

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?

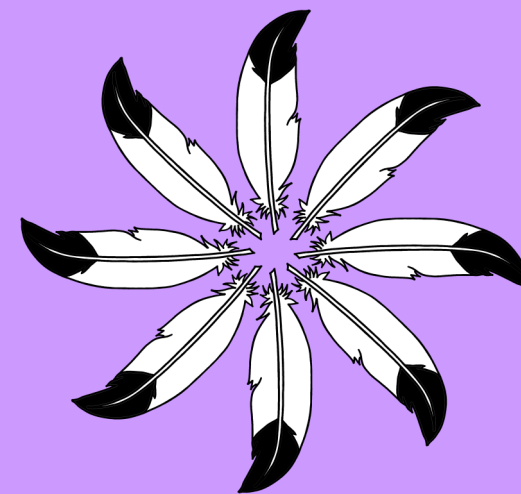
For help and support related to your diagnosis, feelings, symptoms, and care start by talking to your doctor, nurse, community health representative (CHR), spiritual care providers or any other health care provider. A referral can be made by yourself or anyone, including a family member. Share your needs, concerns and wishes with those who are caring for you. Do not feel you are alone.

You may also refer to the **Caring for the Terminally Ill: Honouring the Choices of the People** information booklet made available through your local health representative or at: http://pubweb.lakeheadu.ca/~eolfn/?page_id=199

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Living with a Terminal Illness



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 terminal 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 seem 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

