

Understanding the Diagnosis for Patients and Caregivers

This section provides information and resources that can be used by caregivers to assist them in caring for their loved ones.

What is Palliative Care?

The goal of palliative care is to promote comfort and ease the suffering of our loved ones in the final stages of illness. The term 'palliative' means: making the effects or symptoms less severe or unpleasant; to ease, relieve or soothe. To First Nations, Inuit and Métis people, palliative care means comfort care that is kind and compassionate, given with understanding and respect to relieve a person's pain and symptoms and promote the best quality of life possible. It should honour the person's spiritual beliefs and customs. It should care for the whole person and support their family.

What is a Caregiver?

A caregiver is anyone who looks after and provides direct care for a loved one in need. If your loved one - partner, family member or friend – has been diagnosed with advanced cancer or another terminal illness, you might be taking on the role of 'caregiver'.

The role of a caregiver

As a caregiver, you are an important part of the healthcare team. It is a big job. It is important to know what you are getting into. You may be involved with:

- visits to the doctor and other medical appointments
- reporting and/or managing pain, symptoms and side effects of medication
- keeping family and friends informed
- coordinating care of your loved one
- administering medication
- keeping track of medicines, test results and papers
- physical care of your loved one including feeding, dressing and bathing
- legal and financial issues

Emotional Support

Being a caregiver also includes giving emotional support, such as helping your loved one deal with their feelings and make difficult decisions.

Challenges Caregivers Face

It is normal to be uncomfortable with the idea of giving medicines, giving physical care (such as helping your loved one to the bathroom), or maybe you are worried about juggling the responsibilities you already have at home or work with this new role.

If you are feeling pressured into becoming a caregiver, it is best to be honest about how you feel. Respect and speak up for your own feelings, needs and desires, as well as those of your loved one. Decide your limits and let others know so that both you and your loved one get the help you need.

If you talk about it, you can usually work something out. The healthcare team can provide lots of guidance on medicine, or maybe someone else can act as the main caregiver or share the responsibilities with you.

Planning for Comfort Care at Home

If you are planning to bring your loved one home, it is a good idea to talk to as many of the people involved in your loved one's care as possible. Each specialist and care provider has their own techniques and ways of providing comfort care that you might want to adapt to your care methods.

The following information provides a basic overview of what is involved in providing palliative care to someone at home or in another care setting.

Physical Caregiving: Overview

The following basic caregiving information is designed for those who are caring for their loved one at home. If your loved one remains in or is moved to a hospital or other care setting, most of their care will be provided by health professionals, however you can still play a role in comforting your loved one and assisting in their care.

NOTE: The following information is a general overview only and must not be used in place of any medical advice or instructions provided by your doctors or nursing care providers.

1. Equipment

Hospital Beds

Your loved one will be spending a lot of time in bed so it should be as comfortable as possible. Ask your health care worker if they can assist with obtaining a hospital bed. Hospital beds are adjustable at the head and foot, and can be raised, lowered or rolled up to a sitting position for eating, reading or other activities. Hospital beds also have side rails for safety.

Side Rails and Safety

Side rails can be raised on one side while you are tending to your loved one, for example bathing them in bed. This can help prevent them from falling.

Keep the side rails up on both sides if your loved one is agitated or is not fully conscious. Although side rails are sometimes considered 'restraints', it is very important to prevent falls. Ask the health care professionals for their advice if you have any concerns about this.

Mattress, Sheets and Blankets

To make the bed more comfortable you may want to substitute the regular mattress with an alternating pressure air mattress. These can be rented but may be expensive; ask your health care worker for advice on how to access the.

Another idea for making the bed more comfortable is to put a natural or synthetic sheepskin blanket or foam rubber mattress (also called 'egg crate mattresses') on top of the mattress. These are comfortable and inexpensive. Pillows of various sizes are also recommended for supporting the body and decreasing pressure on bony prominences (parts of the body such as elbows, heels, ankles, hips). This helps to reduce the chance of developing pressure ulcers.

Sheets should be soft (cotton), clean and well fitted. Wrinkles in sheets cause skin irritation, and within a short amount of time can cause skin to break down. Note that some blankets may be too heavy for them at this time; people often prefer a lighter weight blanket, which can be just as warm.

Draw Sheet

A 'draw sheet' (or lifting sheet) is a sheet or pad folded in half and put mid-way on the bed. It is used to re-position the person when they cannot move themselves. One person on each side of the bed holds the lifter sheet and together they lift the person towards the head of the bed so that when they sit up, they will be in the right position to eat, drink or read etc. It can also be used to help turn the person more comfortably from side to side if they cannot turn themselves. Draw sheets can also protect the sheets from getting soiled.

Chairs

Recliner (Geri) chairs are a good alternative to being in bed constantly and they can be wheeled to various locations around the house. Add cushions, pads and pillows for more comfort. Glider chairs are also very comfortable.

Equipment Safety

The following are some general tips for safe use of equipment:

- Ensure that the wheels on the bed and chair(s) are locked before providing bedside care or transferring the person to or from the bed or chair. This will prevent accidents and caregiver's back strain
- If the person is using oxygen, make sure the bed is away from wood-burning stoves or open fireplaces. There must be no smoking in the room
- Arrange furniture so that:
 - you and another caregiver have room to work around the bed
 - there is a hazard-free path to the bathroom that your loved one can access with a walker or wheel chair. Remove area or throw rugs that may pose a hazard

2. Infection Control and Prevention (Universal Precautions)

These guidelines are in place to protect you and your loved one from transferring (and picking up) bacterial germs. As your loved one is in a fragile state of health, it is important to protect them, and equally important to protect yourself from cross-infection or contamination. For more information, go to the World Health Organization:

http://www.who.int/csr/resources/publications/4EPR_AM2.pdf

Below are the basic universal precautions that apply in all health care situations:

- The most effective way of preventing the spread of infection is by washing your hands.
- Dispose of contaminated objects (dirty dressings or anything with blood or bodily fluids) in two (2) plastic bags and always wear disposable gloves when providing such care.
- Wear a disposable apron if providing care when your clothes are likely to get soiled.
- Wear a mask if you have a cold.
- Dispose of needles and syringes in a 'sharps' container or metal container and when almost full, seal it with tape so nothing can fall out. Dispose of this as per instructions from the health care team of professionals.
- Take care when preparing food – follow the Food Handler's Guidelines. Go to: <http://www1.toronto.ca/wps/portal/contentonly?vgnextoid=fb03ebfc2bb31410VgnVC M10000071d60f89RCRD>

- Ensure that any pets near your loved one are healthy. They should be up-to-date with their shots. Wash your hands after handling them or cleaning their cages, litter boxes, etc.

All medical devices that come in contact with the body must be kept clean in order to prevent infection. These may include a urinary catheter, feeding tube, suction tube, tracheostomy, oxygen masks, nasal prongs, nebulizers and more. Health care professionals will provide you with training on protocols (best practices) for their use and care and how often they should be replaced.

3. Daily Care

Once the person wakes, 'toilet' them by whatever means they are used to, e.g. walk them to the bathroom with their walker, on a commode or shower chair. Provide a quick hands and face wash.

Have the person sit up as high as possible to eat. Provide breakfast and feed them as needed. They may need a rest between eating and the bed bath as they tire easily.

Mouth Care

Individuals who are in a weakened state may not be able to brush their teeth as before, or take care of their dentures. It is important to do this for the person 2 to 3 times per day to prevent bacterial buildup and promote a more pleasant eating experience for them.

- Sit the person up unless they cannot, then lie them on their side
- Wash your hands
- Collect: soft toothbrush or toothettes, basin, towel, rinsing solution (not toothpaste)
- Brush their teeth from the gum line to edge of tooth, removing all particles. Look for ulcers in the mouth, bleeding gums
- For an unconscious person: Rinse the inside of the mouth every 2 hours using a sterile gauze and a non-alcohol based product for this purpose or a home-made baking soda solution.

Denture Care

- At night, clean dentures then soak overnight in a commercial product for dentures. During the day, clean dentures in cool water with a toothbrush after each meal
- Poorly fitting dentures can cause mouth sores. Have them refitted, or if this is not an option, leave them out except when eating
- Use a commercial produce to relieve dryness under the dentures

Lip Care

- Put a water-soluble lubricant on the lips. Do not use oil-based products such as Vaseline, Chap-stick or mineral oil. These products irritate open sores on lips, and on an unconscious person, may be breathed into the lungs, causing pneumonia.

Skin Care

As people age, skin becomes papery thin and vulnerable to break down for many reasons: poor nutrition, poor blood circulation, pressure or 'shearing' on bony prominences on mattresses causing breakdown; the skin not being kept clean and free of urine or feces, irritating soaps not being rinsed off the skin, the person not being turned and positioned frequently enough, the aging process in general. Good skin care helps keep skin intact and reduces the chance of infection and breakdown.

The Bed Bath

NOTE: About a half hour before the bath, give pain medications to promote comfort during the bath.

A bed bath can promote relaxation and sleep, stimulate blood circulation and, as well as provide good skin care. This is the time to assess the person's skin for potential pressure ulcers, bruises or any other abnormality. If there is a dressing, it is usually changed at this time. If the person requires a suppository or enema, it is done before the bath.

Collect all the supplies for the bed bath, dressing change and linen change.

Start with a basin of warm water, soap, wash cloths, towels, shampoo, mouth care products – lemon swabs, skin moisturizer/medicated creams, clean linen for the bed (upper and lower sheets, pillow cases, draw sheet), incontinence products, wound care (dressing) supplies, garbage bag and an extra chair to put everything on.

If you and other people are rotating caregivers, it may be helpful to work together on doing the bed bath *before* the other caregiver goes home. This makes it easier for you both.

The following steps can be followed:

1. Place your loved one on their back, with the bed flat, or raised to a comfortable level if they have difficulty breathing
2. When incontinence occurs (loss of control of bowel or bladder), change the incontinence pad (diaper) as soon as possible to prevent skin irritation; wash the genital and rectal area. Change the water as needed throughout the bath

3. Add an oatmeal-based skin care product or prescribed medicated soap to a basin of warm (not hot) water
 4. Keep the person mostly covered and warm with a sheet or towels, until you want to wash that part, then rinse and pat dry and cover up that area
 5. Start at the head and work your way down: wash the face and eyes, from inner to outer corners. If there is an eye infection, use a clean washcloth for each eye so as not to infect the clear eye
 6. Assess each body part as you bath the person: check for any bleeding from the mouth, ears, nose, dry cracked skin, reddened areas due to pressure
 7. Look for signs of edema (swelling) anywhere in the body
 8. Wash the neck and top of body. Wash arms and underarms, rinse and pat dry
 9. Wash the person's legs and feet completely, rinse, pat dry
 10. Wash the genital area
 11. Turn the person over and wash their back and rectal area. This area is washed last so as not to transfer germs to other parts of the body. The genital and rectal area is prone to skin breakdown due to incontinence; urine and feces are acidic and if left on skin, even for short periods, causes burning and skin break down
 12. Wash this area each time the person is incontinent, which may be every hour or two. Apply a barrier cream or prescribed medicated cream at each change
 13. Take this opportunity to give your loved one a backrub while applying moisturizer lotion
 14. Apply moisturizer lotion to the entire body. Massage limbs, applying gentle pressure from the distal parts (hands and feet) and moving towards the centre of the body. This increases circulation and completes skin care
 15. Plan to do dressing changes when the person is lying in the correct (convenient) position for them to be done. Less turning means less pain
- After completing the bed bath, change the bed.

Catheter Care

- If the person has an 'indwelling' urinary (foley) catheter, the point of entry into the body needs to be cleaned at least daily. With a sterile gauze or swab and normal saline solution, cleans around the tubing where it enters the body. Not doing this can result in bacteria entering the body and an infection developing
- Check the skin looking for blood, signs of infection or debris such as feces
- Check to make sure urine is running freely into the bag (and the person is not lying on top of the tubing)
- Check the urine for colour, odour and amount. The drainage bag should not be sitting on the floor. Empty it at the beginning and end of your shift, noting the amount of output. The tubing and drainage bag must be changed regularly (at least every 3-4 days) to prevent

bacteria from building and travelling back up into the bladder and causing a urinary tract infection). Write the date on the bag

- If the person has a condom catheter, remove it every day, wash the penis and re-apply a new condom, or wait a few hours before re-applying. Note the condition of the skin and report any problems to a health care provider if one is available

If the person has an IV

- Check the site to see if it is swollen, hard, red or bleeding, warm or cold to touch
- Check whether the IV fluid is going into the vein properly or if there is liquid running out of the IV (at the point of insertion)
- Check whether the skin is puffy and weepy at the IV site: this indicates that the IV is no longer in the vein but is in the interstitial spaces – this can cause tissue damage
- Write the date on the IV tubing (a piece of tape) as it needs to be changed every other day

Administering Enemas

Warm the enema bottle in a basin of hot water, ensuring that the temperature is warm, not hot when given. Put a pad under the person and place him/her on their *left* side. Administer the solution slowly into the rectum. Have a ‘slipper’ bed pan ready for use. Put the narrow end of the pan closer to their back for comfort. Have them wait as long as possible before sitting on the pan.

4. Body Mechanics

When providing palliative care, it is important to use proper body mechanics. This will make the work of lifting, repositioning and transferring your loved one more comfortable for him or her, and safer for you.

Changing a bed with the person in it

(If possible, make the bed when the person is out of bed, for their comfort as well as it being easier for you.

- If the person cannot get out of bed, place them on their side
- Loosen sheets beneath the person and roll them up as close to the person as possible
- Take the clean sheet and under pad and/or draw sheet and, with them folded in half, place the first half at the center line (at the person’s back (also all rolled up)
- Straighten out the rest of the bottom sheets
- Raise the bedside rail
- Turn the person to the other side (using the leg and arm-over technique), rolling them over the lump of sheets

- Remove the old sheets and under pads
- Straighten out the clean sheet and draw sheet or under pad and tuck in all around the bed

Turning and Repositioning

To prevent pressure areas from developing and to promote comfort, turn and reposition your loved one every two hours.

- Position the person on one side using pillows to support their back, leg, arm and head, alternating from one side, to their back, and to the other side every two hours at least
- If they have a foley catheter, rotate it and the tubing as well, checking that they are not lying on top of it and that it is in position to drain (with gravity)
- Put a pillow between the knees and also under legs and feet to reduce 'edema' (swelling). A pillow or stuffed animal under the upper arm is also comfortable
- Put the head of the bed at about 30 degrees (less than half-way up) to help with breathing. Cover the person with a sheet and blanket – tucked in loosely
- When turning your loved one, check the pressure points – the shoulder, hip, knees and ankles for redness. If red, massage gently around those areas, but not directly over them. They should return to normal colour, but if they remain red, damage has already begun. The person will need to be turned and positioned more frequently
- Note all observations in a journal or written record

5. Daily Monitoring

The following are some things to check regularly in caring for your loved one:

- When you first see your loved one in the morning (or whenever you come to give care), ask the person leaving about any important events that you should be aware of. If no one is there, refer to the journal or written record/communication book for any reported information on how your loved one was during the night.
- If the person has a dressing, check to make sure there is no bleeding underneath them (hemorrhage). Finally, check to see if their incontinence pad (diaper) is clean and dry. Keep notes on how often dressings are changed and how the wound looks. Know the signs of infection (redness, swelling, yellow discharge, pain, hot) and report as soon as they appear.
- Observe the person and make notes on their colour, breathing, and general appearance. If you are still taking vital signs, take the temperature, pulse, blood pressure and count the respirations for one minute. Look for signs of pain and ask them if they are in pain, if they can answer.
- Also check the feet for CSM (colour, sensitivity, movement):

- Colour: Is the skin on toes and feet a normal colour (if bluish it could mean poor circulation; if black it could mean necrosis)
- Sensitivity: Does the person feel sensation (to touch) in their feet; do their feet feel hot or cold to them; do they feel hot or cold to you
- Movement: Can the person move their toes or feet; is the skin on feet intact or are there ulcerations

All of these things you observe can be noted to help inform the health care team.

6. Using Special Equipment

If your loved one has any mechanical equipment or devices and you are required to manage them, you will be trained on how to do this by a health care professional. These may include:

- catheter tube and bag
- oxygen tubing – are the ‘prongs’ in the correct downward position and is the oxygen at the desired level
- IV (intravenous line) – it is running well and there are no skin abnormalities at the site. The right solution is hanging and is running at the right rate

All mechanical equipment should be operating. If not, find out why.

7. Medications

Medication Safety

Talk to health care professionals (nurse, doctor, pharmacist etc.) about the medications your loved one is taking. They should provide you with all the detailed information (in writing) that you need to give your loved one medication safely, to keep a record of medications, and to assess their effectiveness.

Ask about safe storage of narcotic pain medications, proper disposal of used pain patches, syringes etc. When in doubt, always ask. Have phone numbers handy for the nurse, doctor and pharmacist for concerns about medication.

Administering Medications

- If the person has Diabetes, test their blood sugar before breakfast and provide medication (insulin if needed) as required. Record the glucose reading, doses and medication(s) given
- To decrease the chance of making an error in administering medication, check and double-check that you are giving the correct dose at the correct time and frequency, or that you are applying any ointments to the correct site

- Sit the person up and if they can swallow, give them a sip of water before taking medications
- Give medications as per doctor's orders, and medication instructions E.g. before or after meals, with or without food – give accordingly
- Crush medications as required if your loved one has swallowing problems. Dissolve them in water, or mix them with food or jam, and give them by mouth
- If medication is given by feeding tube, a health care professional will instruct you on how to do this, as well as how to administer injectable medications, inhalant medications via puffers or nebulizer, or oxygen
- Give regularly scheduled medications at the correct times. Give other “breakthrough” medication whenever the person asks for it or you observe that they need it, within the dosage guidelines for the particular drug. Keep accurate records of all medications given, providing the reason and its effectiveness
- Re-order medications so as not to run out
- Consult with the doctor or pharmacist about over-the-counter drugs or alternative remedies to confirm that there will be no serious side effects of taking them with prescription medication
- If the person refuses medication, record and report it – the drug may come in another form that they would prefer. They have the right to refuse medication

Self-Care for the Caregiver

- Schedule other caregivers' help on a regular basis for work that you know is too difficult for one person E.g. the daily bed bath, lifting or turning a person up in bed, or transferring a person from bed to a chair.
- Schedule your day into blocks of time: caregiving time, personal time and sleep time. Share the workload. Get other caregivers' commitment to provide care for you loved one on a regular basis, so that you are not the sole caregiver otherwise you may become overtired or burned out.
- Be aware of your loved one's illness. Are there any risks that require you to wear a gown and mask such as TB, pneumonia or other?
- Accept help from volunteers. Schedule care for yourself so that you can maintain your friendships and personal life.

Common Sources of Stress for Caregivers

Here are common sources of stress that caregivers may be faced with²⁴:

- Trying to live up to their clients' high expectations and/or their own
- Intensive caring for others at the expense of self-care
- Inability to set appropriate boundaries
- Pushing themselves too hard
- Mental and physical demands
- Heavy workloads
- Long hours on the job
- Time pressures
- Limited resources
- Competing priorities
- Media requests
- Political and organizational pressures

Signs of Stress

Caregivers are usually alert to the stresses of people they help. They are not, however, always as alert to the stress and fatigue that can slowly surface in their own lives, and need to be reminded of normal stresses that may affect them.

Common Physical/Behavioural Reactions:

- fatigue, loss of appetite, difficulty falling asleep, restlessness, headaches, changes in sleeping, increased blood pressure, changes in eating habits, increased susceptibility to colds, flu, infection, change in libido, changes in smoking habits, changes in alcohol and drug consumption.

Common Emotional Reactions:

- feeling helpless, overwhelmed, inadequate, fragile, vulnerable, unable to cope or go on, increased mood swings, decreased motivation, feeling burned out, crying more frequently

and easily, isolation, changes in communication patterns and other relationship dynamics, withdrawal.

Common Cognitive Reactions:

- confusion, difficulty making decisions, difficulty problem solving, memory blanks, having ambiguous feelings, questioning why this happened in a world that is supposed to be safe, difficulty concentrating or paying attention.

Caregivers are not immune to the above reactions and need to remind themselves that these are normal human responses to stressful circumstances. Although many of the underlying stresses cannot be prevented, you can increase your resistance by taking care of yourself and staying healthy. It is important to pace yourself and know your limits so you can continue to be available to your clients and your community.

Here are some stress-relieving activities:

- **Go for a 15-minute walk** during a lunch or coffee break. Take other opportunities to be physically active.
- **Eat sensibly.** Avoid excessive use of caffeine and alcohol. Drink plenty of water and juices.
- **Know and respect your limits.** If you feel exhausted and need time off, take it. Respect commitment for regularly scheduled time off.
- **Spend time with family and friends.** Talk to them. Listen to their stories. Listen to them if they become concerned with your health and well-being.
- As much as possible, continue to **participate in previous social and recreational activities.**
- **Get some rest.** If you have trouble sleeping, get up and do something relaxing or enjoyable.
- **Be on the lookout for any changes** in your habits, attitudes and moods.
- **Share your own and clients' reactions** and issues with colleagues. Don't hesitate to ask others for advice.
- **Include yourself on the list of people you are taking care of.** Take some time to do something just for yourself every day. Taking care of yourself will put you in better shape to give care to others.
- **Be self-nurturing** and don't forget to laugh.

Avoiding 'Burnout'

Know the Signs of Caregiver stress or 'Burnout; 'if you have any of these signs, it is time to talk to someone.

- You have a strong urge to run away from it all
- Your activity is scattered and frantic

- You notice major changes in your sleeping or eating pattern - you lose more than 10 pounds or sleep less than 3 hours at a time
- You get easily irritated or angry
- You lose concentration easily and forget important details
- You use alcohol, drugs or tobacco more than before

Respite Care

Respite care is about sharing the responsibility for caregiving and getting support for yourself. It can be offered in-home or in a health care facility. The following are some helpful tips:

- Find out if respite care is offered in your community and ask for this service before you become exhausted or 'burned out'.
- Have a list of tasks volunteers could help with and ask them their preferences E.g. providing bedside care for your loved one, helping with childcare, helping manage the housework E.g. cooking, laundry.
- Take physical and mental breaks by doing the things you enjoy such as going out with a friend, working at a hobby, participating in a sports activity, reading, listening to music, meditating/praying

Providing Emotional Support

The following are some tips for communicating with an ill person to lift their spirits and encourage them to voice their needs about pain and symptom management:

- Let your loved one know that you have spoken to the health care team, family and friends about who they want in their circle, so that private information is kept private. Often clients do not want to burden their families with the knowledge of their illness; they think of others before themselves. They have the right to privacy
- Don't pretend to know more than you do i.e. medically; just be yourself and allow your natural feelings to show through
- Don't shut down uncomfortable conversations. Your loved one may finally want to talk about things they have never spoken about before and it is important to let them. Listen with an encouraging attitude.
- Know how to say, "I don't know" when you don't know the answer. Offer to help find someone who may know the answer to their question.

- Call in a spiritual person to talk to your loved one when they have questions of a spiritual nature, and you feel unable to answer.
- Silence is golden. It is not always necessary to keep up a conversation; just being there is a comfort to your loved one.
- Let them cry. Crying can be therapeutic for both you and your loved one
- Think before you speak. Words can be hurtful and cannot be taken back.
- Treat your loved one like a person, not an illness. Focus on the person, not the illness.
- Carry on living life with them, doing the things they like to do as much as possible.
- Pay attention to body language. Try to interpret your loved one's physical signals that tell you for example, they just want to be alone (look away or stop talking) or they are in pain (biting their lip, grimacing), or they don't like their new nurse, (crossed arms).
- Use touch to let them know they are not alone. Hold their hand, give gentle massages, comb their hair, give hello and goodbye hugs if that is what they're used to.
- Smile! Your loved one will feel lighter when they know you can still smile and laugh.
- Don't take anger personally. It is natural for an ill person to feel anger at some point, but know that you are not the cause of it. They may be having trouble accepting their illness or may have other unresolved issues they are struggling with²⁵.

More Tips for Communicating

Communicate with the person in ways that support and uplift their spirit by saying "How are you feeling today?" rather than "How are you?" Keep the focus on their present state rather than their overall condition of illness.

Encourage clients to voice their needs about their pain and symptoms to their health care team as much as possible because there are medications that can help, but only if they know about it.

Find out what their (10) favourite things are e.g. a certain blanket or pillow, certain food or drinks, music, photo albums, flowers, etc.; pamper them with spa treatments such as foot soaks, massage, shampoo and haircut, nail care etc.

Arrange to have elders, spiritual or traditional people available to provide support, ceremonies and blessings for your loved one as per their wishes.

If your loved one chooses to stop treatments, accept it. They have a right to refuse treatment.

When you have the chance for a heartfelt conversation with your loved one, let them know that they are loved and that you forgive them for any problems you may have had with them, and that you understand that there may have been reasons for those problems that perhaps neither of you were aware of.

First Nations, Inuit and Métis people have noted that in caring for their loved one during the last stages of life, *“they come to the place where they need healing and forgiveness too”*.

Quality total care looks at the physical, emotional, spiritual and information needs of the person who is ill and their family members. People who are ill want:

- To be pain free.
 - To be alert and aware of what is happening to them.
 - To have the companionship of their family and friends.
 - To be accepted as the person they have always been.
 - To maintain their individuality.
 - To not be a burden to their family and caregivers.
 - To have familiar things around them: photos, plants, music, flowers, favorite food, pets.
 - To be cared for with love and respect.
 - To have their family get the support they need to help the person staying at home.
 - To have enough information to make informed choices about their treatment and care.
-