

# THE LAST MOMENTS OF LIFE

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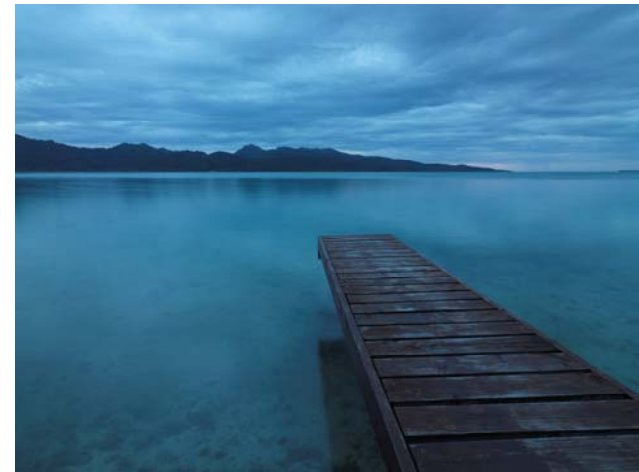
## Production

Réseau de cancérologie de la Montérégie

## Information or questions

450 466-5065

**Guide for Relatives  
Supporting a  
Person at the End of Life**



## Internet resources to consult

Canadian Hospice Palliative Care Association  
[www.chpca.net](http://www.chpca.net)

Réseau de soins palliatifs du Québec  
[www.aqsp.org](http://www.aqsp.org)

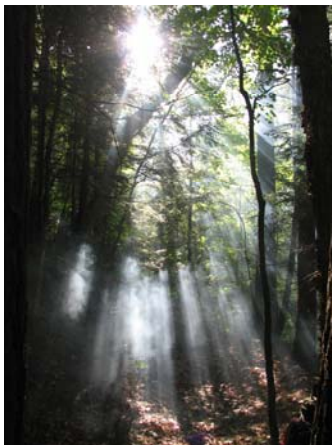
Maison Victor-Gadbois  
[www.maisonvictor-gadbois.com](http://www.maisonvictor-gadbois.com)

Canadian Virtual Hospice  
[www.virtualhospice.ca](http://www.virtualhospice.ca)

This booklet has been designed for you as a close relative accompanying a person at the end of life. Its purpose is to inform and support you during this demanding period.

It encourages a reflection on hope and the last moments of life, while informing you about the main physical and psychological precursors.

Knowing that supporting a person at the end of life can leave you without bearings, a variety of actions are discussed here so that you can find the level of involvement that will best suit your loved one and yourself.



I'm standing by the beach  
A sailboat passes in the morning breeze  
and heads toward the ocean  
She is beauty, she is life  
I watch until she fades on the horizon  
Someone at my side says: she's gone  
Gone? Where?  
From my sight, that's all!  
Her mast is still high, her hull still has the strength to  
carry its human load  
Her complete disappearance from my sight  
is in me, not her  
And just when someone close to me says,  
"She's gone!"  
Others now seeing her appear on the horizon  
coming toward them,  
shout with joy: "There she is!"  
That...is death.

**William Blake**

## Frequently asked questions (con.)

### How can we experience or express our spirituality?

By expressing the meaning of beliefs, disbeliefs, values and experiences regarding life, death and after-death.

For some people, these moments of inwardness and meaningful rituals make it possible to ease, support and work through these moments a little more serenely. Spiritual advisors can give you support. You only need to ask.

**Every situation is unique, feel free to ask your care providers for more information.**

## References

- Coulombe, Manon(2008) « L'espoir: une flamme à entretenir même dans un contexte de in de vie, Première ligne », 12 (1), 9-13.  
CSSS de Laval. (2007). *Guide de pratiques cliniques en soins palliatifs à l'intention des intervenants*. Laval, Québec.
- Cutcliffe, J. R. et Herth, K. (2002). Concept of hope. The concept of hope in nursing 1: its origins, background and nature. *British Journal of Nursing*, 11(12), 832
- Corbeil, L. (2014).Children and Adolescents Coping with a Parent's Cancer: Guide For Families and Care Providers  
*Canadian Cancer Society*: Toronto, Ontario.
- Harlos, M. (2014). *When Death is Near*, Canadian Virtual Hospice, accessible at  
[http://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home/Topics/Final+Days/When+Death+is+Near.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Final+Days/When+Death+is+Near.aspx)
- Institut universitaire de gériatrie. (2013). *Les soins de confort en fin de vie dans la maladie d'Alzheimer et les autres maladies dégénératives du cerveau, un guide pour les proches*. CSSS de Sherbrooke : Sherbrooke., Québec.
- VERSPIEREN, Patrick (1986), Face à celui qui meurt : Euthanasie, Acharnement thérapeutique, Accompagnement. 5

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## This moment of life

“To accompany someone is not to travel ahead, indicate the way, impose an itinerary, or even know the direction to be traveled. It is to walk along side, leaving the person free to choose the road and rhythm of travel.”

(Verspielen), 1986)

Death is the last stage of life. You can offer the necessary support—often better than anyone else—with the help and assistance of care providers. Your presence helps to concretize and enhance the meaning of the life of this unique being, regardless of the person’s great fragility. A deep respect for the person’s beliefs, confidences, silences and retreats testifies to the value you give the person as a human being.

Since the onset of the illness, you may have witnessed or even supported your loved one in decisions about treatment choices, including the level of medical interventions.

“Some families will think that these decisions could make the difference between life and death. It must be remembered, however, that the choices to be made will not decide the life or death of the person but rather the way in which they will live their last days. It is the illness that will lead the person to their final repose, and care decisions must aim to optimize the dying person’s comfort, while respecting their values.”

(Harlos, 2014)

## Frequently asked questions (con.)

### **How can we support our teenagers in this trial?**

Your teens understand the principle of death, but experience it differently. They may be torn between the desire to spend time with the family and to be with friends.

Your teens can act maturely and support other family members, but they also need to interact with friends to work through grief in their own way.

High expectations in their regard could lead to a lack of support and misunderstanding. They need compassionate adults to confirm that it’s okay to feel a mix of contradictory emotions (sadness, anger, fear, anxiety, fun with friends, etc.).

## Frequently asked questions (con.)

### **Why talk about death to our young children?**

Children tend to react better when informed. Thus, the explanations given to your children—appropriate to their age group—are of great importance. If your children are kept in ignorance, their fertile imagination can alter reality and amplify it. So it is preferable to integrate them into the family experience and trust them.

### **How can we support our young children in this event?**

If you are willing to speak openly about the reality of death with your children, it will help them understand that it is natural to feel sorry for the loss of a loved one. To assert that it is okay to feel sad, to cry, to feel anger or guilt helps to normalize the feelings experienced by your children.

Children need to understand and be reassured. A compassionate attitude will encourage your children to express their feelings. This shows them that they, too, are an integral part of the family and have grief to work through.

Note that the exchanges must be appropriate to your children's age and understanding; explanatory books and films are available.

## What about hope?

Present at all stages of life, hope allows people to cope with and adapt to the situation. Despite the deteriorating state of health, hope remains present, changes and varies according to each person. Some might hope to feel better, not to suffer, to die peacefully, make it to the next season or achieve reconciliations.

At the approach of life's end, hope represents a positive future, an inner force that enriches life, which allows us to go beyond pain and suffering and help us live our lives to the very moment of death. (Cutcliffe & Herth, 2002)

Hope can sometimes seem unrealistic. But it represents the light that keeps your loved one alive for days, weeks or months. Hence, it is beneficial to allow it to be expressed.

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

## Importance of the last moments

A difficult but inevitable passage, the approach of death also brings a re-examination of the meaning of life generally, and of one's own life. One's vision and sense of life, values, beliefs, attitude toward life and death are elements of spirituality that express the very essence of human beings.

This stage, composed of successive bereavements and renunciations, can lead to special moments for you and your loved one. It is the time of last thoughts about oneself and one's life; of words, farewells and forgiveness.

An attentive and a loving presence allows your loved one to relate and bequeath the story of his or her life, to relive its good moments and thereby express dreams, regrets, sorrows and fears. Paying attention without interruption will facilitate trust.

The last moments of life, including rituals and contemplation, can be a source of peace and healing. Depending on their availability at your centre, spiritual care providers will be able to offer support throughout the process, while respecting the spiritual and religious values and beliefs of your loved one.

## Frequently asked questions (con.)

### Should I stay with my loved one?

This is a personal matter that depends on you and your loved one's current situation, needs and expectations. What matters is that you have the **desire, ability** and **availability** to stay with the person. Respect your limits, as it is impossible to know the duration of the end-of-life process and exact moment of death. You will need energy for the events that follow.

Make the most of every moment you are near your loved one. If the latter desires a constant presence, it is perhaps wiser to take turns at the bedside.

### How much time is left?

No one can answer this question. The time of death is always a mystery. On the other hand, there are signs that death is approaching without, however, foretelling the exact moment of death. The way in which death occurs is unique to everyone and, in many respects, remains mysterious.



## Frequently asked questions (con.)

### **Does my loved one hear me when unconscious?**

For now, no research confirms the fact that the person hears until the end. On the other hand, previous experience demonstrates that some people calm down to the sound of the voice. It can be beneficial to continue talking softly.

### **What can I do when my loved one is unconscious?**

Simple acts can often provide security and comfort. These should be chosen according to person's previous tastes and habits. For example, touching, talking softly, playing their favourite music.

### **Why does my loved one have a fever?**

At the end of life, the body's temperature regulation is no longer adequate. The person will then experience temperature variations. Use of medication against fever will have little effect on it, but could help alleviate discomfort caused by the rise in temperature.

## Supporting a person at the end of life

Support of a loved one at the end of life requires great dedication. A multitude of upheavals can disturb the balance between the needs of your loved one and yourself.

It could be easy to forget your own needs or feel guilty. Yet, your well-being is important and essential, so here are some suggestions:

- Take care of yourself.
- Reserve a portion of your time for yourself without feeling guilty. This is not selfishness, but an attitude that will allow you to better take care of your loved one who needs it.
- Recognize the limits of your resistance and your strengths by asking for help, even if your loved one at the end of life is reluctant.
- Express your joy, anger, sadness and frustrations.
- Feel pride in what you do for your loved one.
- Continue doing the activities you enjoy.

## One to two weeks before death

Each person has their own way of living this final stage, bringing to the experience a unique dimension. The following psychological signs may appear at random, without necessarily manifesting:

- an assessment of one's life;
- loss of interest in activities;
- progressive withdrawal from the surrounding world or the willingness to be surrounded;
- saying goodbye to beloved people or places;
- detachment and giving away personal property;
- expression of emotions;
- discussion of death with one or more persons.

In physical terms, the body no longer has the same needs and general weakness gradually sets in. Certain physical and behavioural changes can then be observed due to a slowing down of vital functions, circulation and metabolic changes:

- variation in appetite;
- increasing difficulty in moving about;
- difficulty in respiration;
- muscular weakness;
- oedema (swelling) of extremities;
- trouble sleeping (days and nights reversed);
- disorientation (confusion);
- pulling at clothes or sheets.

## Frequently asked questions (con.)

### **Why is my loved one agitated, hallucinated or confused?**

When death approaches, the brain is subject to the same difficulties as other body systems. The weakening of organs such as kidneys, liver and lungs is accompanied by a cognitive decline (memory, confusion, understanding).

There are also other reasons: pain, discomfort, medication side effects, or fear in the face of death.

In addition, confused people may feel frightened and threatened by the people and things around them. It can be upsetting for you to see your loved one behaving abnormally and even saying things that wound you. Remember that these often have no relation to reality and are beyond their control.

You can help your loved one by promoting relaxation with music, reading, massages or recalling pleasant memories. A calm attitude and warm presence are often reassuring. According to the care team's assessment, an adjustment or introduction of an appropriate medication may decrease the symptom or provide relaxation without precipitating death.



## Frequently asked questions (con.)

### **At the end of life, is it still necessary to continue all medication and treatments?**

The goal of palliative care is the comfort of your loved one. The benefits of all care are regularly assessed against their disadvantages.

For example, taking vital signs (blood pressure, heart rate, oxygen saturation, etc.) and blood sampling (such as blood glucose) may be futile, especially if these interventions disturb your loved one.

When swallowing difficulties are significant, it is necessary to stop medication taken orally. Medication continued for comfort is administered in another form; for example, subcutaneously.

### **How do I recognize signs of discomfort in my loved one who no longer communicates?**

Facial expressions, moans, behavioural changes, body tension and posture are possible signs of discomfort. If you observe these signs, feel free to discuss them with care providers. Some medications or procedures might make your loved one more comfortable.

## One to two weeks before death (con.)

**The following suggested actions aim at comfort and respect for the desires of the person at the end of life.**

- Be present.
- Offer desired foods .
- Offer ice, frozen juice (*popsicle*) or ice cream.
- Do not force the person to eat or drink.
- Offer care to the person's mouth.
- Position the person comfortably and give help in getting about.
- Gently massage and warm the person's extremities.
- Name things instead of making the person say it.
- Speak in a calm, natural manner.
- Read aloud.
- Play music according to the person's taste.
- Create a pleasant environment by surrounding the person with familiar objects and photos.
- Air out the room.
- Respect the person's habits and desires (eg sleeping with stockings, applying makeup, keeping pyjamas on).

## A few days to a few hours before death

At this point, your loved one could experience a renewal of energy. Changes observed during the preceding week or two intensify and other symptoms may appear:

- difficulty walking, sitting or turning unaided;
- variation in body temperature (fever, low temperature);
- blotchy and cold extremities;
- increased sweating;
- reduced oedema (swelling);
- glassy, watery, semi-open eyes;
- difficulty swallowing and minimal fluid absorption;
- dry mouth ;
- difficulty talking;
- urine reduction or cessation;
- loss of control over bladder or intestines;
- irregular breathing, shallow with pauses;
- terminal rales: noisy breathing caused by secretions;
- agitation or inactivity;
- loss of consciousness.

## Frequently asked questions (con.)

### **Why use morphine or an equivalent?**

Morphine relieves pain as well as several other discomforts, such as difficulty breathing.

This medication also improves the quality of life throughout the disease and can even prolong life. Many patients receive morphine regularly for months and even years.

### **Should we delay the use of morphine?**

No. Morphine can be used as soon as it is found to relieve pain and other discomforts. It is often advantageous to treat discomforts from the outset, because when you wait too long, they can be difficult to relieve.

### **Is there a morphine dose not to be exceeded?**

No. The right quantity is the one that relieves pain and discomfort with the least possible side effects. Adjustment of the quantity is made gradually, hence the importance of using breakthrough (rescue) doses.

### **Will my loved one die faster with The administration of morphine?**

No. Many people tend to believe that a dose of morphine can cause death. That is untrue. In some cases, when the symptoms are relieved, it is even possible to observe a slowing down of the the process leading to death. Death is the result of a serious disease and use of morphine helps soothe the person.

## Frequently asked questions (con.)

### **Why is there noisy breathing at the end of life?**

Your loved one may have difficulty swallowing saliva and expelling secretions. The sounds of the secretions and air passing through relaxed vocal cords produce rales. These noises are more disturbing to you than to your loved one.

### **How can it be remedied?**

Sometimes, a repositioning of the body, by raising the head of the bed, will reduce the noise. Suction of secretions is usually ineffective and can be trying for your loved one. Some drugs may decrease the production of new secretions.

### **Should we initiate the use of oxygen?**

Before starting or extending the use of oxygen, you need to know what will make your loved one the calmest and most comfortable. In some cases, use of oxygen causes more discomfort than benefits due to the tubing, dryness of the nose and noise of the air circulating.

At the end of life, oxygen is not used much, as the body's needs diminish and the lungs absorb it less.

When breathing is difficult, some drugs, like morphine, are more effective than oxygen.

## A few days to a few hours before death (con.)

In the last moments of life, the **suggested actions** already mentioned, as well as the following, can be done:

- stay close to the person's bed;
- hold their hand;
- talk softly, despite their being unconscious;
- administer artificial tears;
- point a slow-speed fan at their face;
- give mouth care frequently;
- explain what you are about to do before doing it;
- avoid disturbing your loved one while they sleep, are unconscious or during a pause in their breathing.

## Frequently asked questions

### **How do I support my loved one?**

Be attentive and respect their moments of silence even though these may seem heavy. Let your loved one talk about their life, regrets, sorrows and dreams. Your presence in the last moments is often more important than words or acts in themselves. Continue to be together as was the case with your conversations and comforting everyday acts.

### **What should I do when emotions manifest?**

Let your loved one express indwelling emotions without trying to change their ideas or cheer them up. Also, allow yourself to cry and express your emotions. Tears can help release tension.

What you and your loved one are experiencing is intense. A multitude of emotions can arise and express themselves in different ways according to each individual. The important thing is to allow room for these feelings, regardless of how they are expressed (crying, drawing, exercising).



## Frequently asked questions (con.)

### **Why does my loved one no longer eat or drink?**

We associate eating with life. It may be difficult to accept decreased appetite. However, as the disease progresses, your loved one's nutritional needs change and the body no longer absorbs food as before. At the end of life, loss of appetite, weakness and difficulty swallowing intensify. It is therefore important to respect the person's appetite and food choices while heeding their ability to swallow.

### **Is setting up a drip desirable?**

A drip is composed of salt or glucose in a solution containing neither medication nor vitamins. The solution increases fluid content in the tissues and respiratory secretions that exacerbate discomfort.

### **Does my loved one feel thirsty?**

Thirst is usually associated with a feeling of dryness in the mouth. The person must be sufficiently awake to feel it. It is possible to remedy this situation by frequent mouth care. During this care, be sure to wring out the sponge brush well to avoid a surplus of liquid.