Palliative & End-of-Life Care

Guide for Informal Caregivers and People at the End of Life

Québec

© Guide produced in 2024 by
the Direction des services spécialisés,
chirurgicaux et de cancérologie
of the Centre intégré universitaire
de santé et de services sociaux
de l'Estrie – Centre hospitalier
universitaire de Sherbrooke
(CIUSSS de l'Estrie – CHUS)

PROJECT HEAD
Manon Larivière, directrice
des services spécialisés,
chirurgicaux et de cancérologie,
CIUSSS de l'Estrie – CHUS

PROJECT COORDINATION
Nathalie Fortin, coordonnatrice
réseau en cancérologie,
direction des services spécialisés,
chirurgicaux et de cancérologie,
CIUSSS de l'Estrie – CHUS

IN-HOUSE COLLABORATIONS
Physicians, nurses, health-care
professionals, pharmacists, and
managers involved in the palliative
and end-of-life care trajectory
on a daily basis in various clinical
and support departments at
the CIUSSS de l'Estrie – CHUS

COLLABORATION WITH PATIENT AND FAMILY PARTNERS
Josée Lacourse
Luc Martel
Gilbert Leclerc

REVISION
Service des communications
et des relations médias
Présidence-direction générale

VISUAL DESIGN AND LAYOUT
Hémisphères Design Graphique

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To you, patients and informal caregivers, as you make your way through this stage of the journey...

KELLY SIKKEMA, UNSPLASH

> "Palliative care is about adding life to days when we can no longer add days to life."
>
> – Jean Bernard

SIMON-WILKES, UNSPLASH

Palliative and end-of-life care can give rise to many emotions, concerns, and questions. Each person experiences the transition differently, and the end of life is as unique as the people who face it.

Who is this guide for?

This guide is intended for informal caregivers and for people in the final stages of life.

Its aim is to inform and support all those who are going through this period of upheaval. This guide also helps to deconstruct certain beliefs surrounding palliative and end-of-life care.

The person at the end of life and their loved one might wish to read this guide together. If so, reading in pairs could enable them to discuss topics of concern to them as they move through the sections.

This may seem a heavy read and difficult to get through in one go. Don't hesitate to take a break and consult the guide in steps or according to the sections that catch your eye first. Depending on the context, you may need to reread certain passages or come back to them when you're rested.

As you work through this guide, feel free to consult your medical and professional team for further information specific to your situation. Share your needs and questions with them so that they understand that communication is essential to support you through this time.

There's a section at the end of this guide where you can write down your questions and answers, record useful contacts, or simply express your thoughts.

Palliative Care

The aim of palliative care is to achieve the best possible quality of life for patients and their families.

Palliative care is organized and delivered through the collaborative efforts of an entire care team, including the patient and their loved ones. The clinical approach to palliative care should be introduced over the course of medical visits as the life-threatening illness progresses, in parallel with the treatments offered.

Palliative care supports people's lives while treating death as a normal process for everyone.

Palliative and end-of-life care is provided when scientific advances no longer allow us to cure or prolong the life of a sick person. This care aims to achieve the best possible quality of life for people at the end of life and their loved ones by:

- relieving pain and other symptoms of discomfort;
- alleviating psychological, social, and spiritual suffering.

The passage towards the end of life is both difficult and inevitable. Caring for a loved one at the end of life is a great challenge, but it can also be enriching on a human level. Don't hesitate to ask the care team about the support services offered, as these may vary between settings.

Does palliative and end-of-life care hasten death?

The only care that causes death is medical assistance in dying. This is a legally regulated treatment, accessible only under certain conditions. Palliative and end-of-life care does not hasten or delay death. It supports the natural evolution of the disease while making the person as comfortable as possible.

Is palliative care just for cancer patients?

Anyone suffering from an incurable disease can benefit from palliative care.

ALICE DONOVAN ROUSE, UNSPLASH

> "Caring for a loved one at the end of life is a great challenge, but it can also be enriching on a human level."

THOM MILKOVIC, UNSPLASH

> "The patient remains in charge of the situation, in that they retain the decision-making power until the end of their life."

Act respecting End-of-Life Care

The *Act respecting End-of-Life Care* ensures that people have access to quality care and support adapted to their particular situation at this final stage. It specifies the rights of the person at the end of life, as well as the organization and supervision of the care required. **The act includes, among others, the following types of care, all of which are governed by specific accessibility criteria and require written consent.**

CONTINUOUS PALLIATIVE SEDATION

This care aims at relieving the suffering of a person at the end of life, when life expectancy is limited in the doctor's judgment. It consists of administering continuous sedative to keep the patient in a deep sleep until death in order to relieve intolerable symptoms. This technique differs from sedation induced by medication, in which moments of wakefulness can occur. Talk to your care team; they will be able to advise you.

MEDICAL ASSISTANCE IN DYING AND ADVANCE REQUEST FOR MEDICAL AID IN DYING

This exceptional care may be requested by a sick person in order to put an end to suffering that they deem intolerable: its administration results in death. This care is available in all Quebec health-care institutions and most palliative-care hospices. It can also be provided in the home. The use of medical assistance in dying is strictly defined by criteria and governed by the act and the Criminal Code. It can only be given under restricted conditions.

For more information, visit this website:
www.quebec.ca/en/health/health-system-and-services/end-of-life-care

ALES MAZE, UNSPLASH

Planning Ahead

This section offers the person at the end of life a list of things to think about, so that they can organize themselves until the end. Some points may seem premature to you, but it's important for the person affected by the disease to take part in the decisions that concern them. Once these reflections have been addressed, everyone can refocus on the present and preserve their energy for the time ahead.

CARE OBJECTIVES

Your doctor will discuss your care goals (previously called "levels of care") with you, if they haven't already done so. Depending on your personal wishes, the care you receive will respect your health needs, values, and choices. It's a wise choice to be accompanied in these discussions by someone close to you, to ensure that your wishes are respected throughout your care.

Leaflet - Levels of care
Let's talk about it :

ADVANCE MEDICAL DIRECTIVES (AMD)

You may already have completed your advance medical directives in the event of incapacity. If so, don't hesitate to inform the treatment team. Advance medical directives make it possible to indicate in advance the health care that a user might accept or refuse in the event of incapacity to consent, such as resuscitation, assisted ventilation, forced feeding, or dialysis.

For more information, visit the **Régie de l'assurance maladie du Québec** website:

ramq.gouv.qc.ca/en/citizens/health-insurance/issue-directives-case-incapacity

By telephone: **1-800-561-9749**
You can also consult **your notary**.

POWER OF ATTORNEY

This contract allows you to designate one or more persons to act on your behalf, even if you are able to do so. There are different types of power of attorney. You can find them at your banking institution or at various government agencies. You can also contact your notary.

PROTECTION MANDATE

This document allows you to designate, in advance, one or more people to look after your well-being and administer your property, should you become incapable of doing so yourself. This can be a lengthy process, involving medical and psychosocial assessments. To be effective, the mandate must be approved by a judge, subsequent to the person’s loss of capacity.

TESTAMENT

This document enables a person to allocate their property upon death. Contact a notary who can help you with this. You can make a will yourself, subject to certain conditions. The document must still be notarized upon your death.

For more information, contact the **Chambre des notaires**:

cnq.org/en or **1-800-263-1793**

PREARRANGED FUNERAL SERVICES

Arrangements can be made in advance with a funeral home so that things are done according to the person’s wishes at the time of death: embalming, showing, ceremony, cremation, etc. Prearranged funerals are common. If the deceased did not make prior funeral arrangements, the executor of the will, or any other person designated by the estate or survivors, will be responsible for arranging the funeral with the funeral home’s management.

Funeral homes can help you with many of the steps following the death and offer support as you grieve.

BENEFITS FOR INFORMAL CAREGIVERS

Employment Insurance caregiving benefits provide financial assistance when you take time off work to provide care or support to someone who is seriously ill or injured or someone who needs end-of-life care.

For more information, visit:

canada.ca/en/services/benefits/ei/caregiving.html

Remember to inform your executors or a trusted person of the location of your important personal documents: will, documents, insurance, etc. This will make it easier for your loved ones after you have passed away.

If you’ve already completed your Advance Medical Directives (AMD), leave a copy in plain sight at home for the benefit of ambulance services, or leave a copy with someone close to you.

Palliative and End-of-Life Care Environments

Once the progression of the disease has been noted, the discussion generally turns to the various settings where palliative and end-of-life care can be received, such as the home, hospital, CHSLD, or hospice.

All of the following options can be explored, but it's important to know that some environments may not be accessible in certain situations.

IN THE HOME

When a person decides to live the remainder of their life at home, it's essential that they receive the support of a care team (CLSC workers, home-care physician, etc.) to ensure that their quality of life and comfort are maintained at home. The involvement and support of a good network are essential if the end-of-life care is to take place in the home. You should know that follow-up visits from the treating team are organized to ensure that the patient's condition is monitored, and that resource people will be available on call at any time of the day or night. With the required support and instruction, family members help to provide a wide range of direct care to the patient, such as administering medication injections and assisting with mobility.

Depending on the patient's medical needs, end-of-life care at home might be faced with some limits. It may be necessary for the patient to leave home temporarily or permanently. The options of a hospital might be considered.

IN A HOSPITAL

All hospitals offer palliative care in their various care units. Doctors and professionals specializing in this field can offer their advice and expertise in palliative care to care teams. Some centres have dedicated palliative and end-of-life care units. They have a similar vocation and approach to hospices, including a multidisciplinary approach to meet the needs of the patient and their loved ones.

IN RESIDENTIAL AND LONG-TERM CARE CENTRES

CHSLDs have the expertise to provide end-of-life care: care staff are able to answer questions and provide the care needed to ensure comfort, while accompanying the patient through the imminent end of life. Patients can be transferred a return home is no longer an option, or if their state of health does not justify remaining in hospital in a short-stay setting or being admitted to a palliative care home.

Some people may feel they are abandoning their loved one because they were unable to pass away at home. Even if every effort is made to keep a loved one at home, their needs at the end of life are sometimes too great. It's not a failure to ensure that they receive the best possible care, wherever they may be.


KALEI DE LEON, UNSPLASH

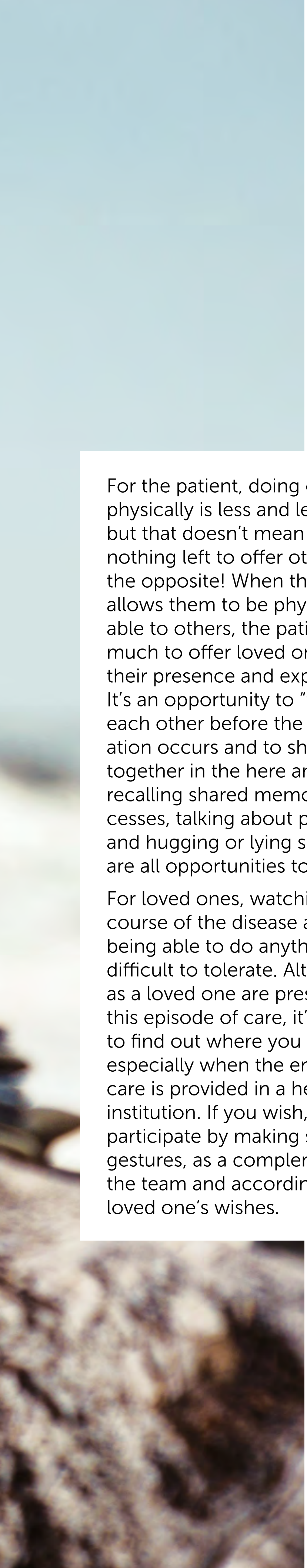
IN A HOSPICE

Hospices are similar to palliative-care units, and also offer multi-disciplinary support to meet different needs. The environment is different from that of a health-care institution. The services offered vary from hospice to hospice. For example, some hospices offer respite services while the patient is still at home, while others offer day-care services or bereavement support. To access hospices in your region, please refer to your care team to find out about their admissions criteria.

Watching this video can help you making your choices and show you the various settings: cisss-outaouais.gouv.qc.ca/language/en/accessing-a-service/obtenir-des-soins-de-fin-de-vie/maisons-de-soins-palliatifs-mathieu-froment-savoie-etc

End-of-Life Support

Faced with illness and death, both the patient and their loved ones share a feeling of powerlessness. Yet everyone reacts differently to these situations. Whatever the reactions, they're part of the personal journey.



TYLER MILLIGAN, UNSPLASH

For the patient, doing or acting physically is less and less possible, but that doesn't mean they have nothing left to offer others. Just the opposite! When their illness allows them to be physically available to others, the patient still has much to offer loved ones through their presence and experiences. It's an opportunity to "fill up" on each other before the big separation occurs and to share. Living together in the here and now, recalling shared memories or successes, talking about past times, and hugging or lying side by side are all opportunities to be seized.

For loved ones, watching the course of the disease and not being able to do anything is often difficult to tolerate. Although you as a loved one are present during this episode of care, it's not easy to find out where you fit in, especially when the end-of-life care is provided in a health-care institution. If you wish, you can participate by making small gestures, as a complement to the team and according to your loved one's wishes.

HERE ARE A FEW SUGGESTIONS THAT MIGHT INSPIRE YOU, DEPENDING ON HOW YOU FEEL:

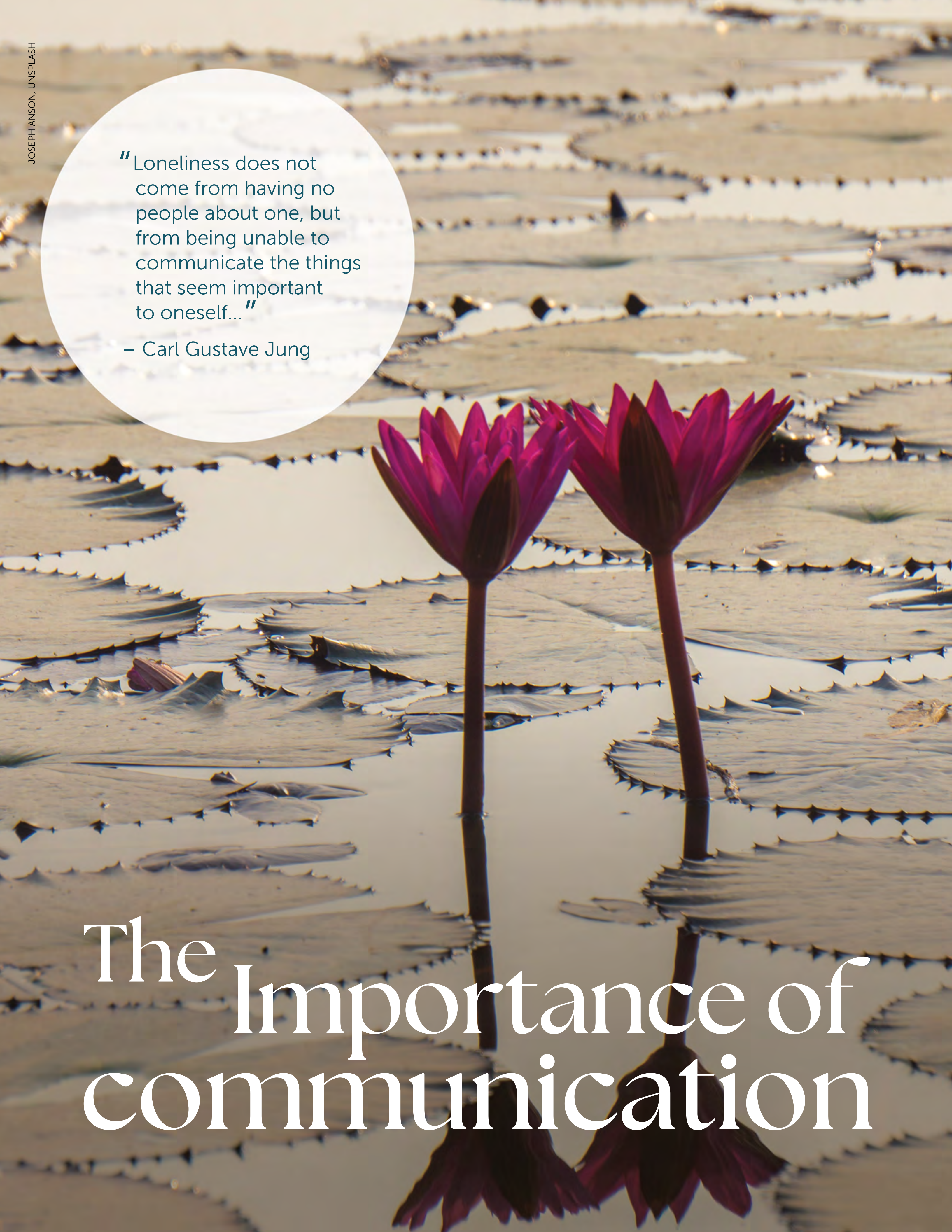
- Help with mouth care, moisten lips, and apply lip balm (people at the end of life often have dry mouths).
- Cool their face with a damp towel.
- Apply moisturizing cream to their hands and feet.
- Offer massages that promote relaxation.
- Help change the bed-ridden person's position to promote comfort, avoid redness, and, possibly, pressure sores.
- Read aloud; sing familiar tunes.
- Create a pleasant environment in the room.
- Pay attention to the sounds around you and see whether they have a soothing or disturbing effect.
- Play soft music or dim the lights.
- Surround the person with familiar objects (blanket, pyjamas, photos).
- Respect your loved one's wishes and habits (makeup, hair, clothes).
- Explain actions before performing them (e.g.,: I'm going to reposition your pillow).
- Offer the patient the foods they like, but do not force them to eat or drink.

Avoid stimulating your loved one when they are sleeping, unconscious, or having respiratory pauses.

Don't force them to eat or drink: their nutritional needs are no longer the same.

Should the patient follow all the advice offered to help them?

The patient must retain control over decisions and discussions concerning their care and end-of-life as long as they are capable of doing so. The care team and you, as a family member, can encourage and advise them, but the patient remains in charge of the situation according to their personal wishes.



JOSEPH ANSON, UNSPLASH

> "Loneliness does not come from having no people about one, but from being unable to communicate the things that seem important to oneself…"
>
> – Carl Gustave Jung

The Importance of communication

COMMUNICATION CHALLENGES

The adjustment forced by illness is deeply upsetting, both for the patient and those close to them. This reality stirs up all kinds of emotions and upsets the established balance in your relationships. Roles and dynamics often change between people. You might find it difficult to understand each other.

Testimonials

"I did everything I could at home. I took care of all the medications and appointments. Even so, I wondered if my wife still loved me as much…"

"You don't learn to be informal caregiver, you just become one all of a sudden! With everything else…"

"I often repeated to my mother to reassure her by saying what is done out of love is not a burden."

"I wondered what meaning my life had had. Was there anything I needed to understand before I died?"

You may need professional help To facilitate communication and help you tackle more difficult issues. A social worker, psychologist, or spiritual advisor might be able to help you through these personal difficulties or questions.

Can an unconscious person at the end of life hear the sound of our voices?

Previous experiments have shown that some people calm down at the sound of a voice. It can be beneficial to continue talking to the person quietly.

COMMUNICATION WITH THE CARE TEAM

It's important to communicate regularly and openly with your doctor and other members of your care team, such as your pharmacist, nurse, orderly, psychologist, social worker, nutritionist, and spiritual-care provider. It's perfectly normal not to remember and understand all the medical jargon.

You can help yourself by:

- Notifying the care team of new symptoms or worsening pain, so that care can be provided as quickly as possible.
- Writing down your questions as they come to mind and, when you discuss them, jot down the answers for future reference.
- Making sure you understand the advice and answers you're given. Asking questions and seeking explanations before the end of the discussion.
- Identifying contact persons to whom the care team can communicate information about changes in your health.
- Asking for information and advice from local resources if you have other concerns such as managing your assets and property, wills, and financial stress.
- Asking the care team to help you set limits for visitors if you feel exhausted, even though you appreciate their support.
- Bringing writing materials (chalkboard, notebook) or asking the team for access to pictograms (representative drawings) if you experience verbal communication difficulties or language barriers during your care. If need be, ask if there is an interpreter on site.

Preparing a Child for the End of Life of a Loved One

When a loved one falls ill, one of the main concerns is to protect the child. **It is now recognized that children need to be informed and involved when illness affects someone close to them but at their own pace.** It's important to encourage communication in simple, clear words, adapted to the child, but without necessarily going into all the details.

Should we avoid talking about death with children?

Being able to talk about the issues surrounding death enables children to grieve fully, at their own pace and according to their own development, which will help them throughout their lives. Like adults, children too need time to say goodbye to their loved ones, consistent with their own cultural beliefs and practices regarding death.

WHY IT IS IMPORTANT TO TELL YOUR CHILD ABOUT SERIOUS ILLNESS AND DEATH

Whatever their age, children have the right and the need to know. They can sense the concern of his loved ones, and in the absence of an answer, they will come up with a cause that could be mistaken. Talking clearly to children sends a message of consistency between what they feel, what they see, and what they're told. This coherence is essential to the child's development and helps them adapt to the challenges they face. When a child asks a question, it means they are ready to hear the answer. You have to trust them. With your help, the child will be able to face reality and adapt to difficult situations. With the right support, this experience can equip them to face, not only the current situation, but future challenges they will encounter in life.

PREPARING CHILDREN FOR THIS STAGE

Who

The parent remains the best person to make the announcement. If he or she is unable to do so, a significant adult can. The parent or adult can be accompanied by someone the child trusts completely, so that they can express themselves and react.

When

As soon as possible. Don't wait for the child to ask questions. The best time is when the child sees, hears, or feels something related to the illness.

Where

In a place where the child feels comfortable to react freely and spontaneously. Ideally, you should tell the child in person. If the news is shared over the phone, make sure an adult is present to provide support.

HOW TO GO ABOUT IT

Remain calm and transparent; use simple words. Don't dance around the situation; be honest. Adapt your language to the child's age. It's important to answer all questions in simple language and according to the child's understanding.

It's okay to admit that you don't have the answer, but that you'll get back as quickly as possible.

Express your emotions. Sharing with the child the emotions you feel about the situation normalizes the fact that the child can also feel and express emotions.

Validate the child's understanding. Verify that the child has understood the information given immediately, or give feedback in the following days. The child must feel that they have the opportunity to clarify the information received.

For more information on how to help a child coping with the death of a loved one, consult the **Support guide for caregivers palliative and end-of-life care accompaniment**:

deuildesenfants.ca

Find out more with info-social 811-2

quebec.ca/en/family-and-support-for-individuals/death/better-cope-with-grief/bereavement-in-children-teens

MARINA SHATSKIH, UNSPLASH

Recognizing the Suffering of Others and Taking care of Yourself

It's normal to sometimes feel overwhelmed by the situation, to feel fear in the face of the unknown, and experience sadness and fatigue. Many caregivers tend to forget themselves as they take on more responsibility for the needs of the person who is sick or the household.

It's important to **recognize the signs of exhaustion**, fatigue, and distress. If you experience any of the following signs, tell your family or care team.

FOR EXAMPLE:

- You feel the need to run away.
- You notice changes in your sleep, diet, or weight.
- You have trouble concentrating and forget important details.
- You feel a loss of interest (in yourself and others).
- You consume more alcohol, medications or tobacco.

CARING SUGGESTIONS FOR THE INFORMAL CAREGIVER

- Set aside some of your time for yourself, without fretting. Once you're refreshed, you'll be better able to take care of your loved one.
- Recognize and respect your strengths and limitations. Professionals are there to help and support you in caring for your loved one.
- Recognize that you're doing your best to help your loved one and be proud of it.
- Ask for and accept outside help. Learn to delegate tasks (e.g.,: reduce the time you spend on household chores by taking advantage of possible home-help programs, have your groceries delivered or order online).
- Suggest that family members or significant others take over from you by being the patient's bedside, so as to conserve your own strength and that of each visitor.
- As far as possible, maintain a healthy lifestyle (hours of sleep, mealtimes, physical activity, etc.).
- Find out about the resources and programs to which you might be entitled (financial support, time off work, food assistance, transportation, etc.). Refer to a member of the care team for guidance. Consult this leaflet to find out about the financial resources to which you might be entitled: cisss-outaouais.gouv.qc.ca/language/en/accessing-a-service/care-and-services-in-the-community/caregiving

Remember that your role is important to your loved one. Your presence is reassuring, but you can't be the sole beacon of light 24 hours a day. It's important to rest to protect your equilibrium, despite the final moments.

To find out more about what it's like to be an informal caregiver, consult this guide:

Info-social 811 option 2

> "Asking for help doesn't mean you're weak, only that you want to stay strong."
>
> – Franck Nicholas

The Care Team Is There for You

There is a whole team around you. A number of professionals from various fields of expertise can be called in depending on your needs. Some resource persons will visit you at home, saving you a lot of daily commuting.

SHANE ROUNCE, UNSPLASH

STEPHANIE HARVEY, UNSPLASH

End-of-Life Symptoms

No one can give a definite answer to the question "How much time is left?" Depending on your assessment of the patient's state of health at the end of life, your doctor can guide you, based on their knowledge and experience of this delicate issue. Nevertheless, the moment of death remains a mystery. Certain symptoms might indicate that the end of life is approaching, although no one can predict the exact moment of death. The way death occurs is unique to each individual.

The following list of symptoms might help you to identify those you might experience at this stage. It's normal not to find or experience them all.

* The time indicated is for guidance only.

Does a person in palliative care who stops eating starve to death?

A person suffering from an advanced illness will not experience hunger and thirst in the same way as a healthy person. If they stop eating, they will die of the illness, not starvation.

In the months preceding death, it is possible that the patient might:

- sleep more
- eat less
- ask to have fewer people around
- communicate less

In the weeks preceding death, the patient might:

- Have breathing difficulties or bronchial secretions;
- Feel muscular weakness;
- Have swelling in the extremities;
- Have variations in body temperature;
- Have increased perspiration;
- Experience disorientation, confusion, or agitation.

In the days or hours preceding death, the patient might present the following symptoms:

- Temporary burst of energy;
- Difficulty moving about;
- Fever or low temperature;
- Marbled, cold, or pale body extremities;
- Glassy, watery, half-open eyes;
- Significant decrease in or absence of appetite;
- Difficulty swallowing or minimal fluid intake;
- Dry mouth;
- Difficulty speaking;
- Decrease or absence of urination;
- Loss of bladder/intestinal control;
- Irregular, shallow breathing with pauses or noisy breathing (caused by secretions);
- Agitation or inactivity;
- Altered state of consciousness.

The Most Common Symptoms at the End of Life

PAIN

Pain is a frequent symptom at the end of life. Assessing pain in someone who can no longer express themselves easily can be a challenge. That's why we need to be attentive to the sick person's nonverbal messages, such as facial expressions, moans, changes in behavior, tense body, or altered posture, which can be signs of discomfort and pain. If you notice any of these signs, don't hesitate to discuss them with the staff. Certain medications or procedures can make your loved one more comfortable.

A FEW DETAILS ABOUT MEDICATION

The use of medication to relieve pain and discomfort in palliative care is important. Each situation requires a medical assessment to determine the best medication for optimal relief. There is no single recipe or set dose for achieving relief. That's why the medical team is constantly reassessing your loved one's comfort. Your cooperation is very important, as your observations will help us adjust the medication. The medical team might discuss with you the possibility of discontinuing certain medications that have become ineffective.

WHAT IS AN INTERDOSE?

An interdose is a supplementary medication that can be administered in addition to regular doses if pain relief or other symptoms is not optimal.

Interdoses are useful for certain activities that can cause pain, such as hygiene care, mobilization, or transport.

It is important to remember that the medication used is not intended to hasten or delay death, but rather to support the patient's quality of life and comfort. Don't hesitate to ask the care team if you have any questions.

Is the administration of analgesics in palliative care addictive?

Higher doses of analgesics are often required to keep the patient comfortable. Their body will adapt and develop a tolerance to the medication, not dependence on it.

Is morphine given to hasten death?

Properly dosed, morphine maintains comfort, but does not hasten death.

DIFFICULTY EATING AND SWALLOWING

People at the end of life often say they no longer feel hungry or thirsty. Some have difficulty swallowing. Sometimes people at the end of life refuse the food they are offered. The situation is often more difficult for loved ones than for the person at the end of life.

As the disease progresses, your loved one's nutritional needs change. At the end of life, loss of appetite, weakness, and difficulty swallowing night intensify. It is therefore important to respect their appetite and food choices, while taking into account their ability to swallow.

Thirst is generally associated with a sensation of dryness in the mouth. The person must be sufficiently awake to feel it. This situation can be remedied by frequent mouth care. The nursing staff can show you how to do this if you wish to take part in the care. Dehydration is not painful at the end of life. It can reduce urine production and lead to a decrease in bronchial secretions and rales.

CHANGE IN SLEEPING HABITS

People at the end of life sleep more and more, which is normal. They might experience fluctuating wakefulness. They can appear disinterested and fall asleep during a conversation. Sometimes, just talking is too much. Don't try to wake the person up; rather respect their sleep.

?

Is it advisable to install an IV solution to hydrate a person at the end of life?

IV solution consists of salt or sugar in water and contains no medication or vitamins. The IV increases tissue fluids and possibly respiratory secretions, thereby aggravating discomfort.

ANTHONY IEVLEV, UNSPLASH

BEN CURRY, UNSPLASH

The Most Common Symptoms at the End of Life (cont'd.)

AGITATION, ANXIETY, DISORIENTATION

In the final moments of life, your loved one might experience changes in their mental and cognitive states.

They could:

- Become agitated, aggressive, or irritable (don't take it personally).
- Have difficulty understanding simple instructions or using everyday objects.
- Have difficulty organizing thoughts.
- Have hallucinations.
- Have difficulty recognizing loved ones.
- Lose the notion of time.
- Not recognize their your surroundings or think that they were somewhere else.

The care team calls this state of confusion "delirium." Remember that these behaviors are due to illness. To support your loved one during episodes of delirium, speak softly to soothe them.

DIFFICULTY BREATHING

Difficulty breathing can be a distressing sensation, but it can be partially relieved by medication or by an appropriate procedure suggested by the care team.

WHAT IS THE RESPIRATORY DISTRESS PROTOCOL?

The respiratory distress protocol is a combination of injectable medications given when breathing deteriorates acutely, and the person presents with agitation and intense anxiety. Applying the protocol in cases of distress rapidly reduces the state of consciousness and relieves severe shortness of breath. This does not result in death. Often, death occurs shortly after a distress protocol is administered, but this is the consequence of the underlying disease that caused the distress.

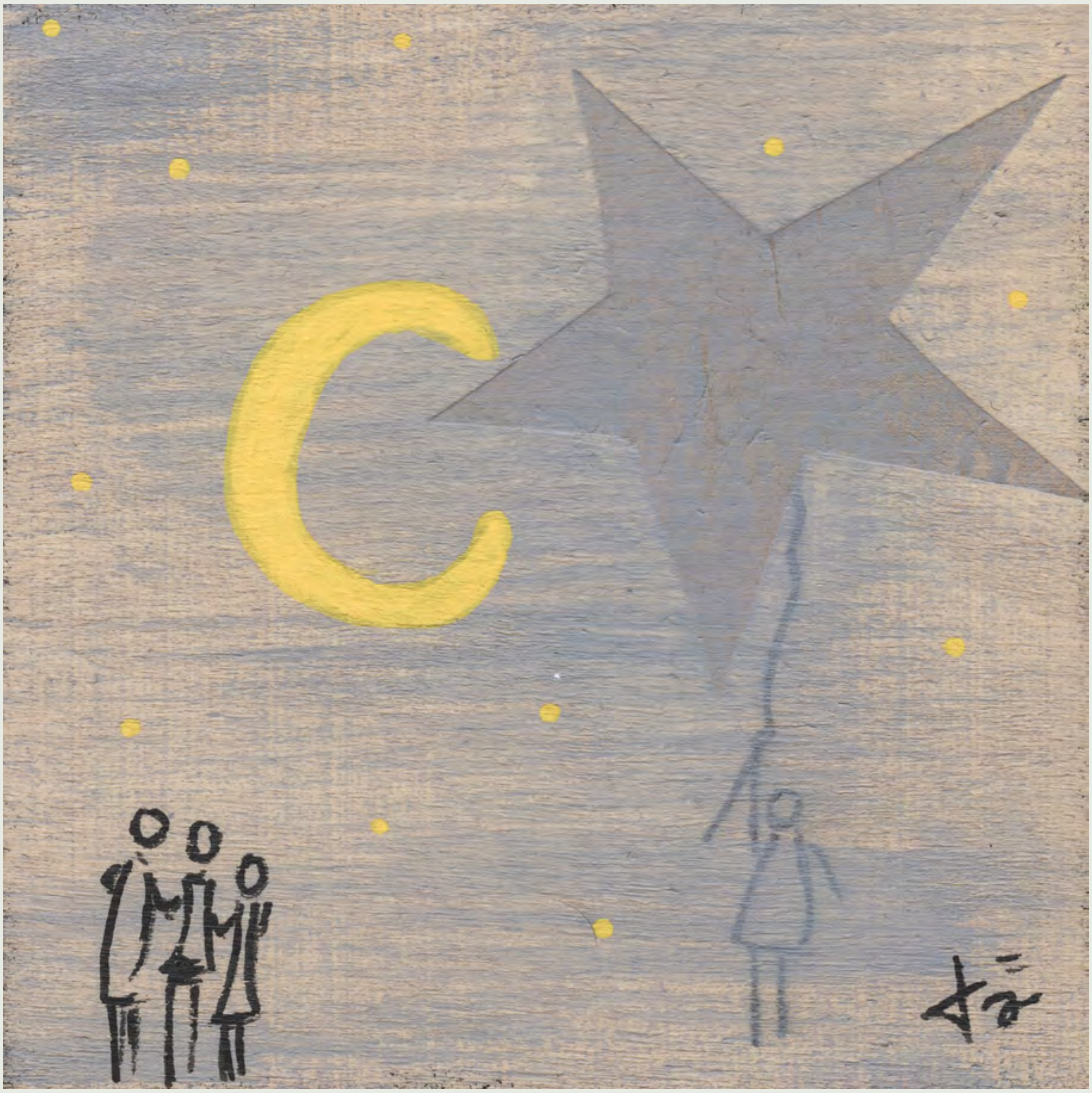
RALES AND NOISY BREATHING

Your loved one might have difficulty expelling secretions from their throat and bronchi. These secretions alter breathing, giving the impression of noisy, labored breathing. Some would say it's like the cooing of a pigeon. It's important to understand that a person at the end of life, if unconscious, is rarely bothered by their rales. This situation will affect you more than them. Medication might be available to reduce the production of new secretions.
It is rarely possible to aspirate these secretions, as they are located in the bronchial tubes. Attempting to aspirate them might cause irritation and increase discomfort.

Does a person at the end of life have to be put on oxygen?

Before starting or prolonging the use of oxygen, ask yourself what makes your loved one calmer and more comfortable. In some cases, oxygen use causes more discomfort than benefit, because of the tubing, the nose dryness, and the noise of the circulating air. The administration of oxygen at the end of life is not mandatory, since the body's need for oxygen diminishes and the lungs are less able to absorb it. When breathing is difficult, certain drugs such as morphine are more effective than oxygen.

If you have any concerns or questions about certain symptoms, please do not hesitate to contact the care team.



ARTISTE : JOSÉE TREMBLAY • TOUS DROITS RÉSERVÉS

"If you love a flower that's in a star, it's sweet at night to look up at the sky."

– Antoine de Saint-Exupéry

The Last Moments of Life

In the very last moments, certain types of care are no longer essential. For example, taking blood glucose, temperature, or blood-pressure readings can cause discomfort. On the other hand, changes of position and hygiene and skin care remain very important for maintaining the comfort and dignity of the person at the end of life.

When death is imminent and inevitable, you may want to be by your loved one's side. It's not always easy to reconcile this presence with your other obligations. The care team can guide you through this process.

WHEN DEATH OCCURS

Even if death is foreseeable, the loss becomes very real when death occurs. Take the time you need to be with the deceased. The moments following a death are often very difficult. If you're on your own, don't hesitate to contact friends and family. The care team will be able to support you and inform you of the next steps and actions that need to be taken.

Grieving

ANN SAVCHENKO, UNSPLASH

Faced with inevitable death, people at the end of life and their loved ones will feel pain and sadness. These are normal human reactions to significant loss.

Grief is prepared during the stage leading to the end-of-life. The grieving process is unique to each of us, and is one of the challenges we face. It's important that everyone respects their own pace and listens to their needs. Having the right support is one of the best ways to get through this stage.

The months following your loved one's death may seem difficult, as the people who formed your support network return to their usual lives, leaving you to define what will become your new reality.

You could observe certain reactions and experience different stages of grief

SHOCK AND DENIAL

The shock and denial phase may last a few minutes, days, or weeks.

During this stage, it can be difficult accepting reality, or you might deny it or be unable to react.

DISORGANIZATION

The disorganization phase may last a few weeks or months. At this point, you might experience great sadness, anxiety, and helplessness. You might also withdraw into yourself and lose interest in your usual activities.

PROTESTING

The protesting phase might last a few weeks or months. During this stage, you might experience anger, incomprehension, a sense of injustice, and varying degrees of guilt. You might look for someone to blame and for a meaning to the loss. You will start to recognize that the loss is permanent.

REORGANIZATION AND ADAPTATION

The reorganization and adaptation phase can last from a few months to a few years. You will be less overwhelmed by loss and gradually begin to enjoy yourself again. You will have renewed interest and start thinking about new projects. You will adapt to your new situation.

Some of these stages may be experienced more intensely or for longer than others. The bereaved person does not necessarily go through all the phases, and might experience them in a different order from the one presented. They might go through certain stages at the same time, or even go back to one already experienced.

How to stay strong in the face of loss

Grieving is difficult and requires a lot of energy. It's more than normal to feel sad.

Do the people around the bereaved person help by avoiding the subject?

On the contrary, giving them the space to talk about it again and again helps their grieving.

Doesn't not crying mean you're insensitive?

Everyone experiences things in their own way. Some people prefer to cry alone or express their emotions in other ways.

KEEPING HOPE ALIVE

At the end of the grieving period, you can:

- Be able to talk or hear about the deceased without being destabilized or emotionally disturbed.
- Regain a state of balance as well as physical and mental energy.
- Rediscover the desire to invest in new projects and create new bonds;
- Be at peace with the death of your loved one.

Talk to a counsellor about resources to help you through this stage. Don't hesitate to join a bereavement support group organized by some community organizations, funeral homes, and hospices. You can also contact your CLSC to request psychosocial follow-up.

READING AND RESOURCES ABOUT BEREAVEMENT

Maison Monbourquette:
maisonmonbourquette.com

> "You're not where you used to be, but you're everywhere where I am."
>
> – Victor Hugo

SEBIN THOMAS, UNSPLASH

Conclusion

The stage you're going through is undoubtedly rich in emotions and questions. It will require a lot of adjustment and energy. But remember that you're not alone. The medical and professional team is always there to hear what you are experiencing and to answer your questions. Expressing your needs and concerns will help you get through these moments with greater serenity.

REMEMBER

You are the expert on your situation. You know your needs better than anyone.

As a person in the final stages of life, or as a caregiver, you are part of the team. Share your observations, views, and personal perspectives, because we need to adapt your care and services.

The care team is there for you. Don't hesitate to refer to it with your questions, concerns, and emotions. Communication is the key to teamwork!

As a caregiver, preserve your personal equilibrium by accepting to delegate tasks or ask for help from those around you.

Personal Notes

References

A number of doctors and health-care professionals in Estrie have contributed to writing and revising this tool to support you in this process.

Thanks to each and every one of them!

Bibliography

Ces derniers moments de vie… Pour mieux vous guider, 2017, Centre intégré de santé et de services sociaux de la Montérégie-Ouest

Preparing Children for the Palliative Illness or Death of a Loved One, 2021, CIUSSS de l'Estrie – CHUS

Don't Use the 'D' Word: Exploring Myths about Children and Death, Canadian Virtual Hospice

Guide d'accompagnement pour la personne en soins palliatifs et de fin de vie et pour ses proches, Centre intégré de santé et de services sociaux de Chaudière-Appalaches

Support Guide For Caregivers. Palliative And End-Of-Life Care Accompaniment, 2019, CIUSSS de l'Estrie – CHUS

Partir pour ailleurs – Quand la dernière page se tourne, Guide de la Maison Aube-Lumière.

Derrière mes larmes d'enfants, 2006, Éditions Ressources, Josée Masson

Palliative and End-of-Life Care, A Guide For Caregivers, Centre intégré universitaire de santé et de services sociaux de la Mauricie-et-du-Centre-du-Québec

Levels of care: Let's talk about it, Institut national d'excellence en santé et en services sociaux

Other Sources of Information

FOR GENERAL SUPPORT

CLSCs in your area

Cooperatives or funeral homes in your area

Ordre des psychologues du Québec

Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec (French only)

TO FIND OUT MORE ABOUT PALLIATIVE CARE

Palli-sciences (French only)

Association québécoise des soins palliatifs (French only)

FOR INFORMAL CAREGIVERS

A Caregiver's Guide. A Handbook about End-of-Life Care, 2014, Canadian Hospice Palliative Care Association

Mental health, Gouvernement du Québec

L'APPUI

FOR MANAGEMENT AND FINANCIAL ASSISTANCE

FADOQ

Your money and property, Ministère de la Justice du Québec

WHAT TO DO IN THE EVENT OF DEATH

Gouvernement du Québec

ABOUT BEREAVEMENT

When to Tell the Children: Preparing Children for the Death of Someone Close to Them, Canadian Virtual Hospice

Deuil jeunesse (French only)

Stages of bereavement, Gouvernement du Québec

GEOVANNI RODRIGUEZ, UNSPLASH

ANTON SHAROV, UNSPLASH

Centre intégré
de santé
et de services sociaux
de l'Outaouais
Québec

FEBRUARY 2024