

I am standing upon the seashore.

A ship at my side spreads her white sails to the morning breeze,
and starts for the blue ocean.

She is an object of beauty and strength, and I stand and watch
her until she hangs like a speck of white cloud
just where the sea and sky come down to mingle with each
other.

Then someone at my side says: “There! She’s gone!”

Gone where?

Gone from my sight – that is all. She is just as large in mast and
hull and spar as she was when she left my side, and just as able
to bear her load of living freight to the place of her destination.
Her diminished size is in me, and not in her.

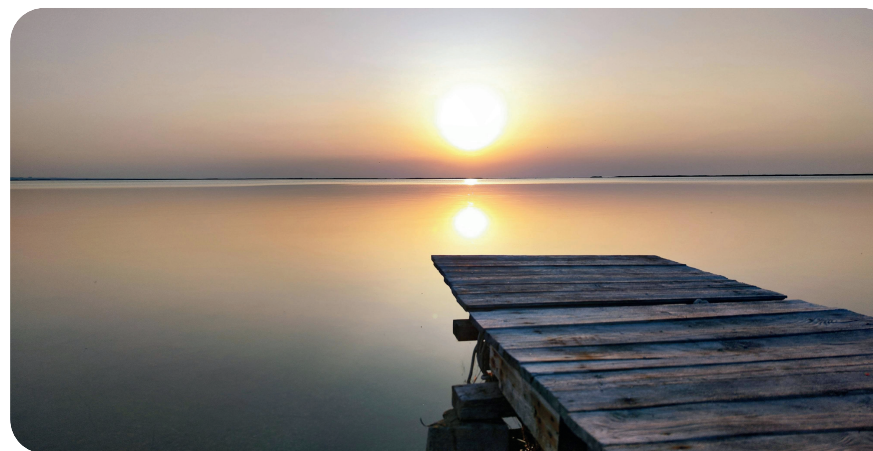
And just at the moment when someone at my side says: “There!
She’s gone!”, there are other eyes that are watching for her
coming; and other voices ready to take up the gleeful shout:
“Here she comes!”

And that is dying...

- Henry Van Dyke

Life’s last few moments

**A guide for people accompanying a loved
one nearing the end of life**



This booklet is intended for people accompanying a loved one nearing the end of life.

The aim of this guide is to provide information and support throughout these difficult times. It can also encourage reflection about hope and the importance of life's last few moments, and presents the main physical and psychological signs that may occur.

Caring for someone throughout the different stages of this journey may be unsettling. That's why we've included a few suggestions to help you find the level of involvement best suited to you and your loved one.

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Reviewed by: The Community of Practice of Palliative Care Nurse Consultants of the Montérégie Cancer Network.

This document was reviewed with the contribution of patient partners, whose lived experience and expertise enriched its content. A list of references is available upon request.

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Online resources

Canadian Hospice Palliative Care Association
www.chpca.ca

Association québécoise des soins palliatifs www.aqsp.org

Organ and tissue donation
www.quebec.ca/en/health/blood-tissue-and-organ-donation/organ-and-tissue-donation

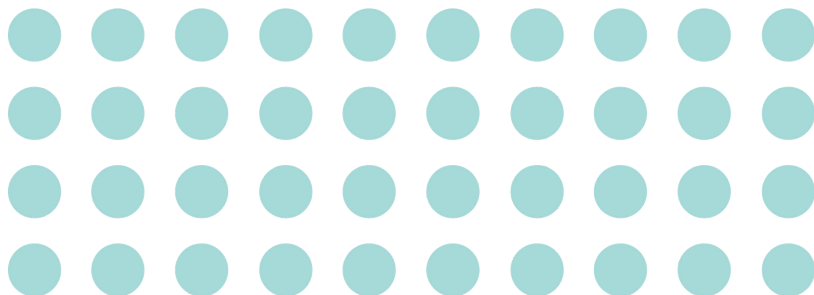
Palli-Science Site québécois de formation en soins palliatifs
et en oncologie de première ligne
palli-science.com

Canadian Virtual Hospice
portailpalliatif.ca

Proche aide québec
procheaide.quebec

Canadian Virtual Hospice grief resources for children and
teens
kidsgrief.ca

Canadian Virtual Hospice resources on grief
mygrief.ca



This moment in life

Loved ones:

“Accompanying someone does not mean going ahead and showing him the way, imposing an itinerary or even knowing which direction he will take; it is walking by his side, leaving him free to choose his path and the pace of his steps.”
— (Verspieren, 1986)

Death is the final stage of life. Often, relatives and close friends are the ones who can best accompany the dying person. With the assistance and support of the healthcare team, you can provide care and comfort for your loved one. Your presence honours their life. The deep respect that you show for the person’s beliefs, confidences, silences, and periods of withdrawal attests to the value that you place on them as a human being.

Since the onset of the disease, you may have been at your loved one’s side or witnessed some decisions they have made. As long as they have the capacity to do so, it remains important to address the person receiving care directly when discussing their wishes and making decisions that affect them. Family members and loved ones can provide support, listen, and accompany them while respecting their wishes, choices, and pace.

“Some families think that these decisions can make the difference between life and death. But, it’s important to remember that the person’s decisions won’t change whether he lives or dies, but merely how he lives out his final days. It’s the disease that will ultimately rob the person of his life, and care decisions should be made from the perspective of making the dying person comfortable in a way that respects his values and beliefs” —(Harlos, 2014)

About Hope

Present at all stages of life, hope allows us to accept and deal with a situation. Despite the person's deteriorating condition, hope remains present, but in a different way for each person. Some may hope to feel better, to no longer suffer, to die peacefully, to live to see the next season, or to make peace with a loved one.

At times, hope can seem unrealistic, but it is important to respect each person's chosen path. Regardless of its form, hope can persist right to the end. It is not unrealistic to hope that something good may happen, for example, a moment of peace, the visit of someone special, or comfort.

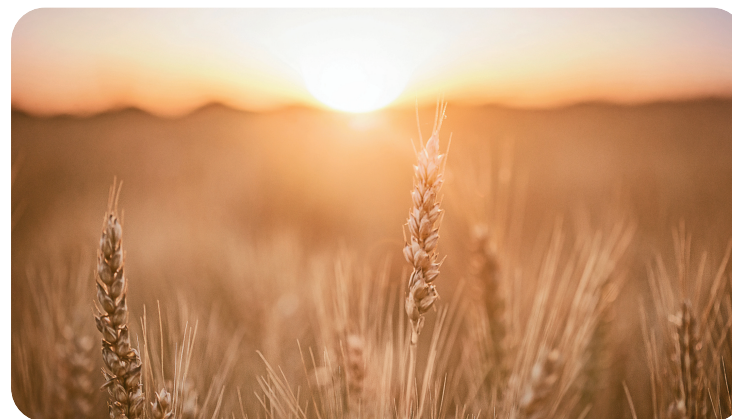
"Recognizing that hope is not the same thing as a promise, means that we have nothing to fear from encouraging it."
- (Coulombe, 2008)



How can I experience or express my spirituality?

You can do this by expressing the significance of your beliefs or lack thereof, your values, and your opinions on life, death, and the afterlife. For some people, such rituals and inner reflection are a source of comfort that helps them to cope with this difficult time with a little more serenity.

Each situation is unique; do not hesitate to speak to your healthcare team for more information.



Advice for better communication

Write down your questions.

Be honest, talk about your concerns.

Find out about the resources available.

There's no such thing as a stupid question.

If there's something on your mind, ask questions!

How can I support my young child during this difficult time?

If you are prepared to talk openly about death with your children, this will help them to understand that it's natural to feel sad when a loved one dies. Explaining to them that it's okay to feel sad, to cry, or even to feel angry or guilty, will reassure them that their feelings are normal.

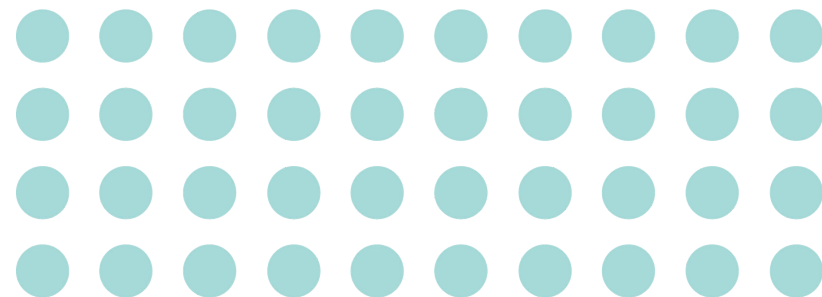
Children need to understand what's going on and to be comforted. A caring attitude will encourage children to express their emotions and show them that they, too, are important members of the family who are grieving a loss. Note that conversations should always be age appropriate.

How can I support my teen during this difficult time?

A teenager understands the concept of death, but experiences it differently. They may be torn between wanting to spend time with family and spending time with friends.

Your teen may handle the situation very maturely by supporting other members of the family, but they also need to spend time with friends in order to grieve in their own way.

High expectations can result in your teen feeling abandoned or misunderstood. They need the support of caring adults who can reassure them that it's okay to feel a wide range of contradicting emotions such as sadness, anger, fear, worry, fun with friends, etc. Any apparent indifference does not mean they are not affected by the situation.



The importance of the final moments

The approach of death encourages thoughts about the meaning of the person's life, their values and beliefs, which are all aspects of a person's spirituality.

This stage, comprised of a succession of losses, can also be extremely rewarding for you. It is a time for some final words about one's self and one's life, as well as the moment for some final thoughts, farewells, and amends.

Being there to listen is an opportunity for your loved one to recount their history, to share important moments, and to express painful memories, joys, failures and successes.

The final moments of life, filled with rituals and contemplation, can be a source of comfort. Depending on availability at the facility, pastoral animators can provide support throughout the process, in a way that respects the values and the spiritual or religious beliefs of your loved one.

Caring for a loved one at the end of life

Accompanying a person at the end of their life requires a great deal of dedication. The many challenges during this period may upset the balance between the person's needs and those of their loved ones.

It can be easy to forget about yourself or feel guilty. However, your well-being is important. Here are a few suggestions for taking care of yourself:

- Take some time for yourself, without feeling guilty. This is not selfish; it will help you to take better care of the person who needs you;
- Recognize the limits of your endurance and strength by asking for help, even if the person who is dying is reluctant to spend time with anyone else.
- Don't hesitate to express your emotions.
- Feel proud of what you are doing for your loved one.



People who are confused can also feel frightened and threatened by the people and objects around them. They may even make hurtful or incoherent remarks. This may be difficult for you, but keep in mind that these statements are generally not intentional: your loved one is not in control of what they are saying.

Should I stay with my loved one during this phase?

This is a personal choice that depends on you and on your loved one's current condition, needs, and expectations. What matters is that you have the desire, the capacity, and the availability to stay with them. Make sure to take time for yourself, since it's impossible to know how long this stage will last or when the person will die.

Take advantage of every moment spent with your loved one. If they do not want to be left alone, it might be a good idea to take turns keeping them company.

How much time is left?

No one can answer this question. While there are certain signs that death is imminent, we can't know exactly when it will happen. Death is different for everyone.

Why talk about death with my young child?

Children tend to react better when they know what's going on. So, explaining the situation to your child in an age-appropriate way is extremely important. Children's imagination is very fertile; keeping them in the dark can lead to them overthinking and blowing things out of proportion. It's therefore best to involve them in the family's experience by informing them of what's happening.

Can my loved one hear me?

At the moment, there is no research proving that a person can continue to hear until the moment of death. However, previous experience has shown that some people become calmer with the sound of a familiar voice. It may be beneficial to continue to speak to your loved one softly.

What should I do when my loved one is unconscious?

Simple gestures are often reassuring and comforting. These should be chosen according to the person's likes and dislikes. For example, touch them, talk to them softly, or play their favourite music.

Why does my loved one have a fever when they are unconscious?

At the end of life, the body's temperature control centre no longer works properly. The use of medications could be tried to bring down a fever but often has no effect.

Why is my loved one agitated, confused, or hallucinating?

As death approaches, the person's body becomes more fragile. The brain is affected alongside the body's other organs. This can lead to difficulties with memory, comprehension and orientation, which can lead to confusion or hallucinations.

Other reasons for agitation include:

- pain or discomfort
- certain medications
- fear or anxiety

One to two weeks before death

Each person has their own way of dealing with this final stage, bringing a unique dimension to this experience. You may notice some of the following psychological signs:

- Reflection upon their life
- Loss of interest in activities
- Gradual withdrawal from the world around them or a desire to be surrounded by people
- Saying goodbye to relatives and friends, and to places they loved
- Detachment and giving away personal possessions
- Final legal and financial preparations
- Expressing their emotions
- Talking openly about death

Physically, the body no longer has the same requirements and weakness slowly sets in. Certain physical and behavioural changes are caused by the body's vital functions slowing down:

- A change in appetite
- Increasing difficulty moving around
- Difficulty breathing
- Muscle weakness
- Swelling in the extremities
- Difficulty sleeping, reversal of day and night
- Confusion
- Unusual or inappropriate behaviour
- Change in skin colour

The following actions aim to make your loved one comfortable and respect their wishes at the end of life:

- Be attentive to their needs
- Respect their pace
- Offer foods that the person enjoys
- Offer ice cubes, frozen juice (popsicles), or ice cream
- Do not force the person to eat or drink
- Provide oral care
- Place the person in a comfortable position and help them to move around
- Gently massage and warm the person's hands and feet
- Speak calmly and naturally
- Read aloud to the person
- Play music that they like
- Create a pleasant atmosphere by placing familiar objects and photos in the room
- Air out the room
- Continue to respect the person's preferences and wishes, for example sleeping with socks on, putting on makeup, keeping pyjamas on, etc.

A few days to a few hours before death

The signs observed over the past week or two may intensify and other symptoms may appear:

- Difficulty walking, sitting, turning on their own
- Variations in body temperature (fever, low temperature)
- Change in pallor

Will morphine hasten my loved one's death?

No. Many people believe that one dose of morphine can be fatal. This is simply not true. In some cases, when the symptoms are relieved, we may even see a slowdown in the process leading to death. The use of morphine provides relief but does not accelerate their death.

At the end of life, is it still necessary to continue giving medication and administering treatments?

The objective of all care provided is to make the person comfortable. The benefits versus the disadvantages of all treatments are considered at regular intervals.

For example, taking vital signs (blood pressure, oxygen saturation, etc.) and blood tests (to measure blood glucose) may be pointless near the end of life, particularly if these procedures disturb the person.

If the person has a great deal of difficulty swallowing, it is necessary to stop giving medications by mouth and to administer comfort medications by injection.

How can I recognize signs of discomfort if the person can no longer express themselves?

Facial expressions (wincing, tense face), groans, rigidity and a stiff posture, changes in behaviour or anything else unusual are all possible signs of discomfort. If you observe these signs, do not hesitate to discuss them with the members of your healthcare team. There are certain medications or procedures that can be administered to make your loved one more comfortable.

Should we give them oxygen?

Before beginning or continuing the use of oxygen, you need to ask yourself whether it is making the person calmer and more comfortable. Sometimes, the use of oxygen can be more uncomfortable than beneficial, due to the tubes, dry nose, and the noise of the air circulating. In the final stages of life, oxygen is rarely used as the body's need for it diminishes and the lungs do not absorb it as much. If there's difficulty breathing, certain medications, such as morphine, are more effective than oxygen.

Why use morphine or an equivalent medication?

Morphine, or hydromorphone, relieves pain and several other discomforts, such as laboured breathing. It can also improve quality of life throughout the disease.

Should we delay using morphine?

No. Morphine can be given as soon as it is observed that it relieves the person's pain and discomfort. It is often best to treat these symptoms from the very beginning because the pain and discomfort can become difficult to manage if we wait too long. Pain or other symptoms that are not relieved can negatively impact quality of life (sleep, eating, level of energy, mood, etc.).

Is there such a thing as too much morphine?

No. The appropriate amount is that which controls the pain and discomfort with the fewest side effects. The amount is adjusted according to comfort.

- Mottled, cold extremities
- Muscle stiffness or slackening
- Increased sweating
- Decreased swelling
- Glassy, watery, half-open eyes
- Difficulty swallowing, minimal absorption of liquids
- Dry mouth
- Difficulty speaking
- Decrease in or lack of urination
- Loss of bladder and bowel control
- Irregular, shallow breathing, with pauses
- Terminal rales: noisy breathing caused by secretions
- Temporary resurgence in energy
- Agitation or inertia
- Loss of consciousness

In the final moments of your loved one's life, in addition to the actions already recommended, the following suggestions may also be useful:

- Hold the person's hand
- Speak softly, even if they are unconscious
- Apply artificial tears (drops)
- Provide oral care on a regular basis
- Explain what you are going to do before you begin
- Continue to change their position
- Avoid stimulating your loved one while they are sleeping, unconscious, or pausing between breaths

Frequently asked questions

How can I accompany my loved one through this journey?

Listen and respect their moments of silence, even if this may be awkward. Allow them to talk about their life, regrets, sorrows, and dreams. Your presence at this time is often more important than anything you could say or do. Continue to spend time with them as you always did, talking to and comforting them.

What should I do if my loved one gets emotional?

Allow them to express their emotions without trying to distract them or make them feel better. Allow yourself to cry and express your emotions, too. Crying and other forms of expression bring relief and a sense of well-being.

What do I do if I see that my loved one is not comfortable?

Various symptoms (anxiety, fear, nausea, confusion, etc.) may appear at the end of life. Our objective is comfort. Talk to the care team, several approaches are possible.

Why is my loved one no longer eating or drinking?

In the end stages of life, loss of appetite, weakness, and difficulty swallowing intensify. These changes can be difficult to accept. As the disease progresses, your loved one's nutritional needs change and their body stops absorbing the food eaten. It is therefore important to respect the person's appetite and food choices, while taking into consideration their ability to swallow. Coughing is an indicator of swallowing difficulties, so it's important to be alert to this.

Does my loved one feel thirsty?

Thirst is generally associated with a dry mouth. The person must be sufficiently alert in order to feel thirsty. You can alleviate their thirst by administering oral care on a regular basis. Ask for guidance from the healthcare team.

Why is breathing noisy at the end of life (rales)?

Your loved one may have difficulties swallowing their saliva and getting rid of secretions. Secretions accumulate in the throat. The sound of air passing through the secretions causes noise called rales. While this noise can be upsetting, it is not uncomfortable for your loved one.

Is installing an intravenous drip (solution) a good idea?

Intravenous solution is comprised of salt or sugar water and does not contain any medication or vitamins. Sometimes, it can increase swelling and secretions during respiration and cause discomfort at the end of life.

Can noisy breathing be remedied?

Sometimes, repositioning the patient can lessen the noise. Suctioning the secretions is not usually effective and can cause distress. Certain medication can reduce the production of new secretions.

