

LIFE'S LAST FEW MOMENTS

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



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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.

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 deal with the situation on a day-to-day basis. You will also find in this guide the main physical and psychological signs of approaching death, as well as frequently asked questions and a list of resources.

THIS MOMENT IN LIFE

“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.”

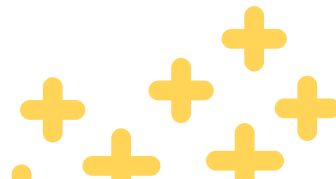
—(Verspielen, 1986)

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 about treatment options, including medical procedures.

“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 this glimmer of hope that will keep your loved one alive for days, weeks, or even months. Its expression must therefore be allowed.

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

—(Coulombe, 2008)

THE IMPORTANCE OF THE FINAL MOMENTS

A difficult but inevitable transition, the approach of death encourages thoughts about the meaning of the person's life. One's vision and interpretation of the meaning of life, values, beliefs, and attitude toward life and death are all aspects of spirituality that make up the very essence of a human being.

This stage comprised of a succession of losses and relinquishments can also be extremely rewarding for the person who is dying, as well as for the family and friends. 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.



Offering a loving presence creates an atmosphere of calm reflection in which your loved one will feel comfortable. Listening without interrupting will allow them to retell and hand down stories about their life, share happy memories, and express dreams, regrets, sadness, and fears.

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

SUPPORT AND BALANCE

Accompanying a person at the end of their life requires a great deal of dedication. This process involves many changes and emotions that can upset the balance between meeting your needs and those of your loved one. 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.
- + Express your joy, anger, sadness, and frustrations.
- + Feel proud of what you are doing for your loved one.
- + Pursue activities you enjoy.



ONE TO TWO WEEKS BEFORE DEATH

Each person has his 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
- + Expressing their emotions
- + Talking openly about death with one or more people

Physically, the body no longer has the same requirements, and weakness slowly sets in. Certain physical and behavioural changes will be obvious because the body's vital functions, circulation, and metabolism are 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
- + Disorientation, confusion
- + Pulling at clothing and sheets

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

- + Be present
- + 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
- + Name things instead of making him say them
- + 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

At this stage, your loved one may experience a resurgence in energy. 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)
- + Mottled, cold and blue extremities
- + 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
- + 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:

- + Stay close to the bed
- + Hold the person's hand
- + Speak softly, even if they are unconscious
- + Apply artificial tears (drops)
- + Direct a fan set to low on the person's cheek
- + Provide oral care on a regular basis
- + Explain what you are going to do before you begin
- + Avoid stimulating your loved one while they are sleeping, unconscious, or pausing between breaths

THE COMPASSION BUTTERFLY

The Compassion Butterfly is a visual symbol designed to inform and raise awareness among employees, volunteers, patients and visitors that we are caring for a patient facing end of life. This butterfly reminds us all to keep on creating a calm and respectful atmosphere for both the patient and their loved ones.

When a patient is at the end of life, the nurse will explain and suggest the use of the Compassion Butterfly to the patient and family. Once permission has been obtained, the nurse will affix the butterfly to the outer door frame, where it can be seen by all.



FREQUENTLY ASKED QUESTIONS



How can I help my loved one go through this journey?

Listen to what they have to say without interrupting and do not try to fill the silences, even if they feel 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 can sometimes be a good way to release tension.

What you and your loved one are going through is extremely intense and can bring up a whole range of emotions, which are expressed differently depending on the person. The important thing is to allow these emotions to come to the surface, no matter how they are expressed (crying, drawing, exercising, etc.).

Why is my loved one no longer eating or drinking?

Food is a necessity of life. A loss of appetite can be a difficult thing to accept. However, as the disease progresses, your loved one's nutritional needs change and their body stops absorbing the food eaten. In the end stages of life, loss of appetite, weakness, and difficulty swallowing intensify. It is therefore important to respect the person's appetite and food choices, while taking into consideration their ability to swallow.

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. The solution increases the amount of fluids in the body, thereby increasing respiratory secretions, thus prolonging the person's discomfort.

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. When doing so, make sure to wring out the sponge of all excess liquid.

Why is breathing noisy at the end of life?

Your loved one may have difficulty in swallowing their saliva and getting rid of secretions. The sound of the secretions and the air passing over the relaxed vocal cords cause wheezing. This noise is more upsetting to you than to your loved one.

Can we help with the noisy breathing?

Sometimes, repositioning the patient by raising the head of the bed can lessen the noise. Suctioning the secretions is not usually effective and can be distressing for the person. We can also give certain medications to reduce the production of new secretions.

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. In patients who are having trouble breathing, certain medications, such as morphine, are more effective than oxygen.

Why use morphine or an equivalent medication?

Morphine relieves pain and several other discomforts, such as laboured breathing. It can also improve quality of life throughout the disease and even prolong the person's life. Many patients are given regular doses of morphine for months or even years.

Should we delay using morphine?

No. Morphine can be given as soon as 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.

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 gradually, which is why it's important to use interdoses between the regular ones.

Will morphine hasten my loved one's death?

No. Some 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. Death is the end result of a serious disease, and morphine can provide the patient with relief.

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, heart rate, 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 in another way, for example, by injection.

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

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

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. On the other hand, 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, and what they are accustomed to. For example, touch them, talk to them softly, or play their favourite music.

Why does my loved one have a fever?

At the end of life, the body's temperature control centre no longer works properly, meaning that the person's temperature will fluctuate. The use of medications to bring down a fever will have little effect, but could help to relieve the discomfort caused by the elevated temperature.

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

As death approaches, the brain is affected alongside the body's other organs. In fact, the failure of organs such as the kidneys, liver, and lungs is accompanied by a cognitive decline (memory, confusion, comprehension).

There can be other reasons for these symptoms. For example, they could be due to pain, discomfort, side effects from the medication, or the manifestation of fear as death approaches.

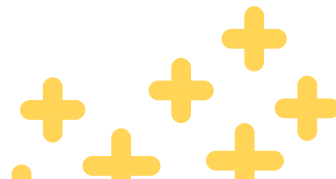
People who are confused can also feel frightened and threatened by the people and objects around them. It may be upsetting for you to see your loved one behaving abnormally and even saying hurtful things. You should know that this behaviour is beyond their control; most often, they won't know what they are saying or doing.

You can help your loved one to relax with music, reading, massage, or by sharing pleasant memories. A calm attitude and warm presence are often reassuring. The health care team can evaluate the need to adjust or add medications to lessen the symptoms or help them to relax without hastening the moment of death.

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, just as no one can predict the exact moment when someone will die. While there are certain signs that death is imminent, we can't know exactly when it will happen. Death is different for everyone and remains shrouded in mystery.

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.

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; there are books and movies available to help you explain this sensitive topic to your children.

How can I support my teen during this difficult time?

A teenager understands the concept of death, but experiences it differently from an adult. 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.

How can I experience or express my spirituality?

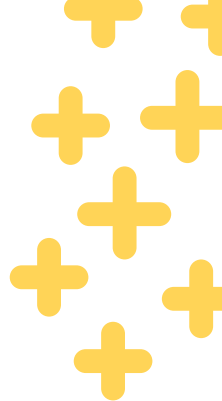
You can do this by expressing the significance of your beliefs or lack thereof, your values, and your opinions on life, death, and the afterlife. For some people, such rituals and inner reflection are a source of comfort that helps them to cope with this difficult time with a little more serenity.

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



REFERENCES AND ONLINE RESOURCES

- + [Centre intégré de santé et de services sociaux de la Montérégie-Ouest](#)
- + [Canadian Hospice Palliative Care Association](#)
- + [Canadian Virtual Hospice](#)
- + [Champlain Hospice Palliative Care Program](#)
- + [Guiding Family Caregivers of People at the End of Life](#)
(Available free of charge on the ACSP Website)



Your satisfaction is important to us

In an effort to continue providing quality care and services to our patients and their families, the HGH would like to know your level of satisfaction with palliative care. To complete the survey, please scan the code. Thank you for your participation.



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