



# *Supporting life until the last breath:*

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Support guide for caregivers  
of people receiving end-of-life care

© Guide produced in 2024 by the Direction du Programme soutien à l'autonomie des personnes âgées (DSAPA) of the Centre intégré universitaire de santé et de services sociaux (CIUSSS) de la Capitale-Nationale. Translated from French into English by Helen Kinsella, Certified Translator, BiRSSH, February 2025. The translation of this document was made possible through the OASIS English-language palliative care program, supported by the Friends of JHSB Foundation.

This text uses the masculine form for ease of reading.

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## **INTRODUCTION**

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This guide has been designed for people like you who care for a loved one. Its purpose is to support you through the different stages of your journey as a caregiver, regardless of where your loved one receives care and services. This guide is a general tool that can be tailored to the living environment, needs and preferences of the person you are assisting. It does not cover all the specific features of each type of environment. These will be explained to you by a member of the healthcare team.

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*"Caring is a life-affirming act.  
To care for someone is to sustain their  
life, all that remains of their life."*

## **PALLIATIVE CARE**

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Palliative care is active, comprehensive care. It is provided by an interdisciplinary team and is intended for people with an irreversible, fatal illness who have received a terminal prognosis. Its goal is to relieve suffering and provide the necessary support to these individuals and their loved ones. This care is provided over a period ranging from a few weeks to several months, depending on the person's condition. Therefore, when a person is receiving palliative care, it does not necessarily mean that they are at the end of their life.

Palliative care is not intended to hasten or delay death. It helps a person maintain the best possible quality of life, according to their rights, needs, plans and wishes, until their death. The priority is to ensure your loved one is as comfortable as possible, while providing respectful and compassionate professional care.

## **TYPES OF CARE AND SERVICES**

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Depending on their needs and condition, your loved one may receive medical and nursing care; help with personal hygiene; assistance with daily living; psychosocial support; or other, more specific, services such as nutrition, occupational therapy, physical therapy, respiratory therapy, or spiritual services.

As the end of life approaches, some clinical activities will be discontinued, such as taking vital signs and monitoring blood-sugar levels. However, hygiene assistance; oral care; skin care; and measures to prevent pressure ulcers will continue, to ensure your loved one's comfort and dignity.

Pain relief and comfort are important aspects of palliative care. Medication and complementary therapeutic approaches are the main methods used, which include music therapy, aromatherapy, massage and relaxation. It is important to choose the approach that best suits your loved one. You will find additional information on palliative care [in Appendix 1](#).

Palliative and end-of-life care can take place in different settings:

- Your loved one's home
- Palliative care unit
- Residential facility (residential centre or senior home)
- Hospital

It is also possible to receive care and services in a hospice.

Healthcare teams consist of different professionals depending on the setting and your loved one's needs. You will find a summary of each person's role [in Appendix 2](#).

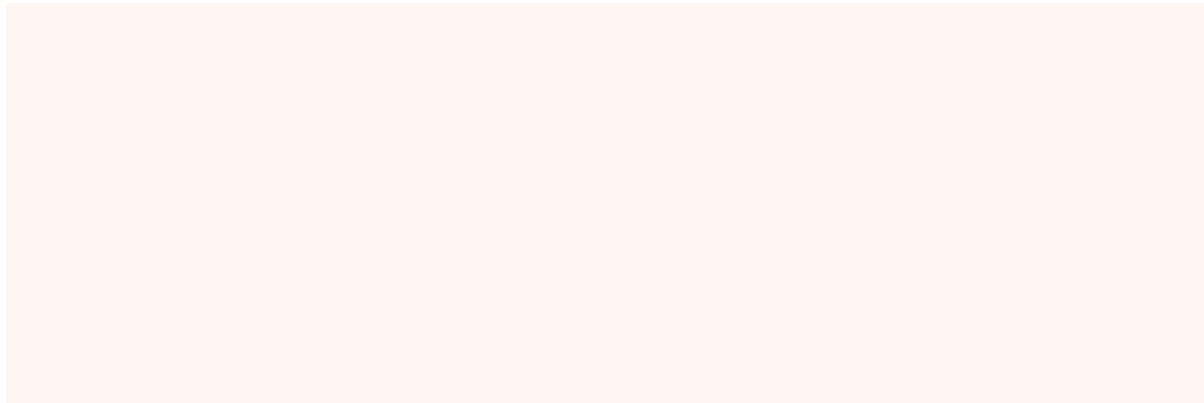
## **TOPICS THAT WILL BE DISCUSSED BY A HEALTH PROFESSIONAL**

Over time, your loved one will need to express their wishes about the end of their life. End-of-life choices and wishes are different for everyone, so it is important to discuss them with your loved one.

A member of the healthcare team will talk to your loved one about the possibility of them eventually losing their ability to make decisions and consent to care. It is recommended that they express their choices, wishes and preferences in advance regarding the care they would like to receive if that occurs. In the event of incapacity, the fact that an incapacitated person has expressed their wishes in advance will help their loved ones make a difficult decision on their behalf. Here are some topics that will be discussed with your loved one:

- their wishes for funeral arrangements
- planning for prearranged funeral services if this has not already been done
- their wishes in the event of incapacity
- advance medical directives (AMDs)
- the level of cardiopulmonary care and resuscitation they wish to receive
- options and wishes for human tissue and organ donation

There are a number of legal avenues available to support your loved one in expressing their end-of-life wishes. You will find a list of links at the end of this document for more information on these topics. Please feel free to discuss this with a member of the care team.



## **END-OF-LIFE CARE**

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Death is the final stage of life, and the support provided to each individual is unique. You, often more than anyone else, can support your loved one by your presence, with help from staff. You may be present and involved during end-of-life care. This care covers a shorter and more advanced stage of the illness, normally lasting from a few days to a few weeks. This care includes various options, which are presented [in Appendix 3](#).

## **HOW THE FINAL MOMENTS UNFOLD**

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It is difficult to predict the exact moment of death, since it occurs in a unique way, at a different pace for everyone, and no-one is immune to sudden complications. During this period, the person can no longer move around on their own and is confined to bed. Their state of consciousness is altered, and symptoms are more difficult to relieve, requiring intensified care and increased monitoring. You will find more information on the most common physical signs and symptoms [in Appendix 4](#).

## **BEING A CAREGIVER: AN ESSENTIAL ROLE**

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Caring for someone who requires end-of-life care is an intense experience. During this period, many emotions and reactions come into play. Some caregivers describe this experience as both demanding and rewarding. When a person takes on the role of caregiver, they embark on a journey whose duration and intensity is difficult to predict. Your role is essential in helping your loved one to make their final days more comfortable. To do this, it is important to take care of yourself and recognize your needs and limits.

## **LISTENING TO YOURSELF TO BETTER CARE FOR SOMEONE ELSE**

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Anticipating the death of a loved one can stir up a lot of emotions. Each person reacts in their own way, and there is no right or wrong emotion. Therefore, you may feel:

- growing fear, impatience, anxiety, irritability, tiredness, sadness, even guilt and regret
- a sense of powerlessness, confusion and loss of control
- mood swings and a range of reactions, such as periods of denial, acceptance, hope and despair
- relief knowing that your loved one's suffering is coming to an end
- moments of deep connection with your loved one

Take the time to acknowledge your emotions and share them with a person you trust. It is normal to experience strong emotions in such a situation; allowing yourself to express these emotions, including through crying, can help reduce stress and make it easier to get through this difficult time. Recalling pleasant or amusing moments can also bring a sense of calm and provide moments of respite.

In the [Resources](#) section at the end of this document, you will find resources available to support you and that you can discuss with a member of the care team.

The mental health continuum<sup>1</sup> presented below is a practical tool to help you listen to yourself more and better identify your needs.

### The mental health continuum

	Healthy	Reacting	At risk	Critical
SIGNS	Calm and steady	Occasional anxiety or sadness	Persistent anxiety or sadness	Excessive anxiety, depression, or suicidal thoughts
	Sense of humour	Irritability or pessimism	Angry or cynical	Angry outbursts or aggression
	Mentally alert	Forgetfulness or intrusive thoughts	Indecision, poor concentration	Unable to concentrate
	Sleeping well	Difficulty sleeping	Sleep disturbances, nightmares	Significant sleep disturbances or oversleeping
	Performing consistently	Feeling overworked or procrastinating	Feeling overwhelmed, poor performance	Unable to complete work tasks
	Confident in self and others	Self-doubt	Distrusts others	Excessive distrust
	Feeling good	Tension or headaches	Persistent physical symptoms	More serious physical symptoms
	Good energy levels	Low energy	Fatigue	Exhaustion
	Physically active	Reduced physical activity	Physically inactive	Lethargic
	Socially active	Reduced social contacts	Avoiding social contacts	No contact with loved ones
	Substance use is occasional and social	Substance use is regular but controlled	Substance use is difficult to control	Substance abuse or dependence
STRATEGIES	Maintain current activities	Recover: slow down and rest	Acknowledge the need for action	Consult a professional immediately
	Practice mindfulness	Build mental health toolkit	Recover: eliminate non-essential tasks	Reach out to peers or someone you trust
	Cultivate social relationships	Identify problems	Reach out to peers	Consider a leave of absence from work
		Act on things that can be changed	Maintain contact with loved ones	Rekindle close relationships

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<sup>1</sup> Excerpted from Checking our Mental Health Vital Signs. Programme d'aide aux médecins du Québec (PAMQ). 2020. Available online at <https://www.pamq.org/wp-content/>

## RECOGNIZING YOUR NEEDS

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When you are caring for a loved one who is at the end of their life, it is normal to feel that your routine and your bearings have been turned upside down. It is important to recognize your needs and limits, and take care of yourself, so that you can be present until the very end.

As a caregiver, it is normal for you to have a variety of different needs too, such as:

- being listened to and supported
- being informed and advised
- being consulted and involved
- having a break and recharging your batteries

Here are some tips:

- be attentive to signs of stress and exhaustion
- take breaks in accordance with your own pace and abilities
- get a minimum amount of sleep and rest when your loved one is napping
- identify the services and resources available to help you
- organize a schedule with other members of the family to avoid burnout
- set aside time for enjoyable or relaxing activities
- avoid isolation and continue social activities as much as possible
- discuss your needs and those of your loved one with someone you trust or a member of the healthcare team

Some community organizations provide services to support people receiving palliative or end-of-life care and their loved ones. Consult the **Resources** section at the end of this document for information about resources available.

*“We need few words to express what is essential.”  
- Paul Éluard*

## **IMPORTANCE OF THE RELATIONSHIP WITH YOUR LOVED ONE**

Everyone at the end of life, regardless of their condition, needs to be supported and feel connected with those around them. Even if the person is more or less aware of their environment and is unable to speak, they can still perceive the atmosphere, presence and affection being offered to them, whether through words, a smile, touch, or simply an attentive presence.

Many people may feel uncomfortable being around a loved one who is dying because they do not know what to say or do, particularly if the person is lucid and conscious. It is perfectly normal to have the reflex to avoid sensitive topics. However, the end of life can be conducive to confidences and meaningful exchanges. The person you are caring for may wish to talk about different topics. They may recount episodes from their life or express feelings such as gratitude or regret. Your attentive presence and willingness to listen can encourage them to confide in you, given that it is an opportune time to take stock of their life. Your loved one may also prefer silence, simply enjoying the caring presence of those around them.

A peaceful and harmonious atmosphere contributes to your loved one's well-being. Simple gestures can help, such as:

- speaking softly
- talking about subjects that you were in the habit of discussing together before (it is perfectly appropriate to talk about your daily life)
- taking the time to listen, without judgment
- providing simple, honest answers to questions
- not making promises you cannot keep
- respecting what they say, even if you disagree with them
- not imposing your beliefs on them
- telling them things that you feel are important to you, for example that you love them or what you regret
- avoiding talking about your loved one in their presence as if they were not there

## TIPS FOR COMMUNICATING THROUGH THE SENSES

Using the senses is a simple and effective way of connecting and communicating with your loved one. However, it is important to let your loved one know what you are doing, and describe it to them as you go along, to avoid surprising them or causing them to become defensive. The sense of smell is very sensitive during the end-of-life period. It is therefore important to adapt to the situation and to your loved one's preferences when applying these examples of soothing gestures:



### Hearing

- Remind them of pleasant moments and loved ones.
- Read to them (poetry, prayers, etc.).
- Play soft music, sing or hum.



### Sight

- Dim the lights. Avoid darkness or overly bright lights.
- Flip through a photo album or watch videos of past events with your loved one.
- Look at objects or images that represent activities or events that are meaningful to them.



### Touch

- Hold their hand or stroke their arm.
- Moisturize their skin with cream.
- Massage their hands or feet.



### Smell

- Bring them flowers.
- Have them smell their favourite dishes or spices.
- Have them smell perfume or body-care products they used to use.

## **PARTICIPATING AND COMMUNICATING WITH THE CARE TEAM**

It is important to communicate regularly and openly with the healthcare team, who are doing their best to meet your needs and those of your loved one. Here is some advice:

- Express your needs and expectations.
- Ask questions, share your concerns, and clarify your perceptions.
- If you are dissatisfied or have a specific request, talk to the nurse.
- Designate one person to be in charge of checking in with the nurse. This person will be responsible for sharing information with family and friends.

Members of the care team meet regularly to discuss the best ways to provide high-quality care to your loved one. You will be invited to participate in these discussions if you wish.

You can also participate in care by helping to make your loved one comfortable through a number of small actions, such as:

- creating a peaceful and comfortable environment
- refreshing the face with a damp washcloth
- moistening and moisturizing the lips and mouth to prevent dryness
- rearranging pillows
- helping to change their position when the person is bedridden

Regardless of your loved one's condition, visits from family members, grandchildren and friends can be a source of comfort. However, it is necessary to adapt the number of visitors and the length of visits to meet your loved one's need for both company and calm.

Watch for signs of pain and discomfort in your loved one, and notify a member of the care team if you feel that your loved one is uncomfortable. If your loved one is no longer able to speak, their sounds, facial expressions and body posture are good indicators of their level of comfort.



## **SPECIAL FEATURES OF CARE IN A FACILITY**

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Your loved one may receive care and services in one of the CIUSSS de la Capitale-Nationale care settings. The institution's staff aims to make your loved one's final moments as comfortable as possible. At the beginning of each work shift, a member of the team will introduce themselves to you. This person will be available to answer your questions, reassure you, and support you. You will be kept informed at all times about your loved one's condition and adjustments to their medication to manage their symptoms. In some settings, you will also be invited to a team meeting to discuss your loved one's preferences and needs.

When you are going to be with your loved one for several hours, wear comfortable clothing and don't hesitate to ask for a blanket if needed. Find out about the amenities and services available in the facility or nearby, such as a cafeteria or family lounge. Plan visiting schedules with family and friends to avoid getting exhausted.

Each setting has its own particularities when it comes to end-of-life care. In some cases, the final moments will take place in the person's usual room. In other situations, it might be possible to find a more private room, to make their last moments more comfortable, especially if they are sharing a room with someone else.

## **SPECIAL FEATURES OF HOME CARE**

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Your loved one may express the desire to spend their final days at home. This would allow them to continue living in a familiar environment. As a caregiver, your role will be to provide most of the care at home, such as administering medication, monitoring, and keeping track of symptoms. In this case, the care team will offer you support and guidance.

This decision must be carefully considered and discussed with family members and friends, while respecting your limits and abilities. Here are some things to consider as you weigh your options:

- Are you able to support your loved one, physically and emotionally, with their disabilities and in all aspects of their being?
- Can you respect their wishes and life choices while respecting your own personal beliefs and limits?
- Are there any responsibilities or care tasks that you do not feel comfortable taking on?
- Can certain tasks or care be shared with family members or friends? If so, how much time can these people give you?
- Can other family members or friends help you at home? If so, how often? For example, how many hours per week can they give you?
- Will you be open to receiving outside help and welcoming different care providers into your home?

A home-care health professional will be able to answer your questions and explain to you in detail what this would involve. Know that if you decide to start home care, you can still change your mind. At that point, you will need to apply for admission to a palliative care unit or hospice. You and the care team will discuss this decision, in accordance with your loved one's condition.

Home-care teams have expertise in palliative and end-of-life care. They can provide rapid assessments and care and services, which will be tailored to the expectations and needs of your loved one and their family and friends. Depending on the intensity of the needs assessed, team members will participate in care and services when their expertise is required.

It is also possible to borrow equipment, such as an electric bed, to adapt your home in preparation for end of life.

On-call nurses and other medical staff are available at all times outside of business hours, as needed.

For more information, please feel free to talk to a member of the team.



## SAYING GOODBYE

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When the end is near, you may want to be constantly by your loved one's side for fear that they will pass away without you. It is often difficult to balance this desire for constant presence with your schedule and other obligations. The healthcare team will be able to guide you in terms of when you will need to watch over your loved one.

Do not feel guilty if, for various reasons, you cannot be present at the time of death. The most important thing is the time you spent with your loved one in the last moments of their life.

Even if your loved one can no longer communicate, their senses of hearing and touch often remain until the end. You can hold their hand, talk to them, or lie down next to them. Give your loved one permission to die, while knowing that do not have control over when they will die. Talk to them about your feelings and acceptance. Take the time you need to stay by their side and say a final goodbye. It is important to see death as a natural part of life, not as an end.

## WHEN DEATH OCCURS

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Even when well prepared, the death of a loved one always has a significant impact, particularly emotionally. Accept your emotions without judgment. The grieving process is unique to each individual and triggers a multitude of emotions.

Regardless of where the death occurs, an attestation of death will be issued. The staff will then prepare the body before the funeral home comes to collect it. Members of the care team will help you through this stage.

The death of a loved one involves certain administrative and bureaucratic procedures. To help you through this process, we recommend you consult the checklist in the [Resources](#) section at the end of this document. This section also contains information to help you understand the different stages of grief and find ways to get through them.



## **CONCLUSION**

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As a caregiver, you play a vital role in assisting your loved one. Your presence and all the care you provide contribute to their well-being in the final moments of their life. If the information in this guide does not answer all your questions, please feel free to talk to a member of the care team, who will be happy to answer your questions.

## RESOURCES

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### COMMUNITY RESOURCES

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- 211: primary source of information on community and governmental social and non-clinical health services  
[www.qc.211.ca/en/home](http://www.qc.211.ca/en/home)
- Appui: organization dedicated to supporting and listening to caregivers  
[www.lappui.org/en/](http://www.lappui.org/en/)

### INTERNET RESOURCES

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- Medical assistance in dying  
<https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/medical-aid-in-dying>
- Death | Checklist  
[https://cdn-contenu.quebec.ca/cdn-contenu/services/quebec/Guide-Deces2023\\_EN\\_2023-10\\_.pdf](https://cdn-contenu.quebec.ca/cdn-contenu/services/quebec/Guide-Deces2023_EN_2023-10_.pdf)
- Grief  
<https://www.quebec.ca/en/family-and-support-for-individuals/death/better-cope-with-grief>
- Advance medical directives  
<https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/advance-medical-directives>
- Rights of a person receiving end-of-life care  
<https://publications.msss.gouv.qc.ca/msss/fichiers/2024/24-828-01A.pdf>
- Incapacity and loss of autonomy  
<https://www.quebec.ca/en/family-and-support-for-individuals/incapacity-loss-independance>
- Revenu Québec  
<https://www.revenuquebec.ca/en/citizens/tax-credits/tax-credit-for-home-support-services-for-seniors/>
- End-of-life care  
<https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care>

# APPENDIX 1 - MYTHS ABOUT PALLIATIVE CARE



## 10 Myths about Palliative Care



Palliative care is still misunderstood. Here are 10 common myths we often encounter. Help dispel these myths by sharing the facts with family members and friends, colleagues, patients, and clients.



**Myth 1: Palliative care makes death occur sooner.**

**Fact:** Palliative care does not make death occur sooner. It helps improve comfort and quality of life from diagnosis until death.



**Myth 2: Palliative care is only for people dying of cancer.**

**Fact:** Palliative care can benefit people who have been diagnosed with any illness that may shorten life. Palliative care can also benefit their families and friends.



**Myth 3: People in palliative care who stop eating die of starvation.**

**Fact:** People with advanced illnesses often don't experience hunger or thirst as healthy people do. People who stop eating die of their illness, not of starvation.



**Myth 4: Palliative care is only provided in a hospital.**

**Fact:** People can receive palliative care wherever a person lives.



**Myth 5: We need to protect children from being exposed to death and dying.**

**Fact:** Talking with children early on in someone's illness, and providing honest and clear information that is age appropriate, is the best way to protect them. Like adults, children also benefit from having time to say goodbye to people who are important to them.



**Myth 6: Pain is a part of dying.**

**Fact:** Pain is not always a part of dying. If pain is experienced near end of life, there are many ways it can be addressed.



**Myth 7: Taking pain medications in palliative care, leads to addiction.**

**Fact:** Keeping people comfortable often requires increased doses of pain medication as the body gets used to the medication. It is not addiction.



**Myth 8: Morphine makes death happen faster.**

**Fact:** Morphine, or medication similar to it, is used to help keep patients comfortable. In proper doses, morphine does not make death happen sooner.



**Myth 9: Palliative care means the patient's doctor has given up and there is no hope.**

**Fact:** Palliative care providers help people achieve their best quality of life, for the rest of their life. Hope changes from curing the disease, to living life as fully as possible.



**Myth 10: If my family member or friend doesn't die at home, I'm letting them down.**

**Fact:** Sometimes a person's needs cannot be met at home despite the best efforts. Ensuring that the best care is delivered, regardless of setting, is not a failure.

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[https://www.virtualhospice.ca/Assets/10%20Myths%20about%20Palliative%20Care\\_2024\\_20250228162059.pdf](https://www.virtualhospice.ca/Assets/10%20Myths%20about%20Palliative%20Care_2024_20250228162059.pdf)

## **APPENDIX 2 -**

### **MEMBERS OF THE HEALTHCARE TEAM**

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Members of the healthcare team vary depending on the setting. The professionals you meet may also vary depending on your loved one's needs. Here is a summary of each person's role:

- **Doctor or specialized nurse practitioner (SNP):** provides medical care and prescribes treatments to relieve the pain and symptoms associated with the disease progression
- **Pharmacist:** cooperates with the doctor or specialized nurse practitioner to adjust, initiate or discontinue drug therapy
- **Nurse:** assesses overall health, provides appropriate medical care, and acts as a resource person within the care team
- **Licensed practical nurse:** collaborates in assessing overall health and provides appropriate medical care
- **Rehabilitation professionals:** provide ways to relieve symptoms and ensure your loved one is comfortable, as well as ways to function and move around safely
- **Psychosocial professionals:** provide support to help your loved one adapt to their illness and accompany them through the various care procedures
- **Health and social-services assistant (at home) or patient attendant (in a facility):** ensures comfort by providing personal care, such as help with personal hygiene, assistance with changing position, help with dressing, etc.
- **Respiratory therapist:** uses their clinical expertise to relieve discomfort related to respiratory problems
- **Nutritionist:** uses their clinical expertise to relieve symptoms and discomfort related to eating and digestion, and implements dietary strategies tailored to individual needs
- **Spiritual care provider:** meets spiritual needs, in accordance with the person's values and beliefs, and accompanies you and your loved one during the disease progression and the grieving process

Community resources, such as volunteers, may also join the care team to offer support.

## **APPENDIX 3 - END-OF-LIFE CARE OPTIONS**

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In addition to standard end-of-life care, which aims to relieve your loved one's symptoms until death, other options are available. These include continuous palliative sedation and medical assistance in dying. These are specialized care options that are only available to those who meet the eligibility requirements. These options also require an assessment by a qualified professional<sup>2</sup>. It is important to note that these options are not exclusive and can be added at any point in your loved one's journey.

### **CONTINUOUS PALLIATIVE SEDATION**

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The use of continuous palliative sedation is an exceptional practice. It is used when standard end-of-life care fails to relieve refractory and intolerable symptoms.

Continuous palliative sedation is a form of care that involves administering medication to a person at the end of life, at their request or that of a loved one. Its purpose is to relieve the person's suffering through inducing and continuously maintaining unconsciousness until their death. Continuous palliative sedation is an option that will be discussed with you and your loved one if standard treatments do not provide adequate relief. If you would like more information about continuous palliative sedation, talk to a member of the healthcare team.

### **MEDICAL ASSISTANCE IN DYING**

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Medical assistance in dying is an exceptional intervention, subject to very restrictive conditions. Its use is strictly regulated and governed by the Act Respecting End-of-Life Care and the Criminal Code.

The support offered by end-of-life care may not be able to relieve your loved one's suffering in a satisfactory way. The Act Respecting End-of-Life Care therefore offers an additional option to those for whom all therapeutic, curative and palliative options have been deemed unsatisfactory and who would prefer to die rather than continue to suffer.

Medical aid in dying is a process whereby a qualified professional, such as a doctor or specialized nurse practitioner (SNP), administers medication to a person at the latter's request. The goal is to relieve their suffering by causing their death. This care is available in all institutions in Québec's health and social-services network, as well as in hospices. A request may be made to receive it at home. For more information on medical assistance in dying, talk to a member of the healthcare team.

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<sup>2</sup>The term "qualified professional" refers to a physician or specialized nurse practitioner, as defined in the Act Respecting End-of-Life Care (section 3.1).

## **APPENDIX 4 - PHYSICAL SIGNS AND SYMPTOMS**

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The transition to the end-of-life stage is characterized by a deterioration in overall health: fatigue, weakness, loss of appetite, drowsiness, etc. Here is some information about the most common physical signs and symptoms:

### **PAIN**

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The most significant physical symptom is pain. This is a subjective experience that only your loved one can describe and quantify. When someone is no longer able to verbalize it, it is necessary to remain attentive to non-verbal signs such as facial expressions, body movements, vocalization, and muscle tension.

Pain is multifactorial. This means that pain is not just a physical phenomenon; it also has psychological, social, spiritual and emotional dimensions. Pain can affect both the body and the mind.

The healthcare team has suitable tools to assess your loved one's pain, whether they are able to express themselves or not.

### **BREATHING DIFFICULTIES**

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Breathing difficulty can manifest as shortness of breath, respiratory distress, or noisy or rapid breathing. It can have different causes and is often caused by an accumulation of secretions in the airways.

Know that medication and comfort techniques can be used to make your loved one comfortable. Training can be provided, if necessary, if you are caring for your loved one at home.

### **DIFFICULTY SWALLOWING AND EATING**

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As death approaches, the person no longer feels hungry or thirsty in the same way. In addition, they have more difficulty swallowing. Dehydration is part of the end-of-life process. Dehydration does not affect the dying person in the same way as it does a healthy person who feels thirsty, which is why it is important to provide regular oral care. However, dehydration of the body is not painful in itself in an end-of-life context.

## **CONSTIPATION**

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Constipation is characterized by infrequent or small amounts of hard stools and difficulty passing them. This leads to a feeling of incomplete emptying. Constipation can be common and is usually the result of a combination of different factors, such as the side effects of medication and being confined to bed.

At the end of life, bowel movements must continue to be monitored, even if the person is no longer eating. The healthcare team will carry out an assessment to avoid possible complications from constipation and ensure your loved one's comfort.

## **COGNITIVE CHANGES**

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As the disease progresses, changes in cognitive function may occur. The ability to react, understand and think may be affected. These changes can take various forms, the main ones being:

- psychomotor agitation or slowing
- difficulty verbalizing thoughts or understanding simple instructions
- inability to recognize loved ones
- continuous drowsiness and inability to hold a conversation

Various pharmacological and non-pharmacological methods are available to promote comfort. Team members will explain them to you if needed.

## **SIGNS OF END OF LIFE**

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The "active" phase is the term sometimes used to refer to the final stage of dying. It generally lasts a few hours. It is a very intense time during which you may observe certain physical signs, such as:

- breathing that gradually becomes irregular and shallow
- increasingly frequent breathing pauses
- drawn, pale facial skin
- blue-tinged fingernails, toenails and lips
- mottled skin on the knees
- short bursts of movement (usually one or two)

Please note that not everyone experiences these signs at the end of life. If you have any questions, do not hesitate to talk to a member of the healthcare team.

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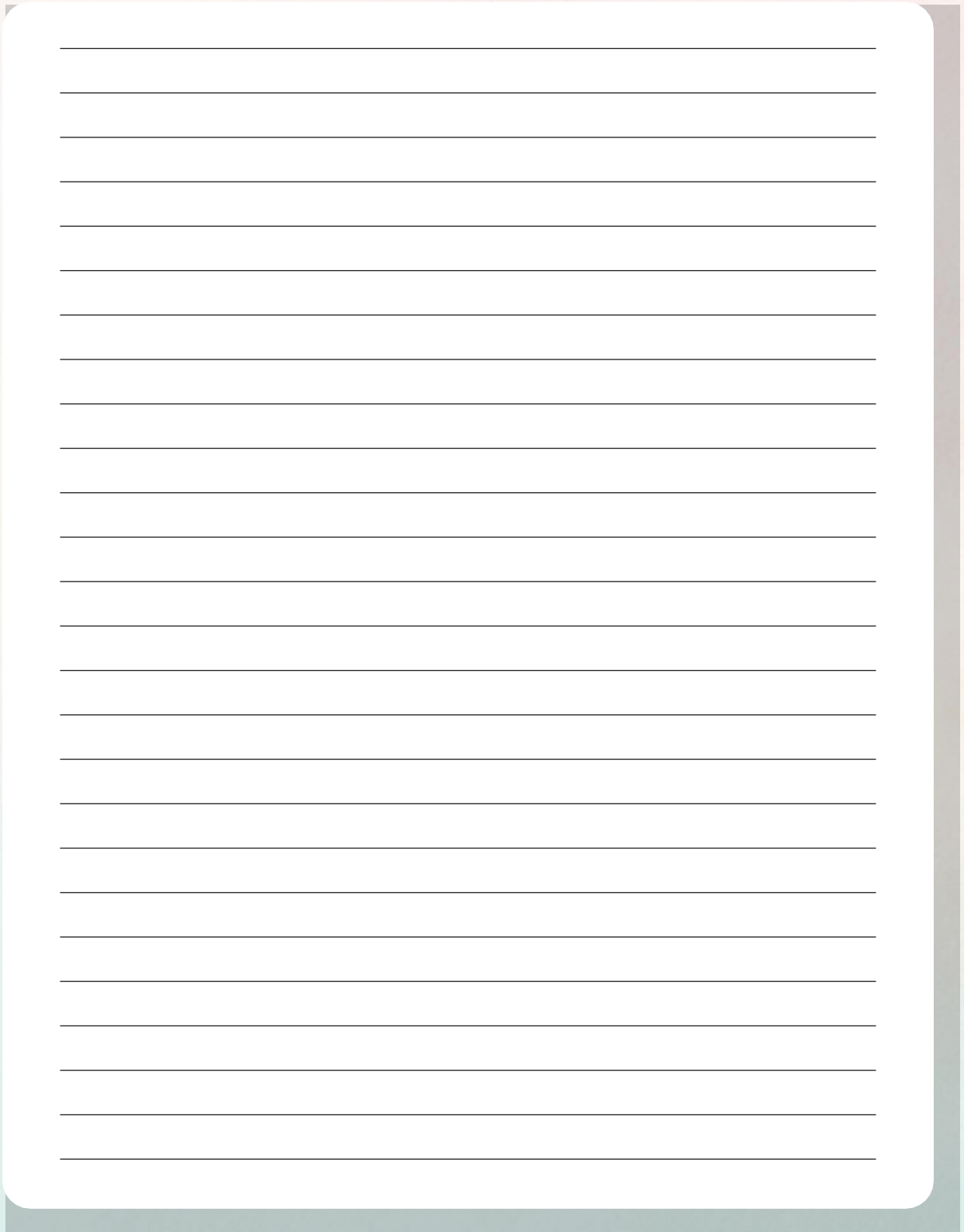
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# Notes



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