about how this is coordinated in your province/territory, visit: advancecareplanning.ca

Spokesperson/Spokespeople:

- Should only be asked to give consent for a treatment when the person is mentally incapable.
- Have the right to say no or withdraw from being someone's spokesperson.
- Have the right to know the benefits, risks, and alternatives of any course of treatment.
- Have the right to refuse treatments being suggested.

How to Start Talking About Your Wishes

- **Ask** someone you trust, who is willing and able, to be your spokesperson.
- **Discuss** your care wishes with your spokesperson and the important people in your life so that everyone is aware and supports your choices.
- **Keep** in contact with your spokesperson.
- **Continue** to talk about your health care wishes with your spokesperson and with other necessary people such as health care providers. Your values and beliefs can change over time; talk about what matters to you.
- **Understand** that health conditions are complex and it is not possible to discuss or anticipate every situation. Continued conversation with your spokesperson while you are capable will guide your spokesperson to make the best decisions.
- Your **health care wishes** include treatment options as well as your physical, emotional, social, and spiritual needs.
- **You and your loved ones have the right** to make an informed decision for your health care.

Additional Resources in the Section Appendix

* *Coming full circle: Planning for your care* Booklet

Coming full circle

Planning for your care

Ensure your wishes are heard and respected.

CANADIAN VirtualHospice

Ensure your wishes are heard and respected.

Coming Full Circle: Planning for your care helps you to reflect on your values, beliefs and wishes for care and to share this information with your loved ones and healthcare providers before a medical crisis happens. It may not be easy to think about, but doing so now can help you, your family and your healthcare providers ensure you get the care you want.

This booklet will help you think through what is important to you, what concerns you have, and who you would want to make decisions for you if a time comes when you can't make decisions for yourself.

How to use this booklet

This will help you to organize your thoughts and feelings about what is important to you. You can go through this booklet by yourself or complete it with a trusted friend or family member(s). You can also use it as a guide when talking with your doctor, nurse and other healthcare providers about your wishes for care.

Take your time reading through the booklet. You can write your answers down if you like. You do not have to answer all of the questions at one time. Please go through the questions at your own pace.

This is not a legal document and cannot be used to provide consent for treatments. It is not a will and has nothing to do with the distribution of your property or finances. It is a guide to help you start having conversations about your care.

How can this booklet help you and your family?

Preparing for future health care

When people get difficult health news, they often say that they only heard a small part of what the doctor or nurse said. The rest is just noise. There is so much information, so many decisions, and so much to think about. Even simple decisions can be very hard. If you have already completed this booklet, it can make a difficult time for you and your family a bit easier. Making these decisions now can help you have other discussions about care and treatment.

If you can’t speak for yourself

If you get sick or have an accident and cannot speak for yourself, making these decisions and talking with family ahead of time can:

- Let family and healthcare providers know what is important to you.
- Give you peace of mind that your wishes are known.
- Help your loved ones avoid conflict and stress when decisions about your care must be made.
- Give you a say in who provides care to you and who does not provide care to you.
- Give you a say in where care is provided to you.
- Help to develop trust with healthcare providers.

> *Taking back is really important, retrieving is very important, reclaiming is very important for us to take back what we lost... It allows us to be stronger for the future. It allows our young people to be stronger, to have more hope for the future and to have a better life, bolder dreams, and bigger aspirations for their own future.*

Getting started: Thinking about what is important to you

First, think about the following: What is important to me? How do I want to live my life? These answers will help you to prepare to talk with your loved ones and healthcare providers.

Some things to think about:

Who are the important people in your life?

(This could include family, friends, spiritual or religious guides.)

What makes your life meaningful?

(For example, spending time with your family, being able to work, practising your spiritual beliefs, being outside, sewing and beading, hunting and fishing.)

Do you have spiritual, cultural or religious beliefs that are important to you?

What have you learned about life that you would want to share with others?

What are you most afraid of?

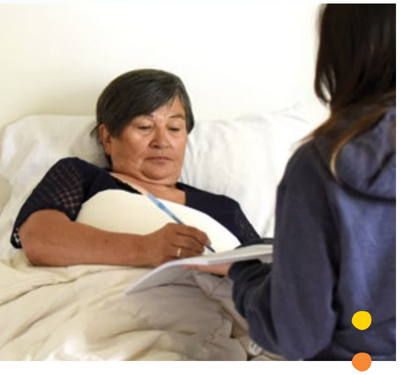
Thinking about your care

Next, think about your wishes for your care and what you value the most. How would you like your physical, emotional, social, and spiritual needs met?

Some things to think about:

If you were to get very sick, what would matter the most to you?

(For example, being able to spend time with your children or having your grandchildren near you; being in the comfort of your own home; having people around you who speak your language; being pain free; receiving excellent medical care; keeping your dignity.)



"I want to be looked after and be able to make my decisions and have everything prepared... I don't want to burden my children. I want them to just be able to come and relax with me and spend time. I don't want to go on machines or anything. When it is my time to go, I just want to go... I want to go peacefully."

If you were to get very sick, what would you be the most concerned about?

(For example, making sure that your children are taken care of, needing to leave your community to receive care, not being able to work.)

I follow a traditional lifestyle and that would be part of my expectations in my care – that it would be woven into Western interventions. That might mean bringing plant medicines, teas or even ceremonies into that context. I would want my healthcare providers' support to do that.

Answer the questions below by circling the answer closest to how you feel.

The statements at each end of the scales represent two opposite feelings. You can choose 1 or 4 as your answer. Or, if you do not completely agree with 1 or 4, you can circle either 2 or 3 depending on which answer is closer to how you feel.*

If I were to get very sick, I would…

1 **2** **3** **4**

Want to know only the basics about my illness and treatment

Want to know all of the details about my illness and treatment

1 **2** **3** **4**

Want someone I trust to make healthcare decisions for me.

Want to have a say in every decision that needs to be made

1 **2** **3** **4**

Not want to know how long I have left to live

Want to know my doctor's best estimate of how long I have to live

1 **2** **3** **4**

Want to receive medical treatments for as long as possible, no matter how uncomfortable the treatments are

Choose to stop medical treatments if they impacted my ability to enjoy my life

1 **2** **3** **4**

Not want traditional healing and medicine as part of my care

Want traditional healing and medicine as part of my care

1 **2** **3** **4**

Want to spend my last days in the hospital

Want to spend my last days at home or in the community

1 **2** **3** **4**

Want my loved ones to follow my wishes exactly, even if they do not agree with them

Want my loved ones to do what brings them peace, even if it goes against my wishes

1 **2** **3** **4**

Want to live as long as possible even if it means leaving my community

Want to stay in my community even if it may shorten my life

1 **2** **3** **4**

Want to be left alone

Want my loved ones to be around me

1 **2** **3** **4**

Want to be kept alive with machines

Not want to be kept alive with machines if I won't recover

1 **2** **3** **4**

Not want my loved ones to know anything about my health

Want my loved ones to know everything about my health

---

*These scales were adapted from The Conversation Project, developed by the Institute for Healthcare Improvement, www.theconversationproject.org

Sharing your wishes

Share your answers from this booklet with the people in your life (mom, dad, child/children, partner/spouse, sister/brother, friend, healthcare provider, Elder or spiritual guide, or others) to ensure that everyone is aware of your wishes. If there are things that you and your loved ones disagree on, it is helpful to know this and talk about it before a crisis happens.

Here are some ways to start the conversation:

“I’ve just filled out this booklet called ‘Coming Full Circle.’ It’s about planning for future health care, and I want to share it with you.”

“My health is good right now, but I want to talk to you about what I’d want if I got sick.”

“I was talking with the Home Care Coordinator and they encouraged me to think about my future and make a plan in case I got sick. Can you help me?”

“One of my biggest fears is that if I got sick, my children/family would argue with each other about what is best for me. I want to share with you what I want so that everyone understands.”

“I was thinking about what happened to ______ when they got sick, and it made me realize that I would never want those things to happen to me.”

Making sure your wishes are honoured

Now that you have shared your wishes with the people in your life, you may want to choose one or two people you feel would honour your wishes and be able to make future health and life decisions on your behalf. This person(s) would speak for you and may be asked to give consent for treatments if you are not able to speak for yourself.

In some provinces/territories, the person(s) who speaks for you might be called a substitute decision-maker, healthcare proxy or health representative or agent.

When choosing who will speak for you, think about the following:

- Do you trust this person(s) to make decisions for you?
- Do you think this person would be willing to speak for you if you can not speak for yourself?
- Does this person meet the legal requirements to speak for you (varies across provinces/territories)?
- Can this person(s) talk clearly with your healthcare team?
- Can this person(s) make difficult decisions in stressful times?
- If you have more than one person speaking for you, have you included each person in the decision-making conversations?

“I have my travelling blanket for when I leave... I have friends who are going to give me my cedar bath and they are going to prepare me. That has already been arranged and looked after.”

Here are some additional questions that you may want to talk to them about:

What kind of medical treatments do you want or not want (for example, CPR or other resuscitation if your heart stops, breathing machine, feeding tubes) if you are unlikely to survive or to live independently after treatment? Why would you want or not want these treatments?

If you have to leave your community for care, who would you like to accompany you? What items would you like to take to remind you of home and family? What spiritual or religious items would you wish to have?

Who do you want or not want providing your care?

Do any of your loved ones disagree with your wishes?

Are there things that you still need to talk to your loved ones about?

(For example, getting your finances together, deciding who is going to take care of your children/grandchildren, preparing for ceremonies.)

I have discussed my wishes for future health and treatment with the person(s) named below. The person(s) who will speak for me if I am not able to speak for myself is:

Name:

Relationship to me:

Phone number or email:

Name:

Relationship to me:

Phone number or email:

I have also discussed my wishes with the following people:

Name:

Relationship to me:

Phone number or email:

Name:

Relationship to me:

Phone number or email:

Note: Some provinces and territories require you to complete certain legal forms to identify your "spokesperson." Find out more about resources in your province or territory by visiting **www.advancecareplanning.ca** *and clicking on "Your Province/Territory."*

Remember: Once you have selected the person who will speak for you, let them know if your wishes, values, and beliefs change over time. Continue to talk with other loved ones and your healthcare providers to ensure everyone understands your wishes. They will then be better able to support the person speaking for you when decisions about your care need to be made.

You can always change your mind about your wishes for care as things change. You can also decide to choose a different spokesperson(s) at any time. It is important to talk about any changes with your loved ones.

> *One of the teachings of one of my Elders was 'When I go, if you need me, I'm in the wind.' When I thought about that, what I find really interesting is that everything that has ever lived on this Earth has left a breath in the wind. No wonder we can see spirits and hear them.*

ADDITIONAL RESOURCES

For more information on advanced illness, advance care planning, palliative care, end-of-life care and grief, please visit:

Canadian Virtual Hospice www.virtualhospice.ca

Living My Culture www.livingmyculture.ca

Improving End-of-Life Care in First Nations Communities Project
www.eolfn.lakeheadu.ca

Speak Up! www.advancecareplanning.ca

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www.advancecareplanning.ca.

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, www.eolfn.lakeheadu.ca.

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CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

CANADIAN INDIGENOUS NURSES ASSOCIATION

Ontario Health Cancer Care Ontario
Santé Ontario Action Cancer Ontario

CancerCare Manitoba
ActionCancerManitoba

Morning Star Lodge

First Nations Health Authority
Health through wellness

MÉTIS NATION BRITISH COLUMBIA

UNION OF NOVA SCOTIA MI'KMAQ

NORTHWEST TERRITORIES
Health and Social Services Authority

Manitoba Region
First Nations
Home & Community
Care Program

Eastern Health

SASKATCHEWAN CANCER AGENCY

This document was prepared by the Canadian Virtual Hospice. It 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 or legal advice and should not be relied upon as such. If you have questions about your health or medical issues, speak with a healthcare provider. If you have questions about your legal rights or someone else's, speak with a lawyer or contact a community legal clinic.

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Aussi disponible en français :
www.PortailPalliatif.ca/BouclerLaBoucle

CANADIAN VirtualHospice

January 2022

DEVELOPING A CARE PLAN

> **“I think what I’d like to see...is for everybody to be on board with a shared ... vision like a goal and then once that I [get] a plan in place, and once that, you know someone is coming home, just make a call and everybody ... has a role and knows their role ...”** [9]

When a person is diagnosed with a serious illness, there are many choices and decisions that they, along with their family, will need to make. This includes where the person would like to receive their care, what treatments or services they would like to receive, and who they would like to provide this care. These decisions help to inform a person’s care plan which is meant to guide all the people who are involved with the person. This group of people is called the ***Community Care Team***.

The Community Care Team

The Community Care Team are all the health care providers, family members, and community members who work together to support a community member who is seriously ill. Caring for someone who is seriously ill requires a team because a person’s care needs may be complex and cannot be carried out by one person.

This team works together to help the person and their family prepare for their journey. Some members of the team may have had specialized medical training in caring for people who are seriously ill, others may be able to provide spiritual and cultural teachings, while some people bring the gift of presence by being able to sit and listen to the person and their family.

The person who is seriously ill and their family members are the most important members of the team.

Other members of the Community Care Team may include:

- Friends and community members
- Doctors
- Nurses
- Home care staff (e.g. care managers, home support workers, and personal care providers)
- Mental health workers and counselors
- Elders and Knowledge Carriers/Keepers
- Occupational therapists and physical therapists
- Health Directors
- Community Health Representatives and Educators
- Emergency service providers
- Indigenous Patient Navigators and Advocates
- Anyone else who is identified by the person who is sick

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[9] Improving End of Life Care in First Nations Communities Research Team, Lakehead University. (2015). *Developing Palliative Care Programs in First Nations Communities: A Workbook*. Retrieved from https://eolfn.lakeheadu.ca

Importance of the Community Care Team

The Community Care Team can help to ensure that a person's needs are being met by:

- Working out differences between and among the family and providers.
- Providing ongoing assessments of the person and preparing everyone for changes. For example, what to expect as the illness progresses and how to provide specialized care if it is needed. Please refer to the appendix section for the Palliative Performance Scale (PPS) which is one assessment tool that the Community Care Team may use.
- Planning for crisis. For example, what if the person has pain in the middle of the night - who do we call?
- Keeping communication channels open. Sometimes written communication notes or an In-Home Chart may be able to be used to pass messages between and among the team but meeting face-to-face is also important.
- Providing support for one another at this difficult time.

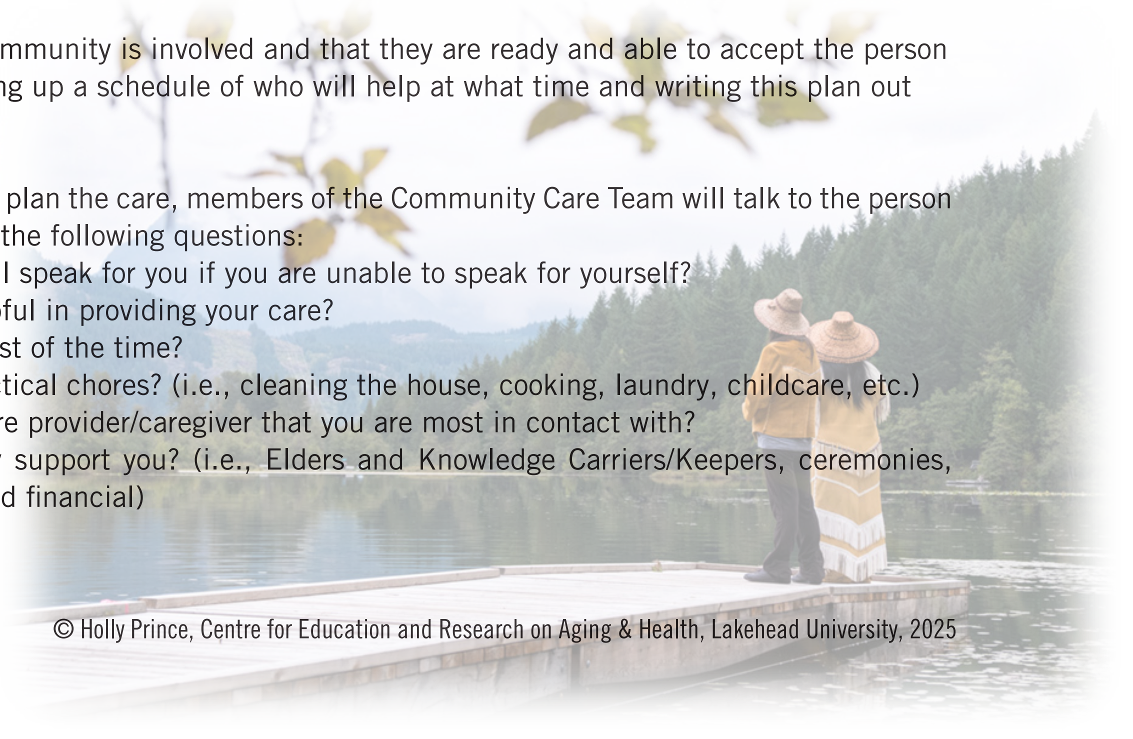
Additional Resources in the Section Appendix

- *Program Checklist for Home Passing*
- *Palliative Performance Scale (PPS)*
- *Seven Guiding Principles for the Community that Provides Care*

Organizing and Developing the Care Plan

If a person is currently in the hospital and wants to go home, developing a care plan with the Community Care Team is helpful. Prior to leaving the hospital, a meeting (care conference) between and among, the person, the family, community and members of the Community Care Team may be organized. The goals of this meeting are to develop a plan for how care will look back in the community and also to make sure that everyone, including the client and family, understands the plan. This meeting can also include instructions for what to do if something changes or goes wrong, including who to call.

- This meeting can be done in person or virtually.
- When this group meets, it may be important to include a translator if the person or family members are not comfortable expressing themselves in English. If possible, the translator should not be a family member.
- It is important that the community is involved and that they are ready and able to accept the person home. This includes setting up a schedule of who will help at what time and writing this plan out for all members.



In order the help organize and plan the care, members of the Community Care Team will talk to the person and their family and may ask the following questions:

- Who is the person who will speak for you if you are unable to speak for yourself?
- Who will be the most helpful in providing your care?
- Who can stay at home most of the time?
- Who can take care of practical chores? (i.e., cleaning the house, cooking, laundry, childcare, etc.)
- Who will be the health care provider/caregiver that you are most in contact with?
- How will your community support you? (i.e., Elders and Knowledge Carriers/Keepers, ceremonies, services, pastoral care, and financial)

Section Appendix

PROGRAM CHECKLIST FOR HOME PASSING

_____Client is assessed using PPS PPS score ____________ Date ______________

_____Family caregivers are identified and committed

_____DNAR order written on in-home chart, signed and dated

_____DNR confirmation form signed and on in-home chart

_____Spiritual support person has been identified family has contact information

_____Family educated on what to expect at time of passing

_____Family knows who to call for crisis management

_____Family knows who to call when passing occurs

_____Plan for pronouncement is in place

_____Funeral home is identified and notified; Name and contact number____________

_____Certification has been arranged between Nurse Practitioner[i] or Physician and Funeral Home

_____Physician has sent letter to Police, notifying of expected passing

_____Local Police detachment notified of expected passing and/or presence of narcotics in home

_____Local EMS is aware of expected passing and presence of DNR confirmation form in chart

_____Care Plan for home passing has been communicated to providers

Checklist completed by: _________________________

Date completed: ________________________________

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[i] Depending on provincial legislation.

Palliative Performance Scale (PPSv2)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100 %	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90 %	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80 %	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70 %	Reduced	Unable Normal Job/work Significant disease	Full	Normal or reduced	Full
60 %	Reduced	Unable hobby/house work Significant disease	Occasional Assistance necessary	Normal or reduced	Full or Confusion
50 %	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40 %	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30 %	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20 %	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10 %	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0 %	Death	-	-	-	-

Instructions for Use of PPS

1. PPS scores are determined by reading horizontally at each level to find a ‘best fit’ for the person. Leftward columns are “stronger” determinants, thereby taking precedence over others.
2. Begin at the left column and read downwards until the appropriate ambulation level is found.
3. Read across to the next column and downwards again until the activity/evidence of disease is located.
4. Read across the self-care column, intake and conscious level columns before assigning the PPS score to the patient.

Ambulation:

- “Reduced” ambulation occurs at PPS 70% and 60%. The difference between 70% and 60% is subtly related to the activity columns – that is whether the person is unable to do work (70%) or unable to do hobbies or house work (60%). Also note that the person at 60% requires occasional assistance with self-care.
- There are subtle differences between “mainly sit/lie” and “mainly in bed”. The difference is subtly related to items in the self-care and intake columns. Use these adjacent columns to help decide. As well, the difference between mainly sit/lie and mainly in bed is proportionate to the amount of time the person is able to sit up versus the need to lie down.

Activity & Evidence of Disease:

- “Some”, “significant” and “extensive” disease refer to physical and investigative evidence showing degree of disease progression.

  Example: Breast cancer

  - local recurrence = “some” disease
  - 1 or 2 metastases = “significant” disease

  - multiple metastases = “extensive” disease

- The extent of disease is also judged in the context of the person’s ability to maintain work, hobbies and activities. For example, “reduced” activity may mean playing 9 holes of golf instead of the usual 18, or continuing with morning walks but at a reduced distance.

Self Care:

- “Occasional Assistance”; most of the time the person can transfer, walk, wash, toilet, eat own meals but sometimes needs help (e.g., once a day or a few times a week).
- “Considerable Assistance”; regularly every day the person needs help (e.g., to get to the bathroom but can brush own teeth; needs food cut but can feed self).
- “Mainly Assistance”; this is an extension of the “considerable assistance” category (e.g., person needs help getting to the bathroom and washing)
- “Total Care”; the person is unable to eat, toilet or do any self care without help.

Intake:

- “Normal”; refers to person’s usual eating habits while healthy
- “Reduced”; a reduction of the person’s normal eating habits
- “Minimal”; very small amounts, usually pureed or liquid, which are well below nutritional sustenance

Conscious Level:

- “Full consciousness”; full alertness, orientation, good cognitive abilities
- “Confusion”; presence of delirium or dementia and a reduced level of consciousness, which may be mild, moderate or severe
- “Drowsiness”; may be due to fatigue, drug side-effects, delirium, closeness to death
- “Coma”; absence of response to verbal or physical stimuli; depth of coma may fluctuate.

Making “Best Fit” Decisions:

- PPS scores are in 10% increments only (e.g., cannot score 45%)
- Sometimes, one or two columns seem easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a ‘best fit’ decision. In these cases use your clinical judgement and the leftward dominance rule to is used to determine the more accurate score for that person.
- PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a person’s current functional level. Second it may have value in criteria for workload assessment or other measurements and comparisons.

  Example 1: A person who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PS 50%.

  Example 2: A person who has become paralysed and quadriplegic requiring total care would be PPS 30%. Although the person may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The person may have normal intake and full conscious level.

  Example 3: However, if the person in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not ‘total care’.

Seven Guiding Principles for the Community that Provides Care

Principle #1: Sharing responsibility is the key to not "burning out"

- no one person has to be in charge all the time
- no one person has to deal with every crisis
- no one person has to be "on call" every single day
- no one person has to try to run his own life plus the entire, complex life of their loved one
- let the others do their share; they want to and need to participate

Principle #2: It won't work unless everyone gains something personally

- recognize the importance of team members feeling good about caring for someone
- the person being cared for will feel too guilty unless you gain something too

Principle #3: Know your limits and stick to them

- whatever you can do to help is enough
- if you can't or don't want to do something, don't. (Someone else is probably good at it, or loves to do it)

Principle #4: There is no one right way to do it

- if there are ten members, there will be ten ways to do it
- it's okay to disagree
- agree on basics, and then follow the rules; you may learn some amazing things

Principle #5: Anyone who wants to help should be encouraged

- a group needs eight, but ten is better
- if main caregivers are "real" family, they must be willing to broaden the circle
- "free-floaters" (people who can help only occasionally) are very important

Principle #6: Trust the group; support each other

- the group has power
- someone has the talent or the answer
- go on vacation; the others are there
- share your feelings; share the goal
- spend time together; acknowledge each other

Principle #7: Keep your own life in good working order

- take care of yourself, or you won't be able to take care of the patient
- exercise, rest, stay in "life"
- lighten the rest of your load
- don't forget about your own family and friends
- let your friends, your boss, and your own family know what you are doing

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SPIRITUAL WELLNESS

> **"The Indigenous Wellness Framework identifies that spiritual wellness is facilitated through a connection to beliefs, values, and identity. As the central vision for life, spiritual wellness creates hope." [10]**

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

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

Positive Effects of Spirituality

Generally, spirituality has a positive effect on well-being and improves quality of life by[11]:

- Reducing anxiety, depression, and discomfort.
- Reducing sense of isolation.
- Helping with adjusting to being very sick.
- Increasing the ability to enjoy life even during illness.
- Potentially improving a sense of wellness and connection.

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

[11] Foley, K. Back, A., Bruera, E., Coyle, N., Loscalzo, M., Shuster, J., Teschendorf, B., Von Roenn, J. (2005). *When the focus is on care: Palliative care and cancer.* American Cancer Society. (p. 228-229).of Health Research, Funding Reference Number AHI- 120535.

A person who is seriously ill may search for meaning as their lives draw to a close. They may want to talk about their spiritual needs, including such things:

- The reason for their illness.
- Exploring the purpose of their life.
- Having a sense of control.
- Forgiving self and others.
- Looking back on life events and accomplishments.
- Things that bring comfort.
- Saying good-bye to important people.
- Making peace.
- Readying oneself for the afterlife.
- Taking part in the rituals of the person's spiritual community (e.g., Traditional ceremonies).

Impact of Serious Illness on a Person's Spirituality

When a person is diagnosed with a serious illness, they may begin to ask questions which impact a person's spiritual wellness including:

- What is the meaning of my journey?
- Has my life made a difference?
- What is next for me?
- Will I see my family again?
- Why did this happen to me?

It is not unusual for people to wonder about what kind of legacy will they be leaving when they are coming to terms with the end of their lives and seeking hope and peace. There are seven parts of life that people usually focus on at the end of life. They include[12]:

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

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[12] Foley, K. Back, A., Bruera, E., Coyle, N., Loscalzo, M., Shuster, J., Teschendorf, B., Von Roenn, J. (2005). When the focus is on care: Palliative care and cancer. American Cancer Society. Chapter 10 p. 222.

Decision Making

A person's spiritual or religious beliefs may affect the decisions they make about their care including what treatments they agree to and when they wish to stop treatments. If the person or their substitute decision maker, family, and health care workers can talk about these beliefs, it may cut down on misunderstandings and conflict at the end of life and provide comfort to the person and family.

Differing Beliefs

It is important to respect whatever the person and family believe and find comforting. Sometimes the person does not have the same spiritual or religious beliefs as the family or community. The person's beliefs and wishes, however, still need to be carried out. It is important to acknowledge these differences and find a way to respect them.

Finding and Maintaining Hope

A person who is very ill may still have hope. They may no longer be thinking about hope in terms of a cure, but rather looking for specific things, people, or events that will give them pleasure and quality of life. Hope changes as a person is very ill. It moves from hoping that the illness will go away, to hoping that they may receive a visit from a special person, that the next sunset will be a beautiful sight, that fresh fish will be available for one last dinner. The hopes that people have as they face the end of their lives tend to be smaller things; things that we can trust will happen and bring us pleasure.

Letting Go

At the end of life, some people may need help reconciling and saying goodbye. Each person is unique with their own spiritual needs. They may need silence, talking, praying, or ceremonies. Some people, along with their families, may need support in letting go and saying goodbye before their spirit can break free.

How You Can Help

Paying attention to the spiritual part of the person you are caring for can be a source of help and comfort. It can support them in focusing on the quality of the time that they have to live. You do not need to have all the answers to the questions the person may have. The gift you can offer them is to:

- Provide space for the person to ask their questions.
- Listen to the feelings behind the words. You might respond with:
    - What is the most important thing to you at this time?
    - What do you hope for?
    - What frightens you most?
- Talk about ceremonies that are important and ask the appropriate person/people to perform them.
- Join them in prayer or meditation if you are comfortable.

EMOTIONAL WELLNESS

> **“The Indigenous Wellness Framework identifies that emotional wellness is facilitated through relationships, having an attitude of living life to the fullest, and having connections to family and community. Emotional wellness therefore creates belonging.”** [13]

When a member of the community finds out that one of their members is seriously ill, they will have a wide variety of individual and community responses, including: shock, denial, fear, anger, and sadness. It takes time for the community to adjust to the new reality of living with a member who is seriously ill. People may find it helpful to talk with others about their feelings and join together to support each other. As the person continues their journey, both the community and the person who is seriously ill may experience reactions to a variety of different losses along the way.

- They may begin to accept the reality of death and what it might mean for their community.
- There may be frustrations around wanting to do more to help or fix an unfixable situation.
- They may feel sadness and anxiety.
- Some community members may become very angry, or some may hide their feelings.
- Others may feel guilty because they feel some relief when the person dies.

These are all normal reactions for people who are part of a community caring for a person who is seriously ill.

Working with Families

The palliative approach to care views the unit of care as both the individual and their family members. The relationship and connection between the two cannot be separated, so care providers need to ensure that everyone’s voice is heard. Working with families can be both challenging and rewarding. It is important to understand that every family is different. Some families may be made up of biological relatives, others may include relationships through or the person’s family of choice (friends and pets). Members of families also have different personalities, experiences, coping abilities, and relationships to the person who is seriously ill.

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

There are several different things which can influence a family’s ability to care for and cope with the upcoming loss.

- The age of the person who is seriously ill – often when the individual who is seriously ill is very young the family is distressed because they feel that this person is sick before their “time.”
- Quality of the relationship – when the family relationship is not positive or is strained, this may influence the response as the family is unable to support each other as effectively through these difficult times.
- Past experiences with loss or death – these can often offer insight into how a family will cope with the impending death. For example, if a family unit rallied around grandpa when he died and worked hard to support one another, it may be expected that this is how the family will work together again.
- The dying person’s role in the family and community – this is important to explore as the family and community will most likely need to figure out who will take on that role when the individual has died.
- Length of the illness – families in general do not cope well when the length of illness is either overly short or overly long.
- Presence of social supports – it is well documented in the literature that the presence of social supports such as friends, group members, spiritual supports, etc. really assist a family unit in coping with the death of one of their members.

Below are questions that members of a Community Care Team can ask themselves to help them reflect on the role that relationships play in a particular situation.

- How does the person/family view the illness?
- Does the person/family member believe the timing of illness should be controlled and that the timing and nature of death can be influenced?
- Is individual decision-making valued? Or collective family decision-making?
- What personal/cultural beliefs does the patient/family hold about serious illness and death?

MENTAL WELLNESS

> **"The Indigenous Wellness Framework identifies that mental wellness is facilitated through an appreciation for both intuitive and rational thought and the understanding that is generated when they are in balance. Having a reason for being creates meaning to life."[14]**

When a community member is seriously ill, one of the biggest challenges to mental wellness is how people respond to loss. People experience many different types of losses throughout their life including the death of a family member, loved one or a pet, the loss of a limb due to amputation, the loss of a job or the loss of a relationship through divorce. Within Indigenous communities, there are also many historical and traumatic losses that affect the whole community including the loss of language, identity, and culture due to colonization and the residential school system.

Grief is a natural reaction to loss. For many people it is an experience, which is common to most cultures and people. It is important to understand how past losses affect the individual who is sick, along with their family and community. It is also essential to recognize that a person living with a serious illness may also be grieving present and future losses including the loss of control, loss of dreams for the future, and loss of security and independence.

There is no set time frame for grieving, and it varies from person to person. Some people may grieve privately, while others are more public about their grief. Grieving can impact the whole person. People have described their grief experiences affecting them in many ways:

Physical/Body
- Hollowness in stomach
- Tightness in chest
- Heart palpitations
- Cannot sleep
- Diarrhea, no appetite for food
- Tiredness

Emotional/Heart
- Anxiety (free floating fear not about anything specific)
- Depressed mood
- Numbness
- Sadness
- Fear
- Anger

Mental/Mind
- Disbelief – experience does not seem real
- Confusion – foggy mind or forgetfulness
- Cannot concentrate or pay attention to anything for more than a few minutes

Spiritual/Spirit
- Anger or questioning God or other religious or spiritual beliefs
- Taking another look at personal faith
- Searching for meaning of the loss

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[14] National Native 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.

Guidelines to Support People Who Are Grieving[15]

There are a number of things to remember when you are supporting someone who is dealing with past, present, and future losses:

- Remember grief and bereavement are normal life events. For some they are also transformative and life changing.
- It is not your job to fix a person's grief. Supporting a person who is grieving is a collaborative process where you companion or walk alongside the person who is grieving.
- The true expert of grief is the person who is grieving. We need to learn from that person and bear witness and normalize the grief journey.
- It is important to maintain a foundation of hope that the individual will find meaning in their grief and move towards healing.
- The person companioning the griever needs to utilize empathy, warmth, caring, and respect for the individual and their unique experience.
- Focus on the individual's strengths and level of wellness to understand their experience.
- Do not try to diagnose or look for complications within their coping.
- How a person understands their grief is impacted by how other people, groups, and their communities honour their experience.
- Learning about past life experiences (particularly family of origin influences), and the nature of the relationship between the bereaved person and the person who died helps with understanding the meaning of the death, and the grief and mourning process for this unique person.
- You will be a more effective helper if you remember to enter into a person's feelings without having a need to change those feelings.
- A major helping goal is to provide a "safe place" for the bereaved person to do the "work of mourning," resulting in healing and growth.
- A bereaved person does not have an illness you need to cure. You are a caregiver, not a cure-giver!
- People are viewed from a multicultural perspective. What is considered "normal" in one culture, may be perceived as "abnormal" in another culture.
- Spiritual and religious concerns and needs are seen as central to the grief processes. We need to support people in their spiritual and religious lives as they search for meaning and purpose in their continued living.
- As a companion, you have a responsibility to help the bereaved person not return to an "old normal," but to discover how the death changes them in many different ways.
- Most people are where they are in their grief journeys for one of two major reasons:
    1. That is where they need to be at this point in their journey; or,
    2. They need, yet lack, an understanding, safe place for mourning and a person who can help facilitate their work of mourning in more growth-producing, hope-filled ways.
- Many people are best served by seeking support from lay companions who have experienced their own grief journey.
- Self-care is essential for the support person if they are to be an effective, ongoing companion in grief.

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[15] Wolfelt, A. (2015). *Introduction to Companioning the Bereaved*. (pp. 21-22). Retrieved from https://www.centerfor loss.com/wp-content/uploads/2015/10/Introduction-to-Companioning-the-Bereaved-by-Dr-Alan- Wolfelt.pdf

PHYSICAL WELLNESS

> **“The Indigenous Wellness Framework identifies that physical wellness is expressed through a unique native way of being and doing and taking care of one’s physical body as the “home” of one’s spirit. It is how we behave and what we do that actualizes the intention and desire of the spirit world. As a result, physical wellness creates purpose.”[16]**

When caring for someone who is seriously ill, family and community members may be involved in providing personal and physical care. This may include things like moving and lifting, preparing food and helping the person with eating, and assisting with personal care such as bathing and toileting. In addition to providing care, there are also a number of physical issues, such as pain management, nausea and vomiting, shortness of breath, confusion that may also need to be addressed.

Physical Care – Practical Considerations

Infection Control

Infection control is important because anyone can carry germs. These topics apply to everyone who comes into contact with the person who is seriously ill. You might need equipment, like gloves and masks; some of this can be provided by your home health care team. Your Community Care Team will support you by giving advice and teaching you how to do the physical care safely and how to use the equipment.

Handwashing - Washing your hands is the most effective way to prevent the spread of infections. Wash them with warm soapy water before and after every contact with the person. Keep nails trimmed so your hands are easy to keep clean. Prevent dryness and chapping with hand lotion. You can also use alcohol-based waterless antiseptic if hands are not visibly soiled. It is important to wash your hands after food preparation and after contact with pets.

Garbage Disposal - Be sure to be aware of garbage disposal in your community. All garbage, especially products with blood or body fluids need to be disposed of in a safe manner.

Medical Equipment - Dispose used gloves, aprons, and masks appropriately. Needles and syringes need to be placed in a hard plastic or metal container with a lid. Place the lid on the container when it is full and tape it shut so the needles will not fall out and stick anyone. Clearly label the container with an alert as to what it contains. Ask your home care nurse how it is done in your community.

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

Helping People Move Around

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

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

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

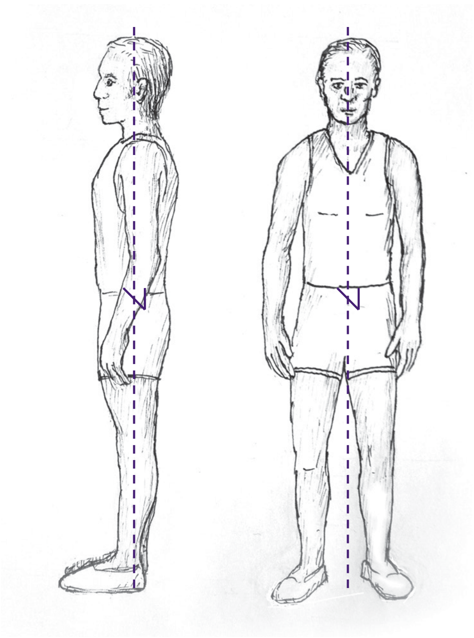


Figure 1

Things to remember:

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

Lifting

When lifting a person, there are a few basic things that you need to focus on to make sure that you prevent injury to yourself and to the person that you are lifting.

- The person may wish to take pain medication about 30 minutes before you are going to move them if movement causes them pain.
- Make sure that the area is clear and that any obstacles are moved out of the way.
- Talk through the lift step by step so everyone involved understands the direction and purpose of the movement.
- Count to three before the movement starts so everyone moves at the same time.
- Take a deep breath before you start and breathe regularly while lifting.
- Turn with your feet or step to avoid twisting your body.
- Always do the least amount of work to achieve your move. Have the person in bed help you as much as possible. Ask your community care team if they have equipment that you can use that will help, including a transfer belt or other transfer aids.

Moving Someone out of a Bed and into a Chair

Getting out of bed when able can help lift the spirit as well as prevent bedsores. A member of the Community Care Team, such as the Home Care Nurse, may be able to give you advice about how to help with moving someone. Ask about the availability and use of a transfer belt or other aids.

- The person may wish to take pain medication about 30 minutes before you are going to move them if movement causes them pain.
- Take your time when moving someone so that you don't injure yourself or the person. If you are unsure if movement can be done safely, wait until someone else can help you.
- Have all your equipment ready and near you for the move.
- If the person has a hospital bed, raise the head of the bed as high as it will go.
- Put a safe and solid chair with arm rests next to the bed facing you. The chair should be high enough to make it easy for the person to get into and out again.
- Help the person put on their slippers or shoes (or do it when they are still lying down if they cannot help).
- Sit the person up in bed and move their legs over the side of the bed. Give them a moment to rest, as they may be a bit dizzy at first from sitting up after lying down for so long.
- Next, help the person slide forward to the edge of the bed. If you have a bed that can be lowered, the feet should touch the floor or if not, a safe, nonslip footstool.

- Keeping your back straight, bend your knees and lean towards the person.
- Put the person's arms around your back, not around your neck. If someone is too weak to grasp, place their arms over your shoulder with their head resting on your shoulder.
- Rock gently for momentum and count to three. In one continuous movement, stand, pivot, and shuffle together backward until the chair touches the back of their knees, and lower the person into the chair (See Figure 2).
- Reverse this procedure when returning to bed.

Figure 2

Walking

While some people are still able to stand and walk, they may need to use a cane or walking device for support. Help is still necessary to prevent falls. Always remember how to position your body properly. A member of the Community Care Team, such as the Home Care Nurse, may be able to give you advice about how to help with moves. Ask about the availability and use of a transfer belt or other aids.

- The person may wish to take pain medication about 30 minutes before you are going to move them if movement causes them pain.
- Make sure that your path is clear and that there are not any rugs that may cause a fall.
- Have a chair nearby in case the person needs a rest.
- Try to ensure both of you are wearing secure, non-skid footwear.
- Provide your support on the person's weaker side.
- If a cane is used, have the person hold it on the stronger side. This will keep the weight on the side that can support it.
- Stand beside and slightly behind the person, facing the same direction. When necessary, remind the person to stand tall and to look ahead, not down at the floor.
- Put your arm around the person's waist and use your other hand to hold the person's elbow or hand. Stay close so that your entire body gives support.
- Try using a belt or folded blanket around the person's waist so you can hang on to it to give added support.

- If the person starts to fall, do not resist the fall. Gently allow them to glide against your body to the floor, making sure their head does not hit the floor.
- Once you reach the floor, take a few seconds to calm down and check that both of you are all right. Call for help if needed.
- To help up from a fall, start with the person kneeling, then holding onto a chair and rising from there.

There comes a time when the person is too weak and they cannot safely get up even with two caregivers assisting and therefore must be cared for in bed.

Helping Someone Change Positions in Bed

As people get sicker and become weaker, they may need help changing positions in their bed. This may mean helping people to move from lying on their backs to lying on their side, or even helping them move their body up towards the head of bed in the event that they have slipped down.

Making sure that someone is moving around is important because changing their position in the bed can help with pressure sores (which is a serious problem), can help keep the lungs free of mucus longer, and can also help ease pain.

Whenever you help someone change positions in bed, remember the following things:

- The person may wish to take pain medication about 30 minutes before you are going to move them if movement causes them pain.
- When helping a person to move, do not drag them as this causes friction, which can cause skin to tear.
- Though the person may have discomfort when being moved it is important to try to maintain a turning routine, depending on the stage of the illness.
- Ensure you have the supplies you need, such as pillows, close at hand before you move the person.
- If the bed has wheels, make sure the bed brakes are on and lower the head of the bed if possible.
- Raise the bed to about your waist level or the waist level of the shortest person if two people are helping the person to move. If the bed cannot be raised, remember to use your knees (not your back) when lifting.
- If the bed has side rails, lower the side rail closest to you.
- Check that no tubes or urine bags will be pulled with the move.
- Remove extra pillows and place a pillow against the headboard.
- Do not rub any reddened areas that remain red after you have changed the person's position. Tell the Community Care Team about these areas.
- Use equipment and tools such as a draw sheet to help you.

Creating a Draw Sheet

- A draw sheet (or turning sheet) is a useful tool to use when moving someone in bed. A draw sheet can be used by one person or two people. It can be used to move someone onto their side or can also be used to help move the person up in the bed.
- To create a draw sheet, fold a regular sheet in half twice and place side-ways on the bed. Get the person to lie on the sheet so that their back and buttock are on top of it with their shoulders and hips fully supported. This will ensure that it will be safe to move the person.

Moving Someone to Their Side Using a Draw Sheet

- While the person is laying on their back, gently move them from the center of the bed toward you, so that they are laying on one side of the bed right beside you (See Figure 3).
- Using a draw sheet, place one end of the sheet over the person and roll them towards the center of the bed so that they are now positioned on their side in the middle of the bed.

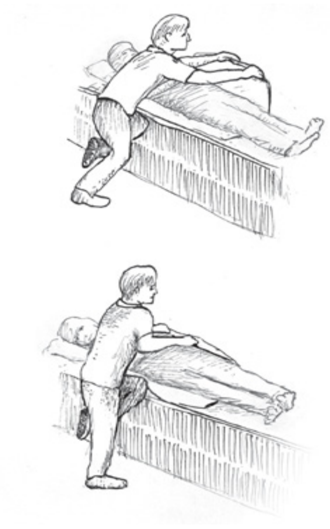


Figure 3

Moving Someone to Their Side Without a Draw Sheet

- Stand on the opposite side of the bed from where the person is lying.
- Position their far arm across their chest towards you. You should also bring the arm nearest you straight out at shoulder level (See Figure 4).
- Bend the far leg at the knee while their foot still rests on the mattress. Bring the bent leg towards you. Place your hand on the knee farthest from you and pull the bent knee towards you. As you do this, their far shoulder will naturally start to move towards you through the leverage of the leg. Reach over with your hand to guide their shoulder towards you comfortably and safely. This will put the person on their side with their bent knee giving extra security (See Figure 5).
- Place pillows to support their back and, if necessary, between their legs for added comfort. Adjust the head pillow as needed. Consult your Community Care Team regarding the use of pillows for different positioning.
- Return the hospital bed to the lowest position for safety, if possible.

Figure 4

Positioning someone on their side:

- Place a pillow lengthways at the person's back and anchor it by pushing the edge underneath the back. Fold the outer side of the pillow under and tuck it in snugly against the person to give more support.
- Place a pillow lengthways under the person's thigh, bringing the leg forward so it does not rest on the lower leg. Position the leg comfortably.
- Place another pillow lengthways under the person's lower leg to prevent skin surfaces from rubbing together and to provide correct support. The pillow should extend well under the foot so the ankle and the foot do not drop and are kept level.
- Make sure the lower arm is in a comfortable position. The upper arm and hand may be more comfortable if placed on a pillow.

Figure 5

Positioning someone on their back:

- Place two pillows lengthways at an angle. They should extend under the person's shoulders.
- Place one pillow across the top of the two lengthways pillows so it is under the head and reaching to the shoulders.
- A bar above the bed called a monkey or trapeze bar is a device that can help with moving in bed if the person has good upper body strength. Ask your home care nurse or occupational therapist if this would be helpful or available.

Helping Someone Move up Towards the Top of the Bed

- Sometimes when people are sitting up in bed, they may slide down towards the bottom of the bed. You may need to help them move up towards the top of the bed. This can be done by one person with the assistance of the person who is sick if they are able to help. If the person who is sick is not able to help with moving, the care provider may need to use a draw sheet or may need to get another person to help with the move.

Moving with One Person without a Draw Sheet

- Face the top of the bed where the person's head is. Your feet should be wide apart, toes pointing in the direction of the move. You can also place one knee on the bed to get close to the person (Figure 6).
- With the person lying on their back, bend the person's knees and place their feet flat on the bed.
- Place one hand under the person's back and the other hand under the person's thighs.
- Ask the person to help move themselves if they can.
- Count to three and work together - the person (with knees bent) pushes upwards as you lift towards the head of the bed.
- If the person is unable to help push upwards, use a draw sheet or ask a second person to help.

Figure 6

Moving with One Person Using a Draw Sheet

- Create a draw sheet using a regular sheet folded several times and placed side- ways on the bed.
- With the person lying on their back, position the person on top with the sheet under their shoulders and hips.
- Bend the person's knees and place their feet flat on the bed.
- Stand bedside the bed near the person's head, facing their feet.
- Grab the sheet with one hand on each side of the person's shoulder.
- Ask the person to help move themselves if they can.
- Count to three and work together - the person (with knees bent) pushes upwards as you lift towards the head of the bed.

Moving with Two People

Figure 7

- Each person stands on opposite sides of the bed.
- Both people face the top of the bed where the person's head is.
- With the person lying on their back, bend the person's knees and place their feet flat on the bed.
- Both people place their hands under the person's shoulders and waist (Figure 7).
- If a draw sheet is being used, grasp the sheet on each side close to the person's shoulders and hips.
- On the count of three, the person (with knees bent) pushes upwards and the other two lift the person (or the draw sheet) toward the head of the bed.

Making a Bed

- For someone who is ill, the bed is often a place of refuge and comfort. If the person is confined to bed, the bedroom is the center of activity. It is important that the bed and surrounding area be kept clean to protect the person from problems such as bedsores or infections. Change the sheets at least once a week and whenever they are soiled.

Making a Bed Without Someone in It

- Start by asking the person if this is a good time for you to change the bed. Wait for another time if tiredness or symptoms seem to be a problem.
- If the person is able they may sit in a chair for the few moments it will take to change the bed.
- As previously mentioned, make sure pain medication is appropriately given.
- Assemble necessary supplies (i.e. clean sheets, pillows, etc.)
- Ensure laundry basket/bags are available for used bedding.
- Raise bed (if possible).
- Remove the unclean bedding and check that the mattress is clean and dry.
- Place a moisture-absorbing mattress sheeting or pad across the middle or full section of the mattress to protect it from moisture, especially if the person has diarrhea or is incontinent. Your home care nurse or local pharmacy may be able to tell you about other products available in your community.
- Be sure the sheets are flat and free of wrinkles to help prevent skin breakdown. (Fitted bottom sheets, if available.)
- Consider placing a turning or draw sheet over the bottom sheet. This can assist with lifting and turning while protecting the bottom sheet from becoming soiled, saving you from changing the entire bed. A flannel sheet or light blanket folded in half can serve as a turning or draw sheet.
- If incontinence pads are available, place a fresh one on the bottom sheet where the person's bottom will lie.
- Lower the bed (if possible).
- Help the person back to bed.

Making a Bed with Someone in It

- Collect necessary supplies (i.e., clean bedding) and ensure that the bed is flat.
- If you are alone, place a non-slip chair on the opposite side of the bed from you for the person to safely hold. If you have a hospital bed, raise the side rail, and have the person hold on to that.
- Remove the top sheets, blankets, and all pillows except the one that remains under the person's head. Cover the person with a sheet for warmth and privacy.
- Loosen the top and bottom sheets all around the bed.
- Help the person to turn onto one side while giving support at the waist and shoulders. Make sure the person's head is resting on a pillow and the limbs are supported.
- If two of you are making the bed, one holds the person while the other rolls each layer of the bottom linens toward the center of the bed, close to the person's back. If the person has been incontinent, take this chance to do a wash, then cover the soiled linens with a towel.
- Place the clean bottom sheet, rolled up lengthways against the rolled-up dirty linens. Smooth out the flat half of the clean sheet and tuck it in. Repeat this process with each bottom layer of bedding you are using (mattress or foam, moisture-absorbing sheeting, bottom sheet, draw sheet, turning sheet, incontinence pads). This will form a small hump.
- Move the pillow to the other side of the bed. Help the person move and turn over the rolls of bedding to the other side. Make sure to warn about the hump.
- Help the person into a comfortable position. Replace the pillowcases and finish making the bed with a top sheet, cover and blankets if needed.
- If a person is at end of life with decreased consciousness, it will require two people to make the occupied bed as the person will need to be held over and turned as needed while the second person positions the bed linens.

Toileting

At some point the person may need help to use the toilet, commode, urinal, or bedpan. This can be very embarrassing for some people. Respect the person's dignity and need for privacy.

Bathroom

When the person is able to get up and go to the toilet, offer whatever help is needed. Stay nearby.

- Make sure the bathroom floor is dry, the person has non-slip footwear, and the path to the toilet is well-lit and free of obstacles.
- Place toilet paper within reach.
- Give privacy if the person can be left alone. Allow as much time as needed. The sound of running water might help someone who is having trouble urinating.
- Help with cleaning and wiping-up as needed. Wipe front and back areas separately with clean tissues or cloths.
- Help the person to wash their hands when finished, then wash your own hands.
- Take your time getting back to the bed or chair.
- Check with your nurse or occupational therapist about equipment that makes toileting safer and easier (e.g., a raised toilet seat, commode, urinal, bedpan with side rails).

Commodes

Commodes are portable toilets in the shape of a chair. They can be positioned close to the bed of a person who is able to get up but too weak to walk to a bathroom.

- Be sure the brakes are locked on the commode.
- Use the techniques described in Moving Someone from Bed to Chair to help the person move to and use the commode.
- Let the person do as much as possible. Have toilet paper within reach.
- Once finished, help the person to wash their hands.
- Empty the commode bucket as soon as you have helped the person return to the bed or chair.
- Wash your hands and return the commode to its usual place.

Urinals

- Urinals are small collection bottles that can be used for passing urine. They come in different shapes and sizes, are usually made of plastic, and can come with different attachments to accommodate the user's body. Some people who find this difficult to use may prefer a bedpan.
- Some people are able to use the urinal lying down, while others prefer sitting on the edge of the bed or standing up. If the person is able and wants to stand, offer support.
- If the person uses the urinal in bed, raise the head of the bed for comfort. Make sure the foot of the bed is down so that urine does not spill out of the urinal.
- If the person wants help, hold the urinal in place being careful to keep it tilted downward to prevent spilling.
- Keep the urinal emptied and thoroughly rinsed and clean after every use. This helps prevent spills and offensive odours. Rinsing it with cold water and baking soda will keep odour down.
- Wash your hands after handling the urinal.

Bedpans

While some people find a bedpan uncomfortable and awkward to use, it may be necessary for someone unable to get out of bed.

- You can warm up a bedpan by rinsing it with hot water and then drying it.
- Try some talcum powder on top of the bedpan so it does not stick to the skin.
- If the person is strong enough, bending their knees and placing feet flat on the mattress can help with positioning the bedpan. Help lift the person's bottom while you slide the bedpan under.
- Alternatively, help the person roll away from you. Place an incontinence pad on the mattress, put the bedpan on the mattress where the person's bottom will be and help them roll back onto the pan.
- Raise the head of the bed to increase comfort. Have the foot of the bed down so that urine will not pour out by mistake.
- Make sure the person is wiped clean and dry.
- Cover the bedpan before removing it to prevent spilling. Empty it in the toilet and clean it. Rinse with cold water and baking soda to keep it odour free.
- Wash your hands and help the person to wash theirs.

Other Considerations

People do not have to have a bowel movement every day to be healthy. It varies from person to person. If the person does not have a bowel movement after three days, they may require further interventions such as an enema that would be ordered by the Community Care Team. Menstruating women should have all the supplies and assistance they need. Again, ask them what they need and what kind of help would be appreciated and who they prefer to help them.

If Someone is Incontinent of Urine or Feces

Incontinence means that the person cannot control their bladder or bowel movements. Odor problems, infections, or rashes may develop if the person is not regularly changed and kept dry. Their skin care becomes especially important at this point to prevent painful bedsores and other uncomfortable skin conditions.

- Get some specific advice from your Community Care Team.
- Use incontinence pads or a clean towel under the person in bed.
- Sometimes odor can be minimized by a container with a vinegar and water solution in it. Also, oranges with cloves stuck in them, and left in the room, can also reduce odors. There are also commercial products to help with odor.

Personal Care – Practical Considerations

Bathing

Bathing is an important part of personal care and offers both physical and emotional comfort. When the person is receiving care, observe to find out if they are in pain. They may need more medication or choose to pass up their bath for the day until the increased dose of medication takes effect. There are medications that can be given just before turning or changing dressings. In the last few hours of life, the person may not want to be disturbed.

What to do:

Before getting the person into the bath gather all the things you will need (i.e. clean clothes, soap, shaving supplies, shampoo, face cloth, towel, lotion, etc.). If the seriously ill person is able and strong enough to get up for a shower, bath or sponge bath:

- Ask your Community Care Team for advice on how to make the bathroom safe and easy to use; order any necessary and available equipment. Equipment such as bars and non-slip surfaces may be helpful. The Community Care Team will also be able to advise of proper body mechanics, so you are not injured.
- Put a bath chair on a non-slip mat in the tub or shower if getting in and out or standing for a long time is difficult. A chair at the sink can also be used.
- Prior to helping the person into the tub test the water temperature of the bath or shower and help them get in.
- The person may need help washing their back, legs, feet, and genital area. Always ask permission and respect their privacy.
- Standby to assist out of the bath or shower and help dry.
- Help the person into clean clothes.

Bed Bath

As the seriously ill person weakens and is unable to manage a shower or bath a bed bath becomes necessary. This is an intimate experience and should be done with respect and compassion, and only as the person is willing to accept the care. Community Care Team members may be available to help with personal care; ask for assistance if required.

What is needed:

- A large bowl or basin filled with hot water (hot enough to be warming)
- Mild soap
- Skin lotion, cream, and/or powder
- Washcloths (for washing and rinsing) and towels
- Personal toiletries: comb, brush, toothbrush and paste, nail file and clippers, make-up, deodorant, shaving items, perfume/cologne (whatever the person needs)
- A suitable change of clothes

What to do:

- Ask the person what time they prefer to bathe, realizing that they may have more energy in the morning. Allow them to do as much as they can and wish to do. This will change as the person gets weaker.
- Provide privacy and make sure room temperature is comfortable.
- Gather the things you will need.
- Wash your hands thoroughly.
- If possible, raise the level of the bed to lessen the strain on your back.
- Cover the person with a light sheet or blanket for warmth. Only uncover and wash one part of the body at a time.
- Put dry towels under the body part being washed to keep the person and bed linens dry.
- Use a mild soap on the skin, then rinse and dry. Start at the face and work your way down the body.
- Wash the chest, legs, arms and sides first, and then help the person to lie on one side while you wash their back. Wash carefully under the skin folds since these are the most likely spots for rashes or other skin problems. This is especially true under the arm, in the groin area, buttocks, stomach skin folds, and under a woman's breasts. The person may prefer washing sensitive areas themselves.
- Cleaning the back is the perfect opportunity to give someone a back rub if they are able to lay on their side. This will be relaxing, promote blood supply, and help prevent sores from developing. Massage the back and pressure areas with lotion. Use soft pressure and move your hands in a circular motion. Check for reddened areas and be sure to bring them to the attention of the Community Care Team. Apply lotion if desired after drying an area.
- People often enjoy having their face, temples, neck, hands, elbows, feet, and heels massaged as well. This can be done using cream or oil. Again, follow their wishes. This can also be done throughout the day, not just during bathing.
- Change washcloths and water, then wash the genital and anal areas last. It is important that these areas be cleaned well, at least daily, as bacteria tend to collect there. Wash between the person's legs from the front toward the back. If cloth becomes soiled use another clean cloth and rinse well.

- If incontinence is a problem, follow the advice of the Community Care Team on treatment of the genital area.
- The bed can be made after the bed bath is complete.
- Apply lotion to all pressure areas (i.e., shoulders, elbows, wrists, tailbone, hips, calves, heels). Massage the back and pressure areas with lotion after each turn. Use soft pressure and move your hands in a circular motion. Ask the Community Care Team for more instructions if needed.
- If a complete bed bath is too tiring, wash the person's face, hands, back, underarms, and genitals daily.
- Remember to ask the person's preferences on deodorant, shaving, make-up and brushing and styling hair, and help them accomplish those tasks. Often a rest before and after these activities will help prevent the person from becoming over-tired.
- Take special care of a person's feet, especially if they are diabetic. Be sure they are clean and dry and encourage the person to wear socks and appropriate footwear to prevent sores and nail problems.
- Ensure that items like reading glasses and hearing aids are returned within reach of the person at the end of the bed bath.
- The bed linens should be changed at the same time as the bed bath. If changing the bed linens at the same time as the bed bath, finish washing the person, then change the pajamas prior to pulling all layers of the clean linens through. Pull tightly to make the bottom straight and wrinkle free, then tuck in the clean sheets.

General Hair Care

People need their hair clean and at least twice a day their hair should be combed or brushed. Clean and groomed hair can promote a general sense of well-being. There are a variety of hair care products available, such as dry shampoo, which may be a good alternative to a normal wash. Follow the directions on the product or the advice from the Community Care Team.

If the person needs a normal hair wash but cannot use the bath or shower, you can wash their hair in bed.

You will need:

- A plastic sheet to protect the bed.
- A waterproof cape (like in a hair salon) or a plastic garbage bag with a hole for the head and cut along the sides to make a cape.
- A jug or pitcher of warm-to-hot water (several if the person has long hair).
- A bucket or large basin to collect water. Ask your Community Care Team if a bed shampoo tray is available. Shampoo trays are available through some drugstores.
- A washcloth or small towel, plus two larger towels for drying.
- Shampoo.
- Comb or brush.
- A hair dryer (if necessary and available).

What to do:

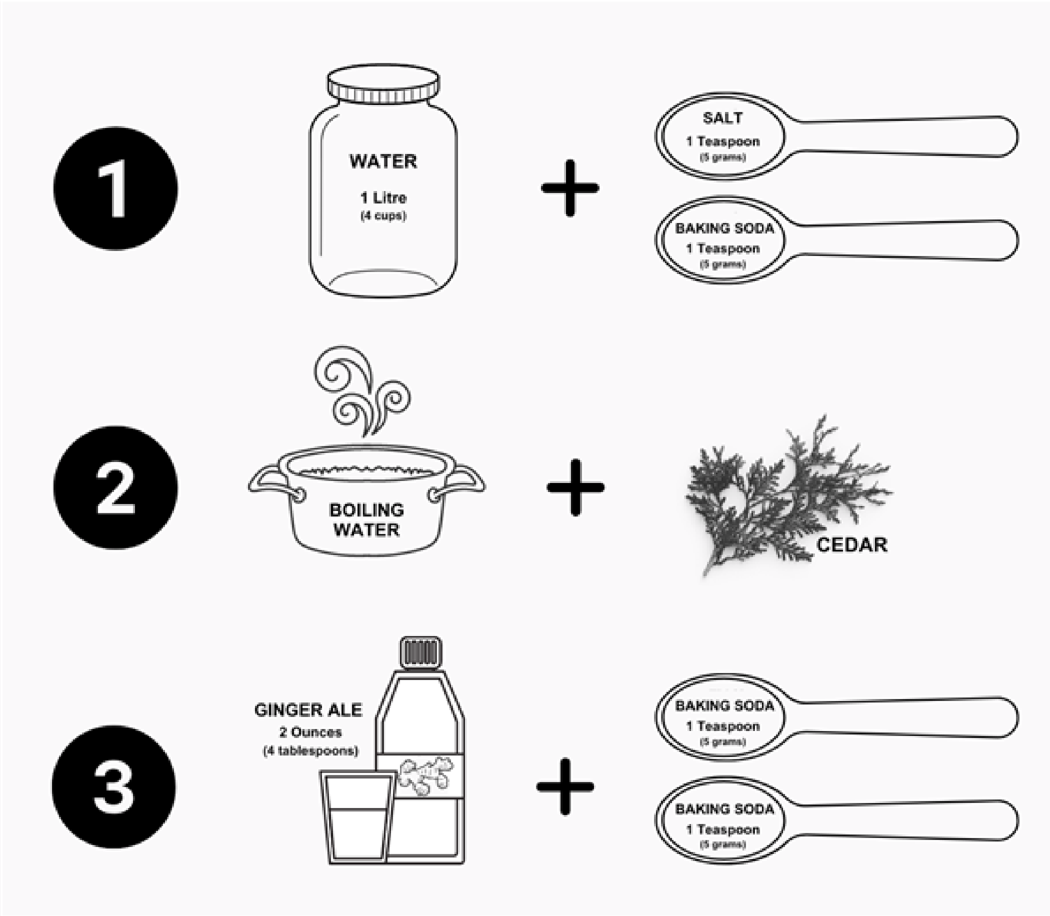
- Place a towel or plastic sheet on the floor under the bucket to catch any spilled water.

- If a shampoo tray is available, follow instructions for use. If not, have the person lie on their back with their head toward the side of the bed (adjust pillows, covers, etc. so they are comfortable). Put the bucket or basin on a small table under the person's hair.
- Cover the area with the plastic sheet and have the person wear their cape with the back side covering their pillow rather than tucked under them.
- Pour warm water from the jug over their hair so that the water falls in the bucket or basin below.
- Put the shampoo into the hair and gently massage it in to lather the hair and scalp.
- Rinse the hair with the remaining water.
- Dry the hair with a towel and then with the dryer if necessary.
- Empty the bucket and remove the cape and plastic sheet. Place the other dry towel on the pillow to soak up any moisture still in the hair. Tidy up the bed as needed.
- Comb and style the hair as requested by the person.

Mouth Care

Cleaning a person's mouth is not difficult and can increase comfort, prevent mouth sores, and make eating and drinking easier. Mouth care should be done at least twice a day. Wash hands well before and after giving mouth care.

RECIPES FOR MOUTHWASH



Sore mouths are common if people are unable to drink their usual amounts of fluids. If a person's fluid intake is reduced, saliva may dry up. If the person breathes through their mouth, it can make dry mouth worse. The person may tell you that their mouth is dry and uncomfortable. There may be a bad taste or odor from the mouth.

What to do:

- Clear the mouth frequently.
- Avoid over-the-counter mouthwashes that contain alcohol as they can further dry out the mouth.
- Use a non-alcohol-based rinsing solution.

  Suggestions include:
  - baking soda (1 teaspoon) and water (2 cups)
  - salt (1/2 teaspoon), baking soda (1 teaspoon) and water (4 cups)
  - club soda
- After cleaning the mouth, lubricate lips.
- Sucking on ice chips or popsicles can help.
- Remove and brush dentures once daily. Swab the mouth with a swab stick or gauze moistened in mouthwash (water, baking soda) after the dentures are removed.
- See the section called "Mouth Problems" to address sore mouth issues located later on in the manual.

Additional Resources in the Section Appendix

* *Mouth Care* Handout

Brushing Teeth

If unable to go to the sink to brush the teeth, it can be done while in bed. If the person is still able to brush their teeth, allow them to follow their regular routine. If they are in a weakened state, assist as needed. Check with the Community Care Team for any equipment that will assist with brushing teeth in bed.

- Help the person into a sitting position.
- Place a dry towel under the chin. Have a bowl handy – it can also be placed under the chin if tolerated.
- Give the person a sip of water to moisten the inside of the mouth.
- Use an ultra-soft toothbrush and soften the bristles in hot water.
- Avoiding using toothpaste as it may be harsh on sensitive gums.
- Moisten the brush.
- Brush the teeth using gentle strokes starting at the gum line and moving to the edge of the teeth.
- Do not put the toothbrush too near the back of the throat as this may cause gagging.
- Have the person rinse with cool water and spit into the bowl or basin.
- Apply any water-soluble lubricant to lips if the person wishes. Avoid oil-based products like ChapStick.

Denture Care

Most people prefer, while they can, to care for their own teeth and dentures. If they can't, remove the dentures and clean them with a toothbrush. Soak dentures using the appropriate commercial product. There are a variety of products such as Oral Balance that can be used to keep the mouth comfortable. As the seriously ill person weakens and is unable to raise their head, do not give mouth care to a person who is lying flat as this may cause choking. Help them to turn to the side and wipe any moisture remaining in the mouth with a clean towel. Check in the person's mouth every day for signs of sores or other problems. If you notice any mouth problems or sores, reach out to the Community Care Team.

Food and Fluids

It is understandably hard to watch the person you care for eat less than usual.

When a person is newly diagnosed with an advanced progressive illness, it is good to ask for early advice, information and direction on food and nutritional care. It also prepares you to know how an advanced illness can change and reduce appetite, taste, and weight as the end stage of life draws closer.

Depending on the person, and their illness, each situation will be different. Concerns about food and fluid need to be discussed and understood by the person, the caregiver, and the Community Care Team.

You may notice the person has no interest in foods, refuses solids, and will only drink liquids. There are commercial or homemade food supplements that may help at this time. These drinks and puddings can provide an easier source of calories and protein. Ask your Community Care Team for suggestions on what is available in your area.

Additional Resources in the Section Appendix

* *Food for Thought: If your loved one isn't eating* Handout

Noticeable weight loss may be caused by their illness, no matter how much they eat. A changing sense of taste may alter the enjoyment of food. If it is connected to a treatment or medication, this may be temporary. They may not be able to eat meat or certain textures and smells of food may bother them. Even when eating and drinking is reduced, regular bowel patterns should be monitored.

What to do:

- You should not force the person to eat. Do not discuss how much they are, or are not, eating.
- Make sure the person does not have sores in their mouth, or problems with their teeth (such as decay or broken teeth), which may contribute to a person not wanting to eat. Let the Community Care Team know so the problem can be looked into to. If dentures are loose, have them relined or try Poly Grip.
- Freshen and clean the person's mouth before and after eating.
- Ask the person what they would like and offer what they can tolerate. Try to make a pleasant, quiet, and peaceful eating environment. For instance, remove bedpans or commodes from the area. Keep cooking smells and noises as far away as you can manage if the person finds them bothersome.
- Serve small portions of favorite foods that are soft and easy to eat.
- Avoid spicy or salty foods.
- Eating protein in any form should be encouraged. Milk and milk products, such as macaroni and cheese, cottage cheese, yogurt, baked custard, ice cream, eggnog, and milkshakes are good sources of protein. If the person has diarrhea from lactose intolerance, a good nutritional supplement may be necessary. Meat, poultry, eggs, and fish are also very high in protein. They can be stewed, creamed, or poached to soften them into a more easily digested form.

- Each person will have different tastes in fruits and vegetables. Prunes and other fruits and vegetables can relieve constipation. Cooked vegetables (i.e. in soups) are soft and may be easier to eat. Fruit or juice can be added to milkshakes, ice cream, and puddings.
- Gravy and sauces may be added to food to make drier foods easier to eat.
- Bread and cereals, like Bran, are helpful in preventing constipation. Crackers and plain cookies may be helpful if nausea is a problem. Get advice from your Community Care Team who may give medication to help.
- Fluid intake should be encouraged. Clear soups, ginger ale, soda, and fruit juice are recommended. Tea can also be served. Care should be used with citrus juices (i.e. orange, lemon, etc.) as they may bother a person with mouth sores.
- Ask your Community Care Team for assistance with sore mouth, difficulty swallowing, and if it is safe to continue to try feeding.
- When the person can no longer swallow it becomes important to continue to gently care for them with mouth care and spending quality time with them.
- Just as with reduced appetite, reduced fluid intake needs to be discussed with your Community Care Team for advice and suggestions.
- Most dying people do not feel thirst or hunger as the end of their journey approaches.

Making sure the person is comfortable includes mouth care (such as ice chips) or other suggestions from the Community Care Team. For more information visit the Canadian Virtual Hospice website (www.virtualhospice.ca).

Giving Help with Eating

Eating for a person with a serious illness can be very tiring and often they have no appetite.

What to do:

- Keep the head of the bed elevated to help digestion.
- Soft foods or small bite-size portions of meat, softened with gravy, are ideal.
- The person may not remember to eat but can be offered small snacks throughout the day.
- Assess the person’s ability to chew and swallow before you serve solid foods. For someone who can swallow but cannot chew, a puree or pudding would be most effective. For someone who can chew, keep food pieces small so less energy is needed to eat. Refer to your Community Care Team to assess if it is safe to continue feeding.
- If nausea becomes a problem, be prepared. Report to the Community Care Team and have a small basin or bowl close by, as vomiting can happen very suddenly.
- Keep your Community Care Team informed about issues with eating (nausea, dry sore mouth, trouble swallowing, etc.) so they can advise on care plan changes.
- Encourage the person to rest after meals.
- Never force a person to eat or drink.

Reduced Fluid Intake

Fluids usually help to flush out a healthy body of waste products and keep cells and skin well hydrated. As the person's condition advances it is often more important to focus on trying to drink some liquids to keep the mouth moist. Just as with reduced appetite, reduced fluid intake needs to be addressed, assessed, discussed, and understood by the person, you, and your health care team. Gradually taking less food and fluid is a common, natural part of the dying process. Most dying people do not indicate they feel thirst or hunger as end-of-life approaches.
What to do:

- Have drinks like water, juice, etc. available. Avoid orange and lemon juice if mouth sores are present.
- Ice chips or popsicles are excellent ways to give fluids. Also, they help to keep the mouth moist and feeling fresh.
- Raise the person's head when helping to drink. Use a few pillows or gently support the base of the head with your hand. It is almost impossible to drink when lying flat.
- Ask the person to take small sips and not big gulps to help prevent choking.
- Use a short straw that bends if the person is strong enough to draw up the liquid through it.

Suggested Readings

How long can someone live without food or water?
This Canadian Virtual Hospice post provides insight into how long someone can live without food or water. You may find it helpful for responding to family members' questions about nutrition and hydration as a loved one's illness progresses.

I feel guilty not being able to get me father to eat. What should I do?
This Canadian Virtual Hospice post talks about some of the guilt we feel when we want the individual to eat but they are not and suggests other things family members can do to offer comfort.

Increasing Weakness

Changes in energy level and strength usually happens over weeks and months, but it can also happen quickly over a matter of days. As the person gets weaker, you will need to change the way you do things. For example, using equipment such as a walker or wheelchair can provide safety and make care in the home easier.

You may notice the person tires more easily, needs to nap more often, and may need more help to walk, bathe, or dress. The person may tire more easily with activity and may have shortness of breath when moving or talking. They may become anxious and frustrated about these changes.

What to do:

- Give reassurance.
- Alert the Community Care Team about the changes.
- Ask the Community Care Team for help with easier ways of doing things for the person.
- Provide time for rest before and after activities.
- Make sure the person has a way of calling for help (a bell to jingle).

Pain

Pain is an individual experience. People talk about it in different ways and experience it differently. No one is more of an expert about the pain than the person who is feeling it. If the person you are caring for complains of pain, believe it. It can also be emotional, social, spiritual, and many other different elements that are often described as "total pain."
When caring for a person who is seriously ill, it is important to remember that pain:

- is enough to make them uncomfortable.
- is as bad as the person says it is and not what others think it should be.
- occurs where the person says it occurs.
- may be constant or come and go.
- can affect moods and can be affected by thoughts or emotions.

Understanding more about the pain will help you to provide comfort and let you know if the help you are giving is working.

If constant, it is usually treated with medication on a regular basis (e.g., a long-acting medication is given every 12 hours). A smaller dose of medication is usually given to help pain that comes between doses. This is called breakthrough medication and will be prescribed and managed by the appropriate Community Care Team member using well established tools and principles.

Someone who has constant pain needs regular pain medication to control it. The goal of pain management is to keep someone alert, with the pain under control as much as possible. It takes time and testing to arrive at the exact combination of medications that will keep a person feeling more comfortable.

You can shorten this process by regularly recording positive or negative effects of a new medication and talking to the Community Care Team about the results.

A record of the pain and of regular scheduled pain medication and break-through doses will help the Community Care Team adjust the dose.

Many people have strong thoughts and feelings about pain medications.

Some people feel that:

- "Taking pills isn't natural." For a person with a serious disease, medication may make the difference between being in pain and doing the things they want to do.
- "They will get addicted." For a person with severe pain, the medication takes care of the pain. If the person has radiation or some special treatment that makes the pain go away, the medication can be reduced gradually and sometimes stopped.
- "They will feel high." Only if they take the medicine for reasons other than pain.
- "The medication will not work later on when the pain is very bad." Now we know you can gradually increase the dose until there is pain relief. We now know we can use much higher doses.
- "They will be sleepy." This may happen at first, especially if the person hasn't slept for a few days. They will adjust. If sleepiness continues, let the Community Care Team know so they can make changes to the medications.

Signs of Pain

- General body tension: clenched hands, hunched shoulders.
- Facial expressions.
- Constant fidgeting.
- Nervous habits: lip and nail biting.
- A change in behaviour, unusual quietness, or sudden agitation.
- Strained or high-pitched tone of voice.

What to do:

It is important to assess for pain regularly as the experience of pain is different for each person. By asking some of the following questions, you can provide accurate information to the Community Care Team so they can take care of the pain.

Some questions you might ask:

- Tell me about your pain. (What does it feel like? Stabbing, burning, aching, etc.)
- When did the pain begin?
- When do you get the pain? Walking? At rest?
- Where is the pain? Does it go anywhere else?
- How long does the pain last – minutes, hours? Does it come and go, or is it constant?
- How bad is it? Mild or severe? Ask the person to rate their pain on a scale from zero to 10, where zero is no pain and 10 is the worst yet.
- What makes the pain go away – rest, massage, movement, meditation, distraction, medication?
- What makes it worse? Was it movement, eating, pressure, the way the person was lying or sitting?
- Does it affect your sleep? Activity? Mood? Visiting with family?
- What medications, therapies or natural ways have you tried?
- Report any change in the pain to the Community Care Team.

What can help:

- When pain is constant, give the medication on schedule. This helps make sure the pain stays away.
- Plan to give physical care after a medication has started to work to reduce discomfort (20-40 minutes).
- When taken regularly, pain medication is just as effective taken by mouth as by injection. Alternative routes such as injections, suppositories, or patches are considered when the person cannot take or tolerate medication by mouth.
- The medicines may be ordered every 4 hours, even through the night, for a short acting medication or every 12 hours for a long-acting medicine.
- It is important to follow the instructions given by the Community Care Team.
- There may be a "breakthrough or rescue dose" that the person can take in between if the pain is bad. If the person needs several rescue doses, they may need to have their regular dose increased. Talk to the Community Care Team.

- Weaker medication may be ordered first for mild pain.
- As the pain worsens, a stronger medication such as a narcotic/opioid may be ordered.
- Other medicine may be added for different pain. Strong pain is usually given strong medication.
- Keeping track of when and how often the medications are taken is important and easier to do if a medication record is used.
- Remember that opioids are potent medications and should be kept safely out of sight and out of reach of children and others.
- As with any other medication, do not talk in public about the fact that you have these drugs in your home. Otherwise, there is a risk someone may try to steal them.
- Taking medications by mouth is best for as long as possible; swallowing more water may help.
- Some pills can be mixed in applesauce or pudding. Some pills must not be crushed. It is important to ask your Community Care Team before doing so.
- When a person is having difficulty swallowing, or can no longer swallow, medication can come in other forms such as: liquids, suppositories or injections given under the skin. A pump may be used to prevent repeated injections.

Additional Resource in the *Developing A Care Plan* Section Appendix

* *Palliative Performance Scale (PPS)* Handout

Possible Side Effects of Opioids

People need to continue using the right dose of pain medication so that they can remain relatively pain free and alert, but they also need help controlling any side effects of that medication. Discuss what side effects to expect with your Community Care Team and what to do if they happen. Always report these to the Community Care Team as quickly as possible so they can manage them.

Constipation

- People receiving narcotic pain medication will have difficulty with bowel functions, especially constipation.
- A laxative should always be ordered and given regularly.
- Tell your Community Care Team if there's any change in regular bowel habits.

Nausea and Vomiting

- When first started, opioids can cause nausea and even vomiting but this usually disappears in a few days.
- Ask your Community Care Team about anti-nausea medication if necessary.

Drowsiness

- When a new opioid medication is first given it may make the person extra sleepy. This should resolve in a few days.
- Remember that the person who is ill may be needing to catch up on sleep and therefore appears drowsier.
- Make sure you are able to rouse the person. Ask the Community Care Team for advice.

Confusion

- A person who is taking pain medications, especially opioids, may feel a little confused.
- Some people may even hallucinate, although this is an unusual response.
- If confusion occurs, tell your Community Care Team.

Jerking (Myoclonus is a twitching or spasm of the muscles that the person cannot control.)

- It is not related to a convulsion.
- Tell your Community Care Team if this is happening.

Difficulty Passing Water

- This may cause the person to be restless and often is confused with increased pain. Although it does not happen often, it is important to be aware.
- It may be necessary to insert a temporary catheter to relieve the bladder periodically.

Addiction, Physical Dependence, and Tolerance

There is a difference between physical dependence, addiction, and tolerance:

- Physical dependence is the body's need to relieve constant physical pain by taking medication regularly to maintain the effect.
  - When the medication is stopped in either case, the body will experience symptoms of withdrawal.
  - People do not become addicted to pain medications that are needed for pain and used correctly.
- Addiction is what happens when there is no physical need for the medication and the person continues to take the medication for the feeling it gives them.
- Tolerance is when people take pain medication on a regular basis and usually need a higher dose over time as the body develops a tolerance for it. The dose of an opioid can be increased as much as necessary by the doctor in order to relieve pain.

Opioid Toxicity

- Someone who is on high doses or long-term opioid pain relief, or has kidney problems, may have wastes from the medication build up in the body. This is called opioid toxicity.
  - The signs that indicate a problem with opioid toxicity include marked behaviour changes such as: delirium or confusion, agitation, hallucinations, restlessness, drowsiness, jerking, pain when touched in a certain way that is not expected.
  - If any of these changes are noticed, contact your Community Care Team immediately.

All of these side effects are signs that the medication(s) may need adjusting. Your Community Care Team can help with this. Because several medications may be used, it is important to keep an updated list of the medications.

Other Non-Pharmacological Ways to Help with the Pain

- Distraction: television, music, games, hobbies, good conversation
- Relaxation: rhythmic breathing, isometric exercises
- Imagery: visualizations, meditation
- Touch: stimulate the skin with gentle massage using steady, slow, circular motions; warm baths or blankets, cold packs; therapeutic touch
- Physiotherapy modalities (e.g., TENS)
- Nerve blocks with local anesthetics/radiation to shrink tumors

Additional Resources in the Section Appendix

- * *Isometric Exercise*
- * *Imagery Exercise*
- * *Rhythmic Breathing Exercise*

Nausea and Vomiting

Nausea means feeling sick to the stomach and vomiting means throwing up. Nausea can happen even when a person is not thinking about food. Vomiting can occur even if nothing has been eaten or there has been no nausea.

Many things can cause nausea and vomiting. These can include the illness, medications, irritation of the digestive system, certain foods, constipation, pain, bowel obstruction, infection, anxiety, movement, and some treatments.

You May Notice:

- The person feels sick and is unable to eat.
- They may vomit occasionally or often.
- They may have trouble keeping down medication.
- They are comfortable at rest but feel sick with movement.
- They may be sensitive to strong smells/tastes (i.e., cigarettes or cooking smells).
- The cause can be discussed with the Community Care Team.

What to do:

- Offer small amounts of food and fluids (broth, Jell-O, ginger ale, ice chips).
- Try cold food as there is less odour.
- Do not offer greasy or spicy foods. Try bland foods such as crackers, toast, angel food cake, soft fruits, and yogurt.
- Cooking smells may trigger nausea.
- Encourage them to take anti-nausea medication as required.
- Freshen the mouth with a non-alcohol-based mouthwash or club soda.
- Always have basins close by and remove and replace immediately if vomiting does occur.
- Fresh air from an open window or fan may help reduce nausea.
- Help the person to rest sitting up, if appropriate, for a short while to aid digesting the meal.

- Always work with the Community Care Team, regarding how often the person is experiencing nausea and/or vomiting.
- Follow the Community Care Team advice on medications to manage the nausea and/or vomiting, and report frequently.

What to Report to the Community Care Team:

- Increased vomiting despite medication.
- Blood in vomit (may be red or coffee ground in appearance).
- When medications are vomited.
- Unusual weakness or dizziness, or the person is suddenly unresponsive.

Mouth Problems

A sore mouth is a very common problem with people who are seriously ill. This can often be caused by a thrush infection. This can affect the seriously ill person's ability to eat or drink normally.

Thrush Infection

Thrush commonly occurs in people who are seriously ill. It can be caused by medications or treatments such as radiation. Thrush can be spread to others through contact (i.e. during care, kissing, etc.), so be sure to wash your hands before and after care.

What to watch for:

- Complaints of sore mouth, scratchy sore throat.
- Hoarseness and problems swallowing.
- White, curd-like patches on the tongue, roof of mouth, inside cheeks, lips and back of throat.
- The tongue may look swollen and red.

What to do:

- Report any of the above things you have noticed to the Community Care Team.
- Thrush infection is treated with medication called nystatin (i.e., Mycostatin, Nilstat).
- The medication is a liquid that is swished in the mouth like a mouthwash then swallowed.
- Clean and rinse the mouth with clear water after eating and prior to medication.
- Use a new, soft toothbrush before treatment begins and replace it again when all the medication is finished.
- If there are dentures, remove before swishing and swallowing the medication.
- Clean the dentures well each time.
- Soak the dentures each night in a solution of one-part vinegar to four parts water.
- The Community Care Team may advise to soak the dentures in the nystatin.

Mouth Sores

Mouth sores are like little cuts or ulcers in the mouth. Chemotherapy, radiation, therapy, infection, limited fluid intake, poor mouth care, oxygen therapy, too much alcohol or tobacco use, and some medications can cause them.

What to know:

- Mouth sores can be very painful and interfere with eating and drinking.
- The inside of the mouth, gums, and tongue may look red, shiny, or swollen with sores that may bleed.
- There may be blood or pus in the mouth.
- The mouth may be coated and look white or yellow.
- Eating food may cause dryness or mild burning and sensitivity to hot or cold.
- There may be difficulty swallowing.

What to do:

- Check for advice from your Community Care Team. Report if the person's mouth looks different or there is a change in taste or sensation.
- Do mouth care after eating and frequently through the day, as tolerated.
- Check mouth often with dentures (if present) out.
- Rinse with any of the solutions suggested in the section on mouth care.
- Offer small, frequent, cold, non-spicy, bland meals as the person tolerates.
- Try chilled foods and fluids (popsicles, ice cubes, frozen yogurt, sherbet, or ice cream, if available).
- Avoid citrus fruits and juices such as oranges, lemons, limes, and tomatoes. Although they may seem to moisten the mouth, they actually have a drying effect.
- If mouth sores are severe, and dentures are present, leave them out except when eating.

Dry Mouth

Dry mouth may occur in a person who is seriously ill if they are not able to drink their normal amount. This may happen with nausea and/or vomiting or because of some medications. Because they are not able to eat or drink their regular amount, saliva may dry up. Mouth breathing is common in a person who is seriously ill and can cause dry mouth. Dry mouth can be a source of discomfort for a person and may be described as a dry mouth or a bad taste in the mouth. The tongue may be red and coated and the lips may be dry and cracked.

Some suggestions:

- The most helpful thing you can do is keep the person's mouth clean and moist, to help it feel fresh.
- Try to keep a bowl of ice chips by the bed. Even if the person does not want or is unable to drink, suggest sucking ice cubes to moisten the mouth.

Remember:

- Use a very soft toothbrush.
- Do not use mouth wash containing alcohol.
- Do not use dental floss.
- Tobacco and alcohol can make mouth sores worse.
- Avoid hard foods like crackers or potato chips.

Bowel and Bladder Problems

Incontinence

A lack of control of the bowels or bladder.

Considerations:

- Skin breakdown is a risk with contact with urine or bowel movement. Clean and dry skin is very important in preventing this breakdown.
- Use of incontinent supplies will help keep the bed dry and assist in preventing pressure area breakdown. Ask your Community Care Team for advice.
- Water-repellent creams such as zinc oxide can be applied to help as well. Ask advice from your Community Care Team.
- If a person who is seriously ill is often incontinent of urine, a catheter may be helpful in preventing skin breakdown. A catheter is a tube put in the bladder so the urine can drain into a bag.
- When the person has a catheter, be sure to wash the area where the catheter enters the body with soap and water and pat dry.
- Your Community Care Team will show you how to care for the catheter bag, tubing, and how to empty the drainage bag.

What to report:

- If there is leaking around where the catheter enters the body.
- If the urine becomes cloudy, has an offensive smell, or the person develops a sudden fever. These could indicate a bladder infection.
- If there is blood in the urine.

What to do:

- The Community Care Team may prescribe medication (pill, liquid, or suppository). It is important to take this medication as advised by the team.
- Keep a daily diary of the person's bowel movements.
- Bulk laxatives such as Metamucil™ are not appropriate. A person must drink three liters of fluid a day for these to be effective, otherwise they make the problem worse.
- If the seriously ill person is able you can increase the fluid intake.
- Avoid foods that cause constipation like chocolate, cheese, and eggs.
- Remember opioids cause constipation so give laxatives as ordered.

- Drinking vegetable and fruit juices (including prune juice) may be helpful.
- Natural fibre recipe: 1 cup All-Bran; 1 cup apple sauce; ½ cup prune juice. Mix to soften the All-Bran. Eat by the spoonful and drink lots of water. Could be spread on crackers or toast if the person is able to eat it.

Constipation

Constipation means infrequent stools or stool that is difficult to pass. May be frequent but small and hard, i.e. rabbit pellet-like appearance. For the person who is seriously ill constipation can be caused by: medications such as opioids; less eating and drinking and physical activity; low fiber in diet; and the type of illness. Bowel changes, such as constipation, must be reported to, and assessed by, the Community Care Team who will make sure there is no obstruction in passing of stool. Tell your Community Care Team if there is blood in or around the stool, no bowel movement for three days (or within one day of taking a laxative), and if there is persistent cramping or vomiting.

Considerations:

- Stool is still produced even when the person is not eating.
- Constipation is uncomfortable and may cause serious problems. Keeping ahead of it through prevention is very important.
- Stool may be dry and painful to pass.
- The person may have large amounts of gas, burping, or feel sick to the stomach.
- There may be pain in the abdomen.
- What may appear to be diarrhea, may in fact be small amounts of runny stool escaping around the hard, constipated stool.
- The person may have small hard bowel movements, but not enough stool to correct the constipation.
- Headaches and possibly confusion may accompany constipation.
- The person's abdomen may look blown-up or bloated.
- If there is no bowel movement in three days, it is important to tell your health care provider so they can adjust the medication, order a suppository or an enema.
- Follow the Community Care Team's direction regarding enemas.

Diarrhea

Diarrhea is the passage of loose or watery bowel movements three or more times a day. There may or may not be discomfort. Causes of diarrhea include infections, some medications, treatments, etc. and sometimes the disease itself.

Considerations:

- Certain foods may make diarrhea worse while others may slow it.
- Diarrhea may cause dehydration and upset the body's balance of electrolytes.
- Report to the Community Care Team if there are six or more loose bowel movements more than two days in a row.
- If you notice blood in or around the stool, tell the Community Care Team.

What to do:

- Avoid foods that irritate the person's stomach.
- Very hot and very cold foods can trigger diarrhea.
- If the person is eating, choose foods that are high in protein, calories and potassium. Ask for advice.
- If they are able to drink, increase fluids and aim for eight to 10 glasses of fluid a day.
- Serve a variety of drinks, as well as water.
- Try frequent small meals.
- Make sure to protect their skin to prevent breakdown.
- Use protective pads on the bed.

Shortness of Breath (Dyspnea)

Shortness of breath has many causes, including the illness itself. It can also occur when someone is not getting enough air/oxygen. This may be caused by anxiety, smoke from cigarettes, a smudge or from a fire. If you are concerned that the person you are caring for is suffering from shortness of breath, contact the Community Care Team for advice about medication or other measures that may help.

What to know:

- Shortness of breath from whatever cause can be very frightening.
- There may be large amounts of thick mucus that the person can or cannot cough up. Tell the Community Care Team if the mucus is yellow, green, or blood.
- Respirations may sound moist and gurgling.
- Breathing may be difficult when moving, talking, or even resting.
- The nail beds, and the skin around the mouth, may look blueish.

What to do:

- Plan frequent rest periods between activities if the shortness of breath is worse with movement, washing, dressing, or talking.
- If talking makes the person feel breathless, limit visits if that is what the person wants.
- Opening a window or turning on a fan that blows across the person's face may be helpful.
- Medication may help, ask your Community Care Team.
- Humidity may help to loosen and cough up the mucus.
- Help the person to a position that makes breathing easier. Lying flat often makes shortness of breath worse. Usually, a high sitting position is best. Put several pillows or a special seat support pillow at the back. Another helpful position involves leaning on a bed table or high table with the head resting on crossed arms.
- Try a recliner chair for sleep as it keeps the body in a semi-upright position.
- Whatever helps the person relax (i.e. relaxation exercises, music, etc.) may help ease tension and breathlessness.
- They may describe the breathlessness as chest pain. Always report this to the Community Care Team.

Skin Problems

When a person is seriously ill there may be changes in the skin that can be very uncomfortable, and lead to restlessness, anxiety, skin sores, and infection.

Itching

Itching is an unpleasant sensation that causes a desire to scratch or rub the skin. Scratching can cause bleeding and skin sores. Common causes of itching may be things like: dry skin, allergies, side effects of medications, some treatments, etc.

What to do:

- Check for areas that are red, rough, and flaky, especially at pressure areas (for example: tailbone, heels, and elbows).
- Observe for any widespread rashes.
- Report to your Community Care Team any itchiness that does not stop after two days; any change in the person's skin colour (i.e., yellow, grey), any areas that have been scratched and look raw; and/or any changes in the skin after treatments.
- If there is a sore that is getting larger or has any liquid draining or smells foul, report to your Community Care Team.

Hints to calm itching skin:

- Apply skin creams with a water-soluble base two to three times a day, especially after a bath when the skin is damp.
- Use warm water instead of hot for bathing, as hot water dries the skin.
- Add baking soda or bath oil to the bath water.
- Wash skin gently using a mild soap. Do not scrub.
- Use baking soda instead of deodorant under the arms.
- Keep nails clean and short.
- Choose loose clothing made of a soft fabric.
- Avoid scented and alcohol-based products on the skin.
- Use gentle laundry detergents.

Bed Sores (Pressure Sores)

A bed sore develops when blood flow to an area is stopped and the tissue in the area dies. Sores are made worse when a person is spending more time in bed causing pressure to certain areas, or when the person rubs against the sheets, or is pulled against the sheets, causing friction. Skin that is irritated because of contact with urine or bowel movements is at risk for breakdown. They are very difficult to heal in the seriously ill once they start. Pressure sores usually happen over bony areas.

Things to watch for:

- Red areas on the skin that do not go away.
- Cracked, blistered, scaly, or broken skin.
- Pain at the pressure points.
- Any staining on clothing or sheets that may indicate oozing from a sore.

What to do:

- Encourage the person to move about and help them change position in bed often.
- Protect pressure points with pillows.
- Ask advice from your Community Care Team about such things has heel pads and elbow pads.
- Check in your area with your Community Care Team about the availability of special mattresses that reduce pressure areas.
- Lift, rather than pull, the person when changing positions.
- Check the skin for any reddened areas. Keep the skin clean and dry.
- Massage the back and areas of pressure with lotion after each turn using soft pressure and moving your hands in a circular motion. A regular back rub promotes blood supply to bony areas and can be relaxing as well.
- Use pillows to support the person in different positions.
- As much as possible, keep the bed sheets dry and free of wrinkles.
- Change the bed immediately and clean the skin if the person has urine/bowel movement on the skin.
- If the seriously ill person is still eating, high protein foods will help nourish the skin.

Trouble Sleeping (Insomnia)

Insomnia may range from trouble sleeping to being fully awake. At one time or another, most people who are seriously ill have difficulty falling asleep or staying asleep. This can be caused by anxiety, fear, sadness, or other psychological or spiritual concerns.

Physical problems such as pain, nausea, vomiting, and coughing may cause insomnia, therefore it is important to give any medication prescribed for these things as directed. Advise the Community Care Team if the person becomes confused at night, and if the caregiver is not able to sleep at night and is becoming tired.

What to do:

- Allow the person to sleep whenever, and as much as needed, without staying to a schedule.
- Provide warm, non-caffeinated drinks such as warm milk with honey before sleep.
- Spend quiet times with the person, listening and talking.
- Try to make the person comfortable. Close contact such as holding a hand, sitting or lying nearby on the bed may give comfort and allow the caregiver to rest as well.
- Offer backrubs or massage the feet to help with relaxation.
- As much as possible, provide a quiet, peaceful area.
- Some people find various types of music helps.
- Ask your Community Care Team for advice.

Swelling (Edema)

Swelling happens when fluid builds up in the tissues of parts of the body such as legs and abdomen. This happens often in seriously ill people with advanced cancer, and end stage heart, lung, liver, and renal diseases. There are a number of reasons why this happens and the Community Care Team will decide the treatment depending on the cause.

Things to watch for:

- Feet and lower legs swell when the person sits, stands, or walks.
- Rings too tight for fingers or a tightness in the hands when making a fist.
- The abdomen looks distended or blown up. Pants feel tighter.
- Shortness of breath.
- Your fingers leave marks in the swollen area.
- Report to the Community Care Team if any of the above are present.

What to do:

- Follow any advice from the Community Care Team.
- Encourage bed rest with swollen feet elevated.
- If seated, keep the feet elevated on a pillow or stool, if tolerated.
- If the arms are swollen, rest them on a table, cushioned on a pillow, to elevate them.

Confusion

A person who has trouble thinking and acting appropriately or has disturbed thoughts is said to be confused. A person who is seriously ill may become confused due to the illness, infection, a side effect of medications, decreased fluids, or during the final days. Tell your Community Care Team if you notice the start of confusion and ask if anything can be tried to help.

What to know:

- Confusion starts very slowly and can look like poor concentration, being unable to make decisions, loss of memory, etc.
- The person may feel like they are losing their mind.
- A confused person may become restless and move about in a random fashion.
- Confusion and restlessness is sometimes thought to be pain.
- The person may hallucinate (see or hear things that are not real), particularly at night.
- The person may or may not be aware and disturbed by the confusion.
- Confusion may be expressed as fear or anger.
- Confusion may move slowly or very quickly.

What to do:

- Watch carefully and protect the person from harm.
- Quietly remind the person who you are whenever necessary.

- Talk slowly and quietly.
- Turn off radio and television if making confusion worse.
- Be aware that trying to correct the confusion or hallucinations may cause more agitation.
- Make your Community Care Team aware if you think the person is becoming confused.

Section Appendix

Mouth Care

PHYSICAL WELLNESS HANDOUT

A seriously ill person may need help to keep their mouth clean because they cannot do it themselves. It is essential to do this because it reduces the risk of infections in their mouth. A healthy mouth has an intact lining and is clean, moist, and pain-free. An unhealthy mouth can be very sore, dry, or infected. It can significantly impact the quality of life of someone who is seriously ill, making it difficult for them to eat or drink or communicate with others.

Who can provide mouth care?

Anyone, including family and caregivers, can perform mouth care. If you are caring for someone who is seriously ill, providing mouth care can be essential to making sure they are comfortable, and it can also help to keep you involved in their care.

How to provide mouth care

When providing mouth care, do so at least twice a day, or more often if necessary. It is important to check for redness, swelling, sores, white patches, bleeding, pain, or dryness. Tell a member of your Community Care Team if there are any changes.

Cleaning the person's mouth

Before you start, ensure the person is sitting up or lying on their side – this protects their airway. Wash your hands well before and after giving mouth care.

Avoid over-the-counter mouthwashes containing alcohol as they can further dry the mouth. Three make-at-home mouthwash recipes are listed in the table below (also depicted and detailed on page 39: of Preparing for the Journey: Caring for Indigenous People who are Seriously Ill):

Recipe 1	Recipe 2	Recipe 3
Combine: 4 cups of water 1 teaspoon of baking soda 1 teaspoon of salt	Combine: 1 ounce of ginger ale 2 teaspoons of baking soda	Combine: Cedar greenery Boiling water

Brushing teeth and denture care are also important mouth care routines. Most people prefer, while they are able, to care for their teeth and dentures. As the seriously ill person weakens and cannot raise their head, family or the caregiver will assist. *Preparing for the Journey: Caring for Indigenous People who are Seriously Ill* has more details on how to provide this help for your loved one.

For more information about mouth care, please read the section on Mouth Care in Preparing for the Journey: Caring for Indigenous People who are Seriously Ill.

Food for Thought: *If your loved one isn't eating*[1]

LAST DAYS AND HOURS HANDOUT

An adaptation of the pamphlet developed by The Palliative Pain and Symptom Management Program

When the body is dying, all the organs begin to shut down and work less and less effectively; the heart, brain, liver, kidneys, and skin are less and less able to perform their functions. The digestive system also becomes disabled, often to the point where food just cannot be digested. The seriously ill person will lose their appetite and may be troubled with nausea and vomiting when encouraged to eat. ***This is the body's way of showing that food is no longer necessary.***

It's a natural process. Not eating is a normal part of dying, and there are definite advantages to little or no food intake as death approaches. This is nature's way of leading to a peaceful death.

Benefits to Not Eating

- When fluid/food intake is reduced, the tissues become dryer and shrink. This means that if a tumour is present, there is less pressure on/from the tumour. The tumour itself may become smaller, and the need for pain medication may also be less.
- Swelling of the feet, legs and other tissues will be reduced. If fluid has accumulated in the abdomen, comfort will be promoted as there will be less pressure on the organs; breathing may also be easier.
- Because your loved one will drink less, they will not need to use the bathroom as often, saving the body energy. If bladder control is a problem, it means less incontinence and a greater sense of dignity.
- Your loved one may have less fluid in their lungs toward the end of life. This will make it more comfortable to breathe.
- If they were having difficulty swallowing, they may need less help clearing the fluid (i.e. less suctioning). With less fluid in the lungs, the sensation of drowning is minimized.
- Your loved one may also have less nausea and vomiting after they stop eating.
- When a person stops eating, they may experience a feeling of euphoria or well-being. This is the body's way of reducing the person's anxiety in the face of coming death.

There are some disadvantages too

Your loved one will not feel hungry, but they may feel thirsty when they first stop eating. You can help them feel more comfortable by giving them a sip of water, ice chips to suck on, or a hard candy. The thirst usually disappears after the first few days. ***See "Personal Care – Practical Considerations" in Preparing for the Journey: Caring for Indigenous People who are Seriously Ill.***

Using a feeding tube or IV fluids (artificial feeding) can keep a person alive for a long time, but they can also cause complications that can actually shorten the life span.

Things to consider

Is the dying person able to make their own decisions? If not, do they have a Power of Attorney for Personal Care? Have they expressed any wishes about feeding at the end of life?

Artificial feeding is a medical treatment like any other. People who are seriously ill are legally and ethically allowed to decline medical treatments, and others must respect this decision[2].

See the "Making Your Wishes Known" section of Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill for more information.

What are your feelings?

Feeling emotional and overwhelmed about a loved one not eating or drinking is normal, and there are valid reasons why you feel this way.

Often people think of food as a basic necessity of life, and we equate it with love and view a good appetite as a sign of good health. Many traditions and social gatherings involve eating and drinking.

You may feel guilty for not providing for them and be afraid that others will see you as uncaring.

You may not know what to do if you are not offering food. You may feel a conflict between yourself and your loved one if your efforts to encourage eating are unsuccessful. You may also feel conflict with other caregivers if their efforts are unsuccessful. You may lose your sense of hope as you see your loved one slipping away, leaving you powerless to stop it. You may fear that your loved one will be abandoned.

What can you do?

***Avoid conflict** by supporting your loved one's decision.*

***Discuss your feelings** with others*

*Try and **make your remaining time with your loved one meaningful** by talking, holding hands, giving back rubs, massaging their feet, playing cards or games they like, sharing stories and reminiscing, looking at photo albums, reading or singing to your loved one, helping keep their mouth moist, or doing something with him that they enjoy. Continuing to spend quality time with your loved one will show them how much you care and that they are loved.*

To learn more about food and fluids, giving help with eating, reduced fluid intake, and increasing weakness, please read pages **63-65** of Preparing for the Journey: Caring for Indigenous People who are Seriously Ill.

How long can someone live without food or water?[2]

It depends. Estimating how long someone may live is very difficult because every situation is different. People's illnesses progress at their own unique pace, and everyone responds to illness and treatment differently.

Our bodies can sustain themselves on the energy from food stored in the body for weeks, but the effects of dehydration happen much more quickly. When a person who is seriously ill is bedridden and stops taking fluids, this person may live as little as a few days or as long as a couple of weeks.

As the normal dying process continues, the body systems start to shut down; the person loses their sense of hunger, thirst, and ability to swallow safely. *Death may be days or hours away.*

Suppose a seriously ill person is on life-sustaining treatments like artificial feeding or intravenous fluids and decides to stop. In that case, their remaining time will depend on how sick they are and if they are experiencing complications like pneumonia. Sometimes, the hydration they receive from a caregiver helping them keep their mouth moist can extend their life. Some people believe that a person's will to live also affects how they experience illness and how long they will live.

All these variables make it difficult to accurately predict when a person's condition will change suddenly. It is therefore important to have conversations about care decisions and wishes before the seriously ill person becomes too weak to do so.

[1] The Palliative Pain and Symptom Management Program. (n.d.). *Food for Thought: If your loved one isn't eating.* Thunder Bay, ON | [2] Canadian Virtual Hospice. (2022). *How long can someone live without food or water?.* https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Asked+and+Answered/Nutrition/How+long+can+someone+live+without+food+or+water_.aspx

Imagery, Isometric, and Rhythmic Breathing Exercies Guides[17]

The following exercises are an adaptation of the National Cancer Institute's "How to Relax Your Mind and Body."

Imagery Exercise

An imagery exercise is something that a person can use to help relax and make positive changes in their life. It helps to deal with anger, stress, anxiety, and can help with sleep and confidence. It is easy to do and can be done in any location, alone or with others, and can be done in a couple of minutes.

The Ball of Healing Energy

1. Close your eyes. Breathe slowly and feel yourself relax.
2. Concentrate on your breathing. Breathe slowly and comfortably from your abdomen. As you breathe in, say silently and slowly to yourself "In, one, two" and "Out, one, two." Breathe in this slow rhythym for a few minutes.
3. Imagine a ball of healing energy, perhaps a white light, forming somewhere in your body. Imagine it taking shape.
4. When you are ready, imagine that the air you breathe in blows this healing ball of energy to any part of your body where you feel pain and discomfort.
5. Continue to breathe naturally and when you breathe out, picture the air moving the ball away from the body, taking with it the pain or discomfort and tension.
6. Continue to picture the ball moving toward you and away each time you breathe in and out.
7. Imagine the ball gets bigger and bigger as it takes more and more discomfort and tension away.
8. When you are ready to end the imagery, count slowly to three, breathe in deeply and open your eyes.

Isometric Exercise

1. Close your eyes. Breathe slowly and relax.
2. Continue breathing naturally while you tense your toes, hold for ten seconds and then release.
3. Next, tense your feet, hold for ten seconds, then release.
4. Next, tense the calf muscles, hold for ten, and then release.
5. Continue this from toe to head and head to toe:
   - calf muscles
   - thigh muscles
   - buttocks
   - stomach
   - arms
   - shoulders
   - fingers
   - neck
   - face
6. After the process is complete, ask the person to determine if any part of their body remains tense and if so, concentrate on relaxing that part by tensing once more.

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[17] National Cancer Institute. (2024, April 11). How to relax your mind and body. U.S. Department of Health and Human Services. https://www.cancer.gov/about-cancer/coping/feelings/relaxation

Rhythmic Breathing Exercise[18]

1. Stare at an object, or close your eyes and concentrate on your breathing or on a peaceful scene.
2. Take a slow, deep breath and, as you breathe in, tense your muscles (such as your arms).
3. As you breathe out, relax and feel the tension draining.
4. Now, remain relaxed and begin breathing slowly and comfortably, concentrating on your breathing, taking about six to nine breaths a minute. Do not breathe too deeply.
5. To maintain a slow, even rhythm as you breathe out, you can say silently to yourself, “In, one, two and “Out, one, two.” It may be helpful at first if someone counts out loud for you.

   If you ever feel out of breath, take a deep breath and then continue the slow breathing exercise. Each time you breathe out, feel yourself relaxing and going limp.

   If some muscles are not relaxed, such as your shoulders, tense them as you breathe in and relax them as you breathe out.

   You should only need to do this once for each specific muscle.
6. Continue slow rhythmic breathing for a few seconds up to 10 minutes depending on your need.
7. To end your slow, rhythmic breathing, count silently and slowly from one to three. Breathe in deeply at the count of three. Open your eyes. Say silently to yourself: “I feel alert and relaxed.” Begin moving slowly.

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[18] National Cancer Institute. (2024, April 11). How to relax your mind and body. U.S. Department of Health and Human Services. https://www.cancer.gov/about-cancer/coping/feelings/relaxation

LAST WEEKS OR DAYS OF LIFE

> **“I am a believer [that] if you understand, you cope better. So, if you understand the whole process, you are going to cope better with it and you will recognize and identify your needs better. Whether you are the caregiver or whether you are the person who has got the terminal illness.” [19]**

No matter how much we prepare for, and no matter what we expect, the moment that someone passes will arrive in its own time and in its own way. The experience of dying is different for every person and for every family. It is important that you do whatever you and the family feel will help during this final stage. The following information may help.

Signs that the End of Life is Near

As the person’s condition worsens, and end of life is becoming closer there will be some changes.

- The person’s ability to think and respond clearly can be affected. Simple directions may be misunderstood.
- Sometimes people seem to be confused or to hallucinate. They experience a reality different from ours, often seeing or hearing people who are not physically present and usually feel quite comforted by this.
- Changes may be due to a number of things. Most often the reason for this is the disease produces chemicals that affect how the brain works. As end-of-life approaches, the ability to think and communicate weakens and eventually stops.

You may notice that the person:

- Becomes restless, excited, or irritable at times for no apparent reason.
- Is easily distracted and is unable to follow simple directions, think clearly or communicate.
- Is unable to remember things or recognize familiar people or objects.
- Seems drowsy all the time and falls asleep even when you are talking.
- Is more difficult to arouse or wake up.

Some things that you can do:

- Sit quietly to provide a comforting presence.
- Reduce confusion by limiting distractions such as television, radio, or too many visitors.
- Gently bring the person to reality with reminders about where they are, who you are, what time it is, etc.

[19] Improving End of Life Care in First Nations Communities Research Team, Lakehead University. (2015). *Developing Palliative Care Programs in First Nations Communities: A Workbook.* Retrieved from https://eolfn.lakeheadu.ca

- Do not argue if the person's reality is different. Sometimes going along with someone who seems mildly confused allows the situation to pass without upset.
- Quietly listen to the person, who may need to express some thoughts, worries, or feelings. Get close and talk gently.
- If it is okay with the person you are caring for, the use of touch to connect with someone who is unable to respond may be helpful to let them know you are there. Soft music may be relaxing. Assume the person can hear everything you say on some level.
- Talk to the Community Care Team about relaxation techniques for the person, yourself, and family members.

Sleeping:

The person may spend more and more time sleeping and it may be harder and harder to wake up the person. This is a normal body change.

- **Help by:** Sit with the person; hold their hand, but do not shake it or speak loudly, speak softly and naturally. Spend time with the person at times when they are more alert or awake. Avoid speaking about the person in their presence. Speak to them directly even if there is no response. Never assume that they cannot hear; hearing is the last sense to be lost.

Confusion:

The person may seem confused about the time, place, and identity of people around him, including close and familiar people. This is also due in part to body changes.

- **Help by:** Identify yourself before you speak, rather than asking the person to guess who you are. Speak softly and clearly.

Restlessness:

The person may make restless, repetitive movements such as pulling at the bed linen or clothing. This may be due to less oxygen going to the brain.

- **Help by:** Don't interfere with or try to restrain these movements. Speak quietly and naturally; lightly massage the forehead; read to the person or play soothing music.

Eating and Drinking Less:

Although this is a normal part of the dying process, it is often a difficult time for family and friends. It is important to talk about feelings and fears.

Do not force the person to take food or fluids. The body prepares naturally for end of life with the organs shutting down and not working well.

- **Help by:** Feeding them may increase the person's discomfort. Keep them comfortable by giving them the food and fluids they want and keeping their mouth moist with gentle mouth care. Hunger is rarely felt. The natural processes respond to taking in fewer fluids by the person having fewer problems with swelling, congestion, and the need to get up to go to the bathroom.

Additional Resources in the *Physical Wellness* Section Appendix

* *Food for Thought Handout*

Coolness:

The hands, arms, feet and then legs may become cooler to the touch. The face may be pale, and the feet and legs a purple-blue mottle colour. This indicates that the blood flow is decreasing to the body's extremities and is being saved for the most important organs.

- **Help by:** Keep the person warm with blankets, using just enough to keep them comfortable. Avoid using an electric blanket.

Loss of control of bladder and bowels:

The person may lose control of their bladder and bowels as the muscles in these areas begin to relax when end of life is very near. The person may not be able to pass their urine. This may cause agitation and pain for the person.

- **Help by:** Find out about appropriate padding, and/or use of an incontinence product. Talk to the health care provider about possible ways to help a person pass urine, such as a catheter.

Congestion:

There may be loud gurgling sounds coming from the person's throat or chest. This is because the person is unable to swallow saliva and does not mean that they are uncomfortable.

- **Help by:** Avoid suctioning, as this may cause sharp discomfort. Turn the person's head to the side and allow gravity to drain the saliva. You can wipe the mouth with a moist cloth. Positioning to the left side is also helpful for the body's natural flow of fluids.

Changes in Breathing Pattern:

Breathing may be irregular and may stop for 10 to 30 second periods (Chayne-Stokes respirations). They may experience periods of rapid, shallow pant-like breathing. After someone dies, there may be a "last sigh" or gurgling sound. These common patterns are due to decreased blood flow to the internal organs.

- **Help by:** Raising the head of the bed or turning the person to the side. Hold the person's hand and speak softly. Note if the person is comfortable by how they look, facial expressions, and movements in the bed.

Decreased Urine:

Urine output normally decreases and may become tea coloured or concentrated. This is due to the decreased fluid intake as well as a decrease in blood flow to the kidneys.

- **Help by:** Ask your Community Care Team if anything needs to be done.

Withdrawal:

The person may seem unresponsive, withdrawn or in a comatose-like state. This shows preparation for release, and the beginning of letting go.

- **Help by:** Since hearing remains all the way to the end, speak to the person in a normal tone; identify yourself by name when you speak; hold the person's hand; say whatever you need that will help them to let go.

Decreased Socialization:

The person may want to be with just a few or only one person. This is a sign of preparation for release. If you are not part of this, it doesn't mean you are not valued or are unimportant. It means you have already fulfilled your task with the person; it is time for you to take leave and let go.

Vision-Like Experiences:

The person may speak or claim to have spoken to a person already dead, or to see places/people not visible to you. This isn't a drug reaction or hallucination. The person is detaching from this life, and is getting prepared for the transition, so it will not be frightening.

- **Help by:** Accept what the person is saying. Avoid explaining away or arguing. The experience is real to the person and is normal and common.

Protocols for End of Life

The palliative approach to care encourages people to honour and respect people's wishes. Many people want the opportunity to receive care in their communities and spend the final days in their home. Just as planning for a person's care throughout their illness is important, having protocols in place for knowing what happens at the end of life, are also important. These help caregivers and family members to know what to expect when someone is going to pass away in the home. It also provides opportunities for individuals and families to discuss what happens after the person passes. This may include deciding upon whether or not to make funeral arrangements ahead of time, or not.

Helpful questions to guide this discussion:

- What kind of service or ceremonies did the person want/does the family want?
- Where and when will it take place?
- Who will do the service? Elder? Priest? Friend?
- Who will be notified?
- Who will do the notifying?
- Will people come from out of town? Do they have a place to stay?
- Does the person want to be buried or cremated, based on their wishes and Indigenous beliefs?
- Where will the burial take place?
- If cremated, where will the ashes be kept?
- Find out who to call when the person dies. The visiting nurse will get direction from the most responsible health care provider concerning pronouncement. It is important to talk about who will pronounce the person and sign the death certificate before death occurs. It is not necessary to call the ambulance or the police.

Having these discussions will help in the following ways:

- Ensures that the person's wishes are known and respected.
- Reduces the number of decisions that will need to be made right after the person passes.
- Provides an opportunity to talk about arrangements, concerns and feelings.
- Allows for affairs to be in order for those left behind.
- Reduces family stress during the early time of grief.

How You Will Know When Death Has Happened

- The person will be entirely unresponsive.
- They will not be breathing.
- The pulse and heartbeat will stop.
- The person's eyes will be fixed in one direction; they may be opened or closed.
- Loss of control of bladder or bowel may occur.
- There will be no movement.
- The person's mouth may be open, and their jaw may be slack.
- There will be no pain.

What to Do When Death Has Happened

- Remain calm.
- Allow tears and feelings to come.
- Breathe deeply and encourage everyone to do the same.
- Allow everyone to be in physical contact with others, i.e., hug, hold hands, or link arms.
- Gather around the person to send blessings and love, in silence, or speaking aloud.
- Ceremonies or prayers according to tradition.
- Know that there is no right or wrong way to be at this time. Do what you feel is right for you and not what you may feel is expected of you. Reassure the family they can do whatever feels right for them.
- Call family and health care providers according to the plan.
- Do not call 911, the police, or the fire department. These calls are not necessary when the death is expected.
- **Call the person who will pronounce the death.** It is important to talk about who will pronounce the death and sign the death certificate before death occurs.
- Allow everyone as much time as they need to take leave and let go. For some this may be hours, while others may not wish to stay. You or family members may want to wash and dress the person, and attend to any rituals that are important to the family.
- Do not be afraid to touch, hug, or kiss the person. Of note in some Indigenous communities is the thought that touching the person after they have died slows their journey to the Creator. Please be aware that others may have needs which are different from yours; be sensitive to and supportive of their special concerns.
- Crying is a personal reaction. For some this is a natural reaction to grief. Others may internalize their feelings and may not be able to cry. This doesn't mean that one grieves more than the other; both reactions are normal.
- **Prayer:** For some, prayers are very important, but unnecessary for others. Be guided by your inner self and do what is right for you.
- **Cultural rituals:** It may be necessary for you to attend to special cultural ceremonies or prayers according to tradition at this time.
- **Spirituality:** For some this is very important, while others may have a lesser need. Talk to the advisor of your choice.

Caring for Yourself

Seeing a community member dying can be very tiring, both emotionally and physically. If the process is a long one, you are at risk of becoming mentally and physically exhausted. Please know that your well-being is just as important as that of the dying person. In fact, one of the best things you can do is to make sure that you are caring for yourself. Both you and the dying person may experience feelings of frustration, guilt, sadness or anger. These emotions are common and normal. They occur in response to the losses you are now experiencing.

Help by paying careful attention to your needs:

- REST: Sleep may not come easily but do try to get adequate rest.
- Nutrition: While you may not feel like eating, do attend to your nutritional needs.
- Time for Yourself: Time away from the person you are caring for is essential if you are to avoid mental exhaustion. Ask other family members or friends to stay with the person to give you an opportunity to re-energize.

Remember that there is no perfect way to care.
Be guided by your love for the person.

CONCLUSION

> **“...cause like when you hold their hand or you, and you’re just touching their hand while they’re asleep, they are more calm, like you can see it in their breathing, they’re more relaxed cause, my sister used to look up, I said I’m not going anywhere, I’m staying right here.”** [20]

The purpose of *Preparing for the Journey: Caring for Indigenous Peoples who are Seriously Ill* is to help build and enhance capacity in Indigenous communities to care for community members. The resource manual provides practice guidance and support in caring for people with serious illnesses. It is based on clinical best practices from a palliative approach to care, grounded within the Indigenous Wellness Framework. The goal of the resource manual is to provide effective and culturally appropriate home care services that will assist individuals to remain home in the community to receive end of life care if that is their wish.

Indigenous communities are encouraged to use this manual in any way they feel would benefit community members who are seriously ill and their caregivers. We encouraged people to photocopy and share any part of this resource manual and use the information in any way that is helpful to them.

[20] Improving End of Life Care in First Nations Communities Research Team, Lakehead University. (2015). *Developing Palliative Care Programs in First Nations Communities: A Workbook.* Retrieved from https://eolfn.lakeheadu.ca

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