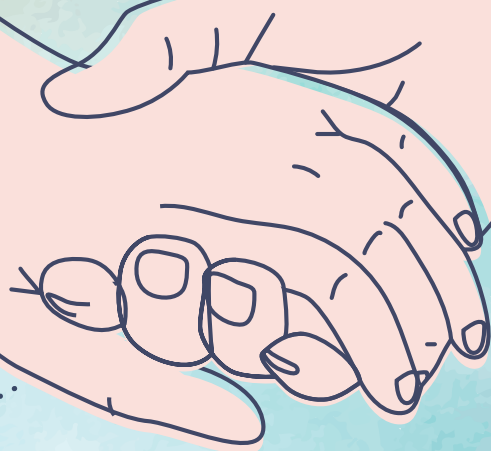

SUPPORT GUIDE FOR CAREGIVERS

PALLIATIVE AND
END-OF-LIFE CARE
ACCOMPANIMENT

*Beyond
surviving,
finding quality
of life!*



Québec 

© Guide produced in 2019 by the Direction des soins infirmiers of the Centre intégré universitaire de santé et de services sociaux de l'Estrie – Centre hospitalier universitaire de Sherbrooke (CIUSSS de l'Estrie – CHUS)

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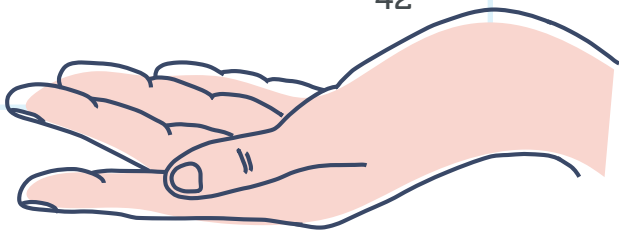
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*The masculine gender is only used to simplify the text.

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INTRODUCTION

When a loved one receives an incurable disease diagnosis, it wreaks havoc on the lives of all those who are close to this person.

Accompanying a loved one in his final moments, whether it's a parent, a spouse, a friend, or a child, can be difficult and troubling.

Like many, **you have decided to opt for at-home care for a loved one.**

Providing him with adequate care can become a daunting task.

However, these are often moments filled with true love, intimacy, and sharing. When you care for a loved one and accompany him throughout palliative and end-of-life care, you contribute to an important milestone that is part of his life path.

This guide aims to support you in the various stages of your role as a caregiver.

It presents resources, different tools, and reflections that will accompany you in your daily activities. Another purpose of this guide is to help you get through this ordeal with serenity, while respecting your own journey.

WHAT IS PALLIATIVE CARE EXACTLY?

Palliative care aims to support life and considers death to be a normal process.

- › It does not hasten or delay death;
- › It alleviates pain and other symptoms;
- › They integrate the psychological and spiritual aspects;
- › It offers all support that is necessary.

Palliative care represents comfort care that is provided to help those requiring palliative or end-of-life care overcome physical, psychological, social, material, or spiritual problems, considering their expectations, needs, hopes, and concerns.

HOW TO USE THIS GUIDE

This guide is divided into three sections:

- **The shock**
- **The ups and downs**
- **The end of your loved one's life**

These are the main stages that caregivers who accompany a loved one through palliative or end-of-life care face. Throughout this guide, you will find different symbols. Each of these symbols refers to a very precise element: a tool, a resource, a tip, etc.



LEGEND

Resources and partnerships

Resources that may help you



Tools

Tools that will help you obtain further information

Website



Reflection

Elements that deserve your attention



Tips

Elements that will make your journey easier



For many of you, supporting a loved one is only natural, and you simply assume your role as a caregiver. For others, this role may be difficult. Regardless of your situation, it is important that you ask yourself certain questions when supporting a loved one at home:

- › Am I capable of **supporting my loved one physically and morally** in his incapacities and in his globality as a person?
- › Can I **respect his wishes and life choices**, while respecting my own beliefs and personal limits (ex.: not administering intravenous medication, managing incontinence, accept his passing at home, etc.)?
- › Have I **obtained all the necessary information** from the hospital or the at-home care team concerning my loved one's health status **in order to ensure that I am able to support him at home**?
- › Have I considered **the repercussions of my role** as a caregiver on other spheres of my life (my job, my health, my social life, my lifestyle habits, my financial situation, my relationships, etc.)?
- › Have I thought about the strategies that will help me fulfill my role as a caregiver **alongside my loved one**?
- › Am I comfortable **openly speaking about death with my loved one and with medical and health professionals** to better plan the stages to come?
- › How much time do **other family members** have to offer? Do those in my personal network want to or can they get involved and help, provide care for my loved one, or share certain tasks? Am I willing to give them the space required to foster their involvement?
- › Am I open to **accepting outside help**, maybe even from within my own living environment (community organizations, CLSC, etc.)?
- › What do I need **to recharge my batteries, rest, and better accompany** my loved one?

If you are unable to answer these questions, don't worry. Reading this guide will help you understand the various stages and find answers at your own pace throughout your accompaniment journey.

It is important that you determine what may help you, so that you can openly tell others and make clear requests. For example:

- I would need someone to prepare food for me, I don't have time to cook.
- I need someone to take over for me for three hours per week so that I can go for a walk.

Although the caregiver role is one that is not easy to fulfill, those who exercise it are often transformed. It's all a question of balance, respect, and acceptance.



Many positive elements are associated with caring for a loved one at home. How can they be a part of your accompaniment experience?

- › Strengthen or maintain **family ties**.
 - › **Take maximum advantage** of the time you spend together to make them **good days**.
 - › **Take the time** to talk, listen to music, watch television, and enjoy certain hobbies per your loved one's capacities.
 - › Share your emotions, what makes you laugh or cry, and your thoughts.
 - › Reminisce about **fond memories and share them** (look at photo albums, videos).
- Relive your memories, your best moments. Your loved one may feel the need to revisit his life, to assess it; accompanying him on this lifelong journey is a privilege.**
- › Create **new memories** (videos, pictures, scrapbooking, etc.).
 - › Spend as much time as possible in a **familiar environment**, where lifestyle habits are already known (routine, meals, visual references, comfort, social network).
 - › **Together, experience** the reality associated with the illness. Find a positive meaning for the time you have spent together and the precious moments you are currently experiencing together. Make peace with the past.
 - › Have the satisfaction of knowing that **you are doing your best to help** your loved one hands-on instead of feeling powerless in the face of the situation.

THE STEPS INVOLVED
IN THE ACCOMPANIMENT OF
A LOVED ONE IN PALLIATIVE
OR END-OF-LIFE CARE

THE SHOCK



Request information, ask yourself
questions, find key resource people
and medical references

When everything is crumbling around us

The shock is the result of bad news that brutally interrupts your life. Palliative and end-of-life care for a loved one causes a wide range of upheavals that can disturb the balance between the satisfaction of your needs and those of your loved one.

REACTING TO THE SHOCK ASSOCIATED WITH THE NEWS

The shock may cause different reactions:

- › Denial
- › Avoidance
- › Loss of hope
- › Fear and concern surrounding the unknown
- › Sense of loss of control and power over your life
- › Insecurity
- › Mourning future projects
- › Frustration, anger, aggressiveness

You may have the impression that:

- › Time has stopped.
- › Your priorities have changed.
- › Life and death have a new meaning.
- › What you took for granted up until now is forever changed.
- › Your expectations for the future must change.
- › Life has lost its meaning, its purpose.

.....
**ALL THESE
 REACTIONS
 ARE NORMAL.**

You may:

- › Not want to believe it.
- › Question the information provided by the doctor.
- › Feel powerless or a sense of injustice.
- › Relive certain resolved or unresolved conflicts (from the past).
- › Maintain hope.

Each person reacts to difficult news, changes, loss, and sadness in a very personal way. It is **very important that you give yourself time to experience this stage**. You or your loved one may experience a sense of emergency to live.

Let yourself experience these emotions; doing so will impact your journey. **You will eventually regain your balance**, thanks to your internal resources and with the help of the healthcare professionals that surround you. Believe in yourself and, above all, give yourself all the time you need.



RESOURCES THAT MAY HELP

At-home support

Palliative care is provided at home. If you do not already have access to this service, it is important that you ask your loved one's healthcare team to point you to it.

Know that palliative care clients are prioritized.

You may also file the initial request yourself if you are unable to contact the healthcare team. Simply call your local service network's point of access for at-home care.

Coaticook | 819 849-9102, ext. 57162

Des Sources | 819 879-7158, ext. 39438

Granit | 819 583-2572, ext. 2520

Haut-Saint-François | 819 821-4000, ext. 38232

Haute-Yamaska | 450 375-1442, ext. 66279

Pommèraie | 450 263-3242, ext. 34231

Memphrémagog | 819 843-2572, ext. 2416

Sherbrooke | 819 780-2220, ext. 48700

Val Saint-François | 819 542-2777, ext. 55268

Patient navigator

Following your loved one's registration for at-home care support (CLSC component), we will evaluate your situation and assign a patient navigator (nurse, social worker, or case worker) who will play the role of a **conductor** to help you organize your various needs and services. For example: bathing or nutrition aid, administering medication, advice on how to adapt the environment and for the use of specialized equipment, etc.



Oncology pivot nurse (OPN)

If your loved one is still undergoing chemotherapy or radiotherapy treatments, an oncology pivot nurse can offer support, to you and your loved one. Thus, she can help answer questions about the treatments and help you make difficult decisions or manage any resulting symptoms. Do not hesitate to discuss any concerns with the attending physician (surgeon, specialist, oncologist, or radiation oncologist) to have your loved one's needs assessed. The pivot nurse can also establish any required links with at-home care per your needs, yours and your loved one's.

Interdisciplinary team

Many professionals from different areas of expertise may be called upon depending on your needs and your region:

- Doctor
- Nurse and auxiliary nurse
- Social worker
- Case worker
- Occupational therapist
- Physical therapist
- Nutritionist
- Psychologist
- Respiratory therapist
- Health and social services auxiliary
- Spiritual care coordinator
- Volunteer
- etc.



Certain resource people can make house calls, and therefore help you avoid many trips.

Family physician

Make sure that you and your loved one have a family doctor.

You don't have a family doctor?

Register with the access service for clients without a family doctor and inform your patient navigator of your situation. He may prioritize your request and help you find a family doctor faster.

- › **Family doctor finder (GAMF)** > sante.gouv.qc.ca/en/
Click on "Finding a resource" and then on "Family doctor".
- › **Guichet d'accès clientèle orpheline (GACO)** > www.sante.gouv.qc.ca/en/votre-gaco



Another option is physician consultations **without appointments**. Visit the following website for information: www.santeestrie.qc.ca/en/gap.

You have filed a request and are waiting for a family doctor?

It is very important that you update the information in your file as well as your loved one's information so that it reflects your current situations. Give your patient navigator authorization to inform your future doctor of any changes in your situation or that of your loved one.

You already have a family doctor?

Schedule a meeting with your family doctor so that he is informed of your current situation and that of your loved one. If he cannot make a house call, discuss the possibility of having access to a doctor who makes house calls with your at-home care coordinator.

Medical specialists

(cardiologist, pulmonologist, oncologist, nephrologist)

Depending on your loved one's situation, you have most likely already been in contact with a specialist for some time now. It is also probable that this specialist has been more present than the family doctor. Ultimately, the family doctor will most likely take back the torch for certain roles that were assumed by the specialist (ex.: pain and symptom relief).

Palliative care doctor

Your loved one's doctor may recommend a doctor who has in-depth expertise in palliative care. He will work in collaboration with the healthcare team in order to alleviate his pain if it remains present despite the usual treatments. Palliative care doctors are present in hospitals, CLSCs, or family medicine units.



SPECIALIZED RESOURCES THAT MAY HELP YOU

Santé Estrie

The CIUSSS de l'Estrie – CHUS' website contains a lot of practical information. It also lists the care and services that are offered as well as the different resources available, if necessary:

- › www.santeestrie.qc.ca/en/home/, under Care and services or Palliative and End-of-Life Care.



A video on the end-of-life journey and locations

Through this video, you will follow the journey of four people, accompanied by their families, who have chosen to live their last moments in hospital, in a CHSLD, in a palliative care home and at home.

www.santeestrie.qc.ca/end-of-life



Which services are available nearby?

With your patient navigator, discuss resources and community organizations that may help fulfill your everyday needs.

Community organizations

Community organizations represent essential partners of the health and social services network. They offer different means to support and inform you. **Consult them!**

You may read the *Aidant pressé, ressources fûtées* guide. It's a regional directory for Eastern Townships caregivers for seniors. It lists all the information pertaining to community organizations that could be useful for you and your loved one:

- › Website: <https://ainesestrie.qc.ca/proche-aidant/>
- › Or ask you patient navigator for a printed copy.



You may also find the resources available near your home, get practical advice, and have access to a calendar of activities organized in your region on the website of an organization called L'Appui:



› **Website: www.lappui.org**

Click on "Find resources" and enter your postal code in the *Advanced search* section.

If you are searching for specific resources, you can type keywords (ex.: respite, grief, transportation, etc.).

› **By telephone: communicate with Caregiver Support by calling 1 855 852-7784.**

Caregiver Support is a free and confidential phone consultation, information, and referral service for caregivers of seniors and their family members, practitioners, and healthcare professionals. Their professional counselors can:

**LISTEN
TO YOU**

with care and
compassion

REFER YOU

to local resources
and services that
meet your needs

INFORM YOU

with clear, accurate,
and up-to-date
information



Use the visit card your patient navigator gave you and read the different documents that you received.

The visit card makes it possible to write the contact information for all at-home care aids and resources you must regularly communicate with in one place.

Per the evolution of your needs, your patient navigator may provide you with different documents that will help you manage everyday life.

Can I take time off work to stay home with my loved one?

Check to see if you are eligible to receive caregiving benefits from the Canadian government:

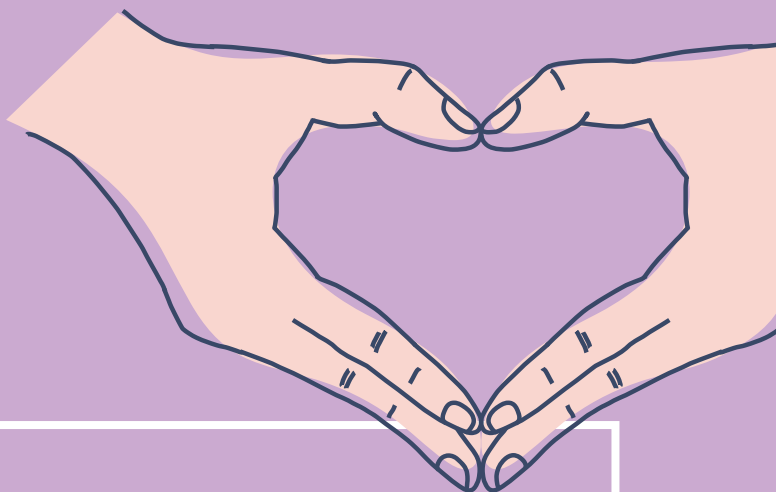
- › Visit the website:
www.canada.ca/en/services/benefits/ei/caregiving.html
- › By telephone: 1 877 644-4545 (toll free)

Could I receive financial help for support services?

Based on your situation, discuss different foundations that can help with your patient navigator. Financial help is also offered via the at-home support service.

Do you have insurance?

Check with your insurance company about possible reimbursements. During appointments with your loved one's family doctor, ask him for a copy of your loved one's medical file so that you may send it to your insurance company to avoid further delays.



THE STEPS INVOLVED
IN THE ACCOMPANIMENT OF
A LOVED ONE IN PALLIATIVE
OR END-OF-LIFE CARE

THE UPS AND DOWNS

Daily life with your loved one,
managing difficult moments,
adapting, preparing

DAILY LIFE WITH YOUR LOVED ONE

Even if we would like all of this to be a bad dream, life goes on and it insists.

Accompanying your loved one through illness is accepting to be by his side with a sense of powerlessness, since you cannot take his pain or sadness away. **Know that your presence is your loved one's biggest solace and that, despite periods of silence, a comforting presence is invaluable.**

"End-of-life is not the end of the relationship."
- Marie Henkel

Illness causes many upheavals and provokes a wide range of emotions. You see your loved one change physically and psychologically. Your roles change. You become a manager: appointments, medication, visitors, transportation, etc. Your loved one may be inclined to rely on you for many aspects of daily life.

Illness tends to take over. Inside, you are fighting a battle, seeking the peace that you desperately desire. **You must accept the fact that you can't do it all. To restore your own balance, it's time to ask for help.**

Beyond the illness, your loved one is there, he is still the same, the one you know, the one you have shared so many life moments with. Make a point of finding that person, taking advantage of the small moments of joy, even the very simple ones. Find your loved one, otherwise your caregiver role will lead you to forget who you are...

"Love is the only engine of survival."
- Leonard Cohen

“Asking for help does not mean that you are weak, it only means you want to stay strong.”

– Franck Nicholas

MANAGING DIFFICULT MOMENTS

Your journey will not always be the same as your loved one's. You are together, but each of you is moving along at your own pace. At times, you may move forward hand in hand. At other times, you may be staggered. One of you may be ready to discuss a difficult subject, such as the end of life, whereas the other may not be there yet. Talk to a professional to get the necessary support.

Your loved one's physical and psychological symptoms can be compared to an ocean that causes you to drift through tides and currents. At times, it may feel like huge waves are crashing down on you. Know that they will, however, lead you to a calm beach, where the setting sun shines bright before the cycle repeats itself...

The team, your lighthouse



You may face certain situations. **Know that you are not alone.** When you are going through difficult moments, talk to a member of the interdisciplinary team. He will put you in contact with the right professional or resource and help you take the necessary steps or act for you.

An entire team is available to support you!

EXAMPLES OF SITUATIONS THAT YOUR LOVED ONE MAY EXPERIENCE FOR WHICH MEMBERS OF THE INTERDISCIPLINARY TEAM CAN HELP

| | |
|---|---|
| Pain If managing pain at home is difficult, short stays in the palliative care unit or hospital are possible. | <ul style="list-style-type: none"> • Doctor • Nurse • Pharmacist • Physical therapist • Occupational therapist |
| Loss of appetite Weight loss Digestive problems, nausea Constipation or other problems | <ul style="list-style-type: none"> • Nutritionist • Nurse • Doctor |
| Breathing problems | <ul style="list-style-type: none"> • Doctor • Respiratory therapist • Nurse |
| Anxiety Insomnia Emotional problems Grief Mental or existential suffering Symptoms of depression | <ul style="list-style-type: none"> • Doctor • Psychiatrist • Social worker • Spiritual care worker • Nurse |
| Loss of meaning Spiritual questions | <ul style="list-style-type: none"> • Social worker • Spiritual care worker |
| Loss of mobility and autonomy Falls Physical weakness Adaptation of the environment | <ul style="list-style-type: none"> • Health and social services auxiliary • Occupational therapist • Physical therapist |
| Blood collection Injections Wounds | <ul style="list-style-type: none"> • At-home nurse • At-home auxiliary nurse |
| Medication management Drug interactions | <ul style="list-style-type: none"> • Doctor • Nurse • Pharmacist |
| Legal aspects (ex.: will, protection mandate, etc.) Financial difficulties | <ul style="list-style-type: none"> • Social worker • Notary • Funeral advisor |

Is your loved one acting out?

Your loved one may become highly demanding, irritable, or seem unappreciative although you are doing everything in your power to ensure his well-being. **Don't take it personally, respect your limits, talk to someone who is not involved in the situation, talk to your loved one.** He is experiencing the biggest loss being loss of power, of control over his life. Even if your loved one's reactions are normal, that does not mean you should accept the way he is treating you.

Communicating with your loved one

Communicating involves talking, but more importantly, listening. Communicating also involves offering the "gift of your presence". This simply means to be there, to express an interest in the person, without having expectations, or even the need to speak. Sometimes, communicating also involves establishing physical contact with the person, if he is open to it and allows it. Simply touching the person, holding your loved one in your arms or gently caressing him represent excellent ways to express your affection, your acceptance, your empathy. This can be very important for both of you.

Tips for fostering good communication:

- › To protect your loved one, you may instinctively avoid certain things. However, it is very important that you **discuss** your feelings, your concerns, and your fears, even if certain sensitive issues are more difficult to talk about.
- › Develop the ability to **simply accompany your loved one in silence**; doing so may provide just as much comfort as a conversation, and it requires much less energy.
- › Respect your loved one's intimacy, whenever possible, **give him control when making decisions** concerning his care and activities.
- › Avoid **giving too much advice** and accept the fact that your loved one may reject your advice from time to time.
- › Encourage, but do not push.

Ask your patient navigator about the possibility of using a communication chart if your loved one has difficulty communicating verbally.

Communication with the healthcare team

It is very important that you regularly and openly communicate with the doctor and all members of the healthcare team. Your patient navigator wants to know what is going on so that he can act quickly.

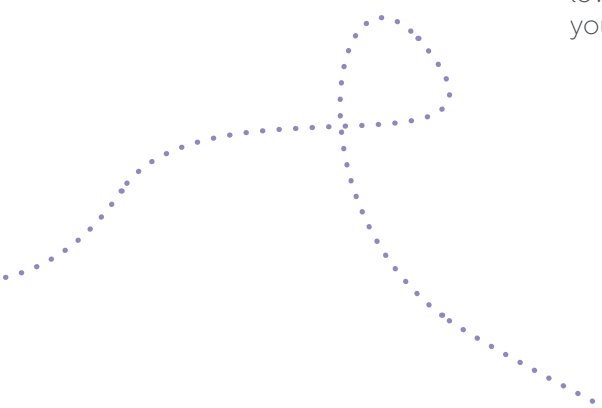
To help, you may:

- › Write down any questions you may have for the healthcare team as you think of them and note their answers so that you may refer to them later.
- › Make sure you fully understand the advice and answers you are given, ask questions and request explanations before ending any discussion you may have with the team.
- › Immediately inform the healthcare team of any new symptoms or new pain so they may intervene as quickly as possible.

Take care of yourself:

Your loved one remains concerned for the well-being of those who surround him, particularly for his caregiver. The risk of exhaustion is high during this period and your loved one may worry about being a burden for others.

You must keep in mind that your loved one will most likely mourn his autonomy as the weeks go by. You will have to support your loved one through various daily struggles. Show him that you are taking care of yourself physically, emotionally, and spiritually. In doing so, you will spare your loved one from worrying about your health.



“When communicating, the most important thing is to hear what is not spoken.” – Peter Drucker



Recognizing signs of FATIGUE, EXHAUSTION, and DISTRESS is important. If you experience one of the following signs, mention it to your patient navigator:

- › You feel the need to flee.
- › You feel overwhelmed and disorganized.
- › You notice changes in your sleep habits or your diet.
- › You are experiencing emotional changes (irritability, anger, crying, sadness...).
- › You are having difficulty concentrating and forgetting important details.
- › You have lost or gained weight.
- › You have lost interest (in yourself and others).
- › You are consuming more alcohol, medication, or tobacco.

In such circumstances, respite and psychological support services could be helpful and help you push through.

"Thinking of yourself is not selfish. It's simply a question of preserving balance so you are able to give to others." - Alexandra Julien



Your WELL-BEING is important. Here are a few tips that will help you take care of yourself:

Plan an at-home presence if your loved one cannot stay home alone (resources offering respite, a family member, volunteers, etc.).

- › Reserve some of your time for yourself, **without feeling guilty**. This attitude will help you take care of yourself so that you can better take care of the person who needs you.
- › **Pursue activities** that are important to you to replenish your energy (walking, going to the movies, meeting with friends, reading, crafts, meditation and prayer, etc.).
- › **Share your concerns** with those around you (family, friends, colleagues, neighbours, healthcare staff).
- › **Recognize and respect your limits**, ask for help even if your loved one is reluctant.
- › Be **proud** of what you are doing for your loved one.
- › Find what **makes you happy**.

- › Maintain a healthy diet.

When you cook, prepare extra portions so that you always have meals that are ready in the refrigerator or freezer.

Have large quantities of healthy snacks that can be eaten on the go: fruit, cheese, yogurt, peanut butter, whole grain crackers. They will be useful when you don't have time to stop and eat.

- › Keep records.
- › Do not neglect your own routine appointments with your dentist or doctor.
- › Try to plan your sleep schedule around your loved one's schedule.

- › Limit household chores by hiring someone who can take care of the most demanding tasks, such as laundry or vacuuming (ask your patient navigator, if applicable, if such services are offered within your sector).
- › Be sure to also make time for others who play an important role in your life and try to integrate moments with them in your schedule.
- › Make sure you have enjoyable moments with your loved one. It is important that you set all the tasks that need to be done aside and take advantage of the moments you can experience together.

Ask your patient navigator about respite measures!

BE PREPARED

- Starting a discussion with your loved one to prepare for the end of his life is far from easy. Your patient navigator will guide you through this discussion. Being prepared eliminates fear of the unknown and helps your loved one maintain power over his life.
- No matter where you choose to experience these last moments with your loved one, professionals will oversee palliative care, alleviate his suffering, and maintain your loved one's quality of life.



Is picking an end-of-life location while respecting your loved one's wishes and your capacities possible?

At home

Your loved one may wish to end his life at home. Staying home makes it possible for your loved one to preserve habits, to continue to live in a familiar environment, and fight the upheavals caused by the illness. However, this decision involves an important personal investment and an increased presence of outside support.


Essential conditions of at-home end-of-life

- › Caregiver's willingness to keep loved one at home and ability to provide certain types of care with the support of the team
- › Accessible and adaptable environment
- › At-home support team's involvement and a doctor who can make house calls (if this isn't the case, talk to your patient navigator)
- › Support from network (family, neighbours, friends, etc.) and respite measures
- › Ability to tolerate surprises and respond quickly

When a loved one decides to spend his last days at home, the at-home support team accompanies the family.

At a palliative care home

These homes aim to welcome those who have reached the end-of-life stage in an environment that is serene and much like a home environment. A healthcare team (doctors, nurses, volunteers, psychologists) is present to support your loved one, you, and your family. These homes also offer respite services. Beyond that, they accompany those left behind throughout the grieving process.



Ask how you can go
to a professional of the
interdisciplinary team.

At the hospital

Certain hospitals have palliative care units that complement at-home support. Depending on the condition of your loved one, temporary hospitalization in such an environment may be necessary. Your loved one may return home afterwards.

Nursing homes and long-term care facilities (CHSLD)

Long-term care facilities provide comfort care. Personnel working in these facilities are equipped to support you and alleviate your loved one's pain.

Illness is unpredictable. Even if everything is well prepared and your loved one's wishes are known, his body may serve a few surprises and push you to react quickly. The ambulance service remains a key solution in the case of an emergency. Your loved one could be treated at the hospital in an urgent context. Depending on the evolution of his condition, other decisions may have to be made (transfer to a palliative care home, return home, etc.).

Your loved one's last wishes

As the weeks go by, your loved one will share his last wishes, concerns, and questions pertaining to the end of his life. **It is important that you discuss these topics so that you can respect your loved one's choices and take the necessary measures.** For information about the different resources that can provide support throughout this stage, see the *Available Resources* section. Certain documents can help make the various steps somewhat easier.

Anticipated medical instructions

This represents a written document in which an adult considered able to consent to care indicates, ahead of time, the medical care he accepts or refuses to be given in the event that he should become unable to consent to care, during specific clinical situations. These instructions bear binding force. Therefore, health professionals that have access to these instructions, as well as those close to the person, are obligated to respect them.

To ensure that your loved one's choices are respected, be sure to mention them (ex.: request a do not resuscitate order and display it where paramedics are sure to see it).

Proxy

This is a written document through which one person gives another power to act on his behalf regarding his finances, assets, or needs in terms of personal care. A proxy, as opposed to a protection mandate, makes designating one person or several people to act in your name possible, even if you can do so yourself.

Protection mandate

This document designates, ahead of time, one person or several persons to oversee your well-being and administer your assets if you were to become unable to do so yourself.

**I was told:
we only have one life, we
must take advantage of it.**

**I answered:
we only have one death,
we must prepare it.**

Cardiopulmonary non-resuscitation

This is a form signed by the attending physician confirming that the person who is at the end of his life is not to be resuscitated.

Funeral prearrangements

Funeral prearrangements are more and more common. They guarantee that things are done per the deceased person's wishes. If the deceased person did not make funeral arrangements ahead of time, the will executor, or any other person designated by the estate or family members shall plan funeral arrangements with the funeral home. Funeral advisors can meet with you in your environment.

Memory aid

To make the will executor's task easier, your loved one could prepare a list of important information. Some people have difficulty discussing legal and financial issues.

Will

This document makes distributing a person's assets after his death possible.



AVAILABLE RESOURCES

Info-Santé and Info-Social

If you have questions or are experiencing a difficult situation, you can communicate with Info-Santé and Info-Social (811). This service is always available (24 hours a day, 7 days a week).

› By telephone: dial 811

Option 1 - To speak with an Info-Santé nurse.

Option 2 - To speak with a psychosocial counselor.

On-call team

Keep in mind that you can contact the on-call team of the at-home support service at any time by calling the number provided by your nurse at the time of registration.

Which services are available nearby?

Discover activities for caregivers and end-of-life and grief accompaniment services available in your region on the L'Appui organization's website. To search the website, enter your postal code or search directly by service type.

› Website: www.lappui.org

<https://repertoire.lappui.org/en>

› By telephone: contact Info-Aidant at 1 855 852-7784

Did you know that certain organizations hold coffee meetings?

Palliative care units

Your loved one may be admitted to a palliative care unit during episodes of chronic pain or to stabilize complex symptoms requiring the expertise of a palliative care team. This team can support you and offer respite on a timely basis. This pathway can help avoid a stay in the hospital emergency department.

Ask your patient navigator about eligibility requirements.

Palliative care home

Palliative care homes aim to foster quality of life through symptom relief. They make it possible for your loved one to continue to live in dignity until the very end with the constant support of interdisciplinary teams (doctors, nurses, social workers, volunteers, psychologists).

Maison Aube-Lumière
3071, 12^e Avenue Nord
Sherbrooke, J1E 5H3
aubelumiere.com
info@aubelumiere.com
Tel.: 819 821-3120

Services offered for caregivers:

- › Respite, day centre (activities for caregivers)
- › Sick people can stay on site for a few days while medication is adjusted
- › At-home accompaniment
- › Accompaniment throughout the grief process
- › etc.

La Maison Au Diapason
50, rue du Diapason
Bromont, J2L 0G1
audiapason.org
info@audiapason.com
Tel.: 450 534-2002

Ask your patient navigator about services offered by palliative care homes in your region and/or visit their websites.

Maison La Cinquième Saison
6900, rue des Pins
Lac-Mégantic, G6B 2M1
maisoncinquiemesaison.org
adjadm@maison5s.org
Tel.: 819 554-8129

The following associations can be helpful:

Canadian Hospice Palliative Care Association

www.acsp.net • 1 800 668-2785 • info@chpca.ca

This association fosters sustainable development and the promotion of quality palliative care in Canada. Visit the *Family Caregivers* section of the website to access the Canadian directory of Hospice Palliative Care Services.

Association québécoise de soins palliatifs

www.aqsp.org • 514 826-9400 • info@reseaupalliatif.org

The Association québécoise de soins palliatifs aims to facilitate access to quality palliative care for the Quebec population. In the *Babillard* section of the organization's website, you will find the complete list of Quebec palliative care homes. Furthermore, the Association publishes newsletters. You may find them online in the *Bulletins* section.

Chambre des notaires du Québec

www.cnq.org • 1 800 263-1793 (toll free)

The Chambre des notaires provides basic legal information. You will also find information about proxies, mandates given in anticipation of incapacity, wills, and estates.

Conseil pour la protection des malades

www.cpm.qc.ca • 1 877 CPM-AIDE (276-2433) • info@cpm.qc.ca

You can reach the Conseil pour la protection des malades (toll free) to obtain information linked to the rights of a sick person or to report abuse or a situation that violates the rights of those who use the health and social services network. All disclosures will be kept confidential.

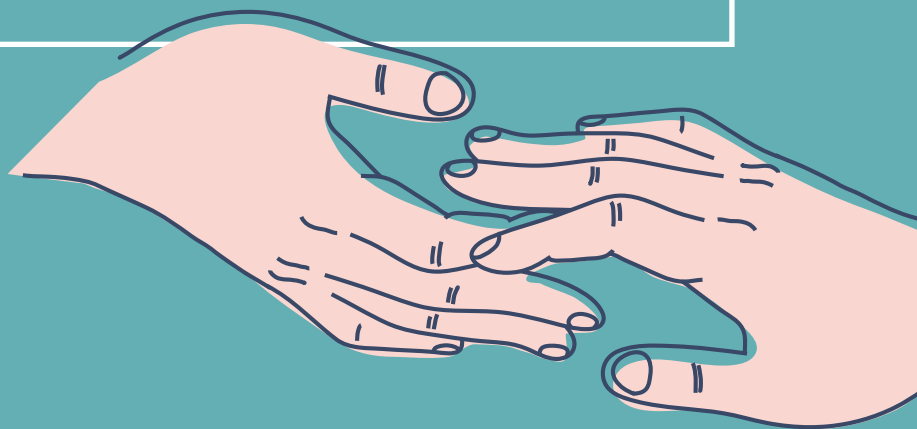


Advance care planning provides the tools and resources required for the process that involves reflection, communication, and the consignment of wishes for end-of-life care.

- › Visit the planificationprealable.ca website for details.
- › “*Practical checklists for natural caregivers*”, The Guide to Practical Support for caregivers, www.gpsprocheaidant.ca.
- › *Caregivers: Practical legal tools*, Educlooi, <https://www.educlooi.qc.ca/en/caregivers-practical-legal-tools>

THE STEPS INVOLVED
IN THE ACCOMPANIMENT OF
A LOVED ONE IN PALLIATIVE
OR END-OF-LIFE CARE

THE END OF YOUR LOVED ONE'S LIFE



Validate options, be alert,
accompany your loved one,
stay strong as you face news

Recognizing signs indicating that the end of your loved one's life is near remains one of the biggest challenges. When we are alongside a person we love, a person we have accompanied so faithfully, it is easy to miss certain signs. Messages we perceive and hear may contradict themselves. Could this be true because we so wish to push back the heartbreaking moment, the end of our loved one's life?

The moment when your loved one leaves...

When your loved one's condition deteriorates and, with the team, you agree that the end is near, it is time to enter another stage: the transition to the end-of-life location he has chosen.

This stage represents one of the most difficult moments. Your loved one must part with his possessions, memories, and life. For you, it also represents a separation from your life together, one that is filled with the sense that your loved one's final departure and the enormous void it will cause is near. This emotion is often intense, but it quickly settles once you are welcomed in your loved one's chosen end-of-life location, if it is not at home.

End of life at home

If your loved one opted to experience the end-of-life stage at home, you must expect, at some point, a more important deterioration of his condition and signs that the end is near. The healthcare team will evaluate the situation and intensify care and services according to your loved one's needs.

Examples:

- › More frequent medical follow-ups
- › Adapted equipment (ex.: electric bed)
- › Changes in prescriptions
- › Increased support (ex.: hygiene, respite, etc.)

Know that your healthcare team will guide you and your loved one when the time comes.

Sooner or later, the inevitable shall happen. Even if we do our best to prepare for it, the death of a loved one always comes with important consequences, namely on an emotional level. No matter where the death occurs, personnel from the health and social services network will accompany you throughout this stage.

End-of-life rights

Many legal paths exist to support the expression of your loved one's end-of-life wishes. Following the creation of the Select Committee on Dying with Dignity, a palliative care bill was submitted. This bill aims to specify the rights of the person at the end of his life as well as the organization and management of end-of-life care.

Continuous palliative sedation

Continuous palliative sedation is palliative care that involves administering medication or substances to a person in the end-of-life stage to alleviate his suffering, rendering him unconscious up until his time of death.

Medical assistance in dying

Medical assistance in dying is a form of palliative care that may be requested by a person at the end of his life to alleviate suffering, by bringing about his death. Resorting to medical assistance in dying is strictly regulated and prescribed by law and can only be provided in exceptional situations.

THE FINAL MOMENTS

As the end of a loved one's life approaches, we can want to remain by his side more than anything. We don't want to take our eyes off him, and fear that if we do, our loved one will leave without us. Certain people fervently wish to be present for their loved one's final breath.

It is often difficult to work around your needs and offer a continuous presence. Medical personnel can guide you and let you know when you should stay close to your loved one. Your loved one knows you; he may choose the ideal moment to quietly slip away. Do not feel guilty.

During these final moments, you may:

- › **Inform family members** and ask them to preserve your loved one's energy:
 - Plan short visits, no more than three people at a time.
 - Ask the healthcare team to manage visits, if your loved one is not at home.
- › **Hold your loved one's hand, speak to him, lie down next to him.** Even if your loved one can no longer communicate, the ability to hear often remains intact until the very end.
- › **Speak openly with the doctor and healthcare team,** ask any questions you may have. Thus, you will have a great deal of information linked to end-of-life signs and symptoms. The team may also guide you as to how to act with your loved one.

DEATH

Your loved one is gone. You are overwhelmed with sadness. Stay by your loved one's side for as long as you wish and say one last goodbye. Surround yourself with those who are close to you, do not stay alone. You will be accompanied for the steps to come.

"You are no longer where you were, but you are everywhere I am." - Victor Hugo

At home

When a loved one chooses to experience end-of-life at home, accompaniment is provided by an at-home support team, for you and your loved one. Upon passing, the family doctor or the on-call doctor will come to your home to confirm the death and complete a death certificate request. The death can also sometimes be confirmed by paramedics. They are qualified to do so and to accompany you in this ordeal. In this case, the paramedics will communicate with the doctor to have a death certificate request completed. Once the certificate is issued, the family will communicate with the funeral home who will come get the deceased person.

At a palliative care home

When a loved one passes at a palliative care home, the healthcare team (doctors, nurses, volunteers, psychologists) accompanies the family. The on-call doctor will confirm the death. You may remain by your loved one's side in the hours that follow his death. In the weeks after your loved one's death, you will receive a follow-up phone call for support. Assistance is provided for family members who need it.

At the hospital

When a loved one dies at the hospital, medical personnel evaluate the needs of those who accompanied the person who has passed. Do not hesitate to request psychosocial support.

At a long-term care facility

When the death occurs at a long-term care facility, medical personnel are equipped to support you, namely the auxiliary nurse, social worker, or any other member of the team with whom you have developed a meaningful connection. At the time of death, the family must communicate with the funeral home so that they will come get the deceased person and coordinate the funeral and administrative formalities.



**"What to do in the event of death:
My personal list"**

<https://www.quebec.ca/en/government/services-quebec/death/>

Grief is a natural human reaction linked to an important loss. For example, when a loved one dies, everyone feels pain and sadness.

GRIEF

The grieving process had inevitably already begun, at least in part. Nonetheless, grieving represents a stage that can be difficult. The months that follow the death of a loved one may be arduous, because those who made up your support network will return to their daily life, leaving you alone to define what your new reality shall look like.

You may observe certain reactions and experience different stages of grief:

- 1 **The shock, denial**
When a loved one's death is confirmed, we enter what resembles a bubble. We feel numb and detached from the situation. We feel excluded from normal life and the world of the living. Some refuse to believe what is happening and continue to plan activities with the deceased person.
- 2 **Anger**
We can be angry with our loved one for "leaving" us, angry at life, circumstances, medical personnel... Intense anger can be overwhelming. Guilt is often present throughout this stage too.
- 3 **Bargaining**
We want to get back to our normal life, the life we had "before", and we are ready to change to make that happen. In fact, this is another form of denial, of avoiding reality. Although we don't really believe the deceased person can come back, we imagine that if we had acted differently at the time of one or more events, our loved one may not have died. This stage also feeds off guilt.
- 4 **Depression, sadness**
Reality catches up with us. We understand that we will never again see the deceased person. We realize that dreams and projects that we shared will never happen. We are submerged with sadness and this emotion can turn into depression.
- 5 **Acceptance**
We have mourned our life with the deceased person, the life we knew. Gradually, we get used to our new reality. We have new projects, new dreams. We continue to think about the deceased person, but not as consistently, and the pain is less severe.

The grieving process is different for everyone. Respect your rhythm. Pay attention to your needs and do what feels right to you. Do not isolate yourself.

Some of these stages may be experienced with greater intensity or last longer than others. **These stages do not necessarily occur in a specific order.** You may be angry one day, extremely sad the next, and your anger or guilt can return the following day.

Speak with a resource person with whom you have developed a meaningful connection about resources that may help you get through this stage. Do not hesitate to join a support group for bereaved people offered within certain community organizations, funeral homes, and palliative care homes or call your CLSC to request psychosocial services.



Myths linked to grief:

- › The pain will go away faster if you ignore it.
- › You must forget your loved one to get back to a normal life.
- › You must “be strong” as you deal with your loss.
- › Those who surround a grieving person can help by avoiding the subject.
- › Not crying means you are insensitive.
- › The duration and the different stages of grief are fixed.

These preconceived ideas are false. What’s more, they can prevent you from experiencing grief in a healthy manner.



Maintaining good mental health

<https://www.quebec.ca/en/health/advice-and-prevention/mental-health/maintaining-good-mental-health/>

Guide des proches aidants. Un manuel sur les soins de fin de vie.

<https://www.pmh-mb.ca/images/PalliativeCare/CaregiverGuideFr1.pdf>

My grief: understand and work through your grief

mygrief.ca

Le processus de deuil

https://www.usherbrooke.ca/etudiants/fileadmin/sites/etudiants/documents/Psychologie/Brochure_deuil_2021_finale_01.pdf

CONCLUSION

As a caregiver, you participated, as a main actor, in one of the most important moments of a person's life. Be proud of having given the best of yourself, despite your fears, resistance, and fatigue. All the care you provided, and your simple presence, were beneficial for your loved one. You contributed to your loved one's well-being and helped him leave this world as peacefully as possible. You guided your loved one to his final stop through the greatest commitment of love.

Now, it's time for you to learn to reclaim your life, to live with the emptiness of your loved one's presence, even if he will forever remain engraved in your heart and in your memory...

"It's as if you and Dad were learning a new dance, where you are searching for ways to coexist in transformed circumstances, where you are life, and he is a memory. Take the time to master this dance, to learn to move with Dad's presence inside you, without hurrying things along, without guilt. Discover your own way of making the wisdom you saw in him flourish in you, of pursuing, in your own way, what you appreciated and loved about him..."

Dominique Lepage, daughter of a caregiver

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PALLIATIVE CARE CONTINUES TO NOT BE FULLY UNDERSTOOD IN CANADA

HERE ARE 10 COMMON MYTHS



1 Palliative care precipitates death.

Reality: Palliative care does not precipitate death. It aims to ensure the person is comfortable and to optimize his quality of life, from the diagnosis of advanced illness to the end of the person's life.



2 Palliative care is only for those who are dying from cancer.

Reality: Any person suffering from illness that is susceptible of shortening his life may take advantage of palliative care immediately after the diagnosis. This is also true for the person's loved ones.



3 When a person in palliative care stops eating, he dies from starvation.

Reality: A person suffering from advanced illness does not feel thirst or hunger like a healthy person. If he stops eating, death will occur because of the illness, not because of hunger.



4 Only hospitals offer palliative care.

Reality: A person may receive palliative care no matter where he lives (at home, at a long-term care facility, or at the hospital).



5 We must shield children from death.

Reality: Being able to talk about questions pertaining to death helps children develop healthy attitudes that will be useful once they are adults. Like adults, children need time to say goodbye to loved ones.



6 Pain is part of death.

Reality: Pain does not always accompany death. However, when it is present at the end of one's life, it can be alleviated in various ways.



7 Administering painkillers in palliative care causes dependency.

Reality: To keep the person comfortable, administering important doses of painkillers is often necessary. His body will adapt and begin to tolerate medication, but it will not develop a dependency.



8 Morphine is given to precipitate death.

Reality: In proper doses, morphine helps keep the person comfortable, but it does not precipitate death.



9 If I am sent to palliative care, it means my doctor can no longer help me.

Reality: Palliative care helps optimize the quality of life of a person who has received an advanced illness diagnosis. The goal is no longer to heal the person, but to help him live life to the fullest.



10 I feel as if I abandoned a family member because he was not able to die at home.

Reality: Even if we do everything in our power to keep a loved one at home, his needs may be too important. Making sure your loved one receives the best care possible, no matter where this is done, should not be considered a failure.

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