

Life's Last Chapter



Sage Centre &
Rosedale Hospice
Hospice Calgary

Life's Last Chapter

*Life's last chapter comes whether we are ready or not.
It comes for some before the whole book has been written.
Turning the last pages of the last chapter means turning
towards dying,
living our dying, like we lived our life.*

*Taking a moment to breathe, we enter stillness.
Stillness frees the heart to be present with what is.
Presence requires nothing from us but to breathe in,
keeping with the universal cycle of life and death.*

*Breathe with all who have entered this chapter before us;
breathe with all who will come after.
Being a small part of this universal truth
and the endless cycle does not diminish our birth,
our years on this earth, our impact, or our death.
Stillness, breath, presence.*

Life's last chapter unfolds.

Anonymous

People remember the death of their family members or friends until their own last breath. These experiences are part of the stories of our lives.

The road ahead may have moments of heartfelt joy and peace, as well as sadness, pain, and suffering. Each person's journey to the end of life is unique.

This guide will help you understand how a person's body and mind may change as death approaches. It includes information and reflections for friends and family members who accompany those approaching the end of life.

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What to expect: The last months and weeks

The experience of caring for someone who is dying is different for everyone and the following information about bodily changes is just a guide to help you prepare. Here are some of the changes you may see in the last stages of life:

Fatigue generally increases over time. It is the most common symptom as illness advances. The patient spends more time indoors and eventually more time in bed. They may stop using the bathroom and need to conduct all their activities of life from their bed. **Implications for care:**

- ◆ Conserve the finite supply of energy for the most important activities and people.
- ◆ Limiting visitors to close family and friends may be necessary near the end.

Decreasing appetite is almost universal. The disease, related illnesses, and certain medical treatments will suppress their appetite. Eating becomes limited to fewer and smaller meals; it is more about experiencing good tasting food and habits rather than providing nutrition. Ultimately, the patient uses more energy to sit up and eat than they gain from consuming the meal. **Implications for care:**

- ◆ Offer food if the patient feels like eating.
- ◆ Put food out of sight if they have no appetite. The sight of food can make a patient feel nauseous when they can't or don't want to eat.

- ◆ Only offer food or drink if they can sit upright and maintain a good level of alertness.

Pain will be managed to the best of the team's ability until death. Sometimes, the patient's body gets used to the pain medication so that it is less effective. If this happens, doses are adjusted to maintain good pain control. However, for some people, pain never develops. **Implications for care:**

- ◆ Distractions from the pain are the primary goal—engaging in a gentle activity or quiet conversation or listening to music may be helpful. These activities can redirect the patient's mind to non-painful aspects of the experience.

Pain medications can be a source of worry for some people, especially as they are often opioids at this stage (also known as narcotics). Our experience is that people near the end of life generally do not become addicted to their pain medicine. Addiction means that someone actively seeks more medicine for the “high,” even when the substance is harming them. However, when properly prescribed, even those people with active substance addictions who have moderate to severe pain can have strong pain medication. *Palliative care doctors are specialists in the treatment of pain, and staff always monitor the patient for the safety of the drugs they are given.*

Shortness of breath or “air hunger” can occur if the patient has a lung disease, like chronic obstructive pulmonary disease [COPD] or asthma. Shortness of breath may also occur if the lungs have tumours, infection, or fluid, or if they have collapsed.

Your health care team may be able to order medications that may help to alleviate the patient's anxiety, as may relaxation techniques, fans, or other methods. **Implications for care:**

- ◆ Oxygen may be used, but it is intended to give comfort rather than achieve a measured oxygen level. However, the flow of oxygen can be bothersome and drying to the nose, so patients often decline oxygen near the end of life.
- ◆ Opioids can reduce the feeling of shortness of breath, just like they reduce the feeling of pain.

Nausea and vomiting may occur if a patient has a bowel obstruction, constipation, liver failure, brain tumours, or high levels of certain minerals in their body. The medical team will monitor and treat these symptoms. **Implications for care:**

- ◆ Stopping medications from being given by mouth can ensure that the patient absorbs them. Medications may be given through a tiny plastic tube left in place under the skin (*sometimes called a cannula*), into which medication is injected. This saves the skin from being pierced each time medicine is given.

Delirium is a confused state that is quite common near, and at, the end of life. It is the inability to focus or maintain attention and includes problems with memory or communication. It affects other aspects of the patient too:

- ◆ their personality can change or be exaggerated,
- ◆ they can appear quite drowsy or more agitated,

- ◆ they may look like they are in pain as they grimace frequently, even though they aren't experiencing pain or the cause of their pain is unchanged, and/or
- ◆ they can become restless and helping them settle can be challenging.

Delirium has many causes; liver failure, mineral imbalances in the body, kidney failure, decreasing blood oxygen levels, infections, and medication side effects. **Implications for care:**


- ◆ Maintaining a peaceful, quiet atmosphere around the patient is easier for them.
- ◆ The physician will assess whether it is possible to reverse the cause: they will discuss options with you.

Psychological and cognitive changes become noticeable.

Patients may start to withdraw, closing their eyes even when awake, while people in the room have conversations and are carrying on with activities. They may not speak or will just speak to select people. This behaviour can look like depression or sleepiness due to their medications. However, it often reflects decreasing energy and a "turning inwards" as they prepare for the last days and hours of life. They may also start sleeping much more. **Implications for care:**

- ◆ Balancing medications to manage symptoms and minimize drowsiness is what the physician will aim for—but this balance is not always possible.

Physical touch can be a powerful way to maintain a loving connection with the patient. It is an essential aspect of being human and may be an avenue of communication when speaking is difficult. **Implications for care:**

- ◆ Place a gentle hand on the patient. If you observe any response that suggests your touch does not seem comforting, please talk to your health care team about other ways to stay connected.
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Spiritual perspectives

Spirituality is an important part of life and is often the focus of reflection at the end of life—by both patients and their family and friends. It is about finding and making meaning of life’s experiences and relationships, a process that is different for everyone. For some people, spirituality connects them to their higher power, and end-of-life experiences invite them to look at new or renewed ways of understanding this connection. This kind of contemplation is normal and sometimes challenging, but it can be a helpful process. During times of despair, conversations about spirituality can be a form of “medicine for the soul” and may offer a fresh perspective. Drawing support from spiritual communities or from spiritual care providers can also aid you during this time.

What to expect: Last days and hours

The time of death is approaching and you may see some additional changes that tell you that death is near. Some of the signs will be the same as in the last few weeks but they may be more noticeable than before:

Withdrawal from activities and people may occur as the body conserves energy for the vital functions of life. The patient may talk little or not at all, but they can still be a passive participant in visits from friends or family.

- ◆ Visits may need to be shorter and limited to family and significant friends.
- ◆ Assume that the patient is listening to quiet conversations and include them even though they may not be able to communicate as before.

Drowsiness or sleep increases. Breathing muscles become weaker and waste products in the blood accumulate, leading naturally to deeper sleep. However, sometimes agitation occurs instead.

- ◆ Stopping or reducing medication does not usually increase alertness at the end of life.

Eating and drinking continue to decline and may stop altogether. This is a normal process as feelings of hunger are rare. The patient is not suffering because of this. As swallowing muscles weaken, coughing may occur, and fluid may enter the lungs. The medical team will talk to you about this and advise on the best course of action.

- ◆ Moistened sponges dipped in water or favourite flavours can feel good when the lips and tongue are dry.
- ◆ A specially designed toothbrush and club soda may provide relief to their dry mouth.

Dehydration is also a normal part of the end-of-life process. Water from the bloodstream can leak into the lungs and cause gurgling breaths. This means that it is often better for the patient to receive decreased fluids at this time, rather than more.

- ◆ Very rarely, the physician will advise you about situations when it would be better to have fluids provided by other routes, like intravenously, at the end of life.

Skin changes occur. As the heart and lungs work less efficiently, oxygen does not get to the feet and hands very well. Skin colour varies from blue or grey-tinged, to blotchy purple, red, or white. Parts of the body may be cold or warm to the touch as the body loses control of its' internal thermostat. Sweating may occur even in the absence of infection. These changes are not painful or uncomfortable for the patient.

Restlessness/delirium may occur. The patient sometimes tries to get out of bed, or pick at or throw the covers in an aimless way.

- ◆ The medical team may offer medication or other gentle methods to calm this restlessness.

Rattled breathing may occur, which can sound like there is fluid in the chest. This is because the patient can no longer swallow their saliva, or they may have fluid in their lungs.

They are often unaware of the sound they are making.

- ◆ If there is no cough, changing the patient's position may help quiet the sounds.
- ◆ Medications may reduce the volume of fluid, but the healthcare team will be careful to avoid causing increased dryness of the mouth.
- ◆ Suction is very rarely used. The team will assess whether a brief suction would be more helpful than irritating.

Changed or irregular breathing patterns will likely occur.

The patient may breathe very rapidly or their breaths may get very slow. There may be long pauses between breaths that can sometimes look difficult, as if the patient is gasping for air—you may notice gulping-like breaths. Their jaw may move as they breathe. All of these changes are caused by automatic brain responses to increased carbon dioxide in the blood, but the patient is unaware of these breathing patterns.

- ◆ Oxygen in this situation does not help. Medication may ease the work of breathing.

How long will it be?

Estimating the patient's remaining time is challenging. Their medical conditions, the rate of bodily changes, as well as psychological factors—such as waiting for the arrival of significant family members or upcoming anniversaries—all play a part.

Energy surges or rallies can occur very near the end of life. Occasionally, hormones may “wake up” the person for hours or days. The team may have prepared you for imminent death and then the patient seems to regain some energy. No one can predict if, or when, someone may rally and these energy surges can seem like a rehearsal for the actual death—rather than a false alarm.

Signs that death is imminent:

- ◆ Pale, waxy skin around the lips, eyes, and face.
- ◆ The fold between the nose and lips may be less than normal as the facial muscles relax.
- ◆ The eyes may not close.
- ◆ The pulse is weak at their wrists and feet.

For Family and Friends

As you well know, supporting your family through illness and uncertainty can be exhausting. The challenges of maintaining your spiritual, emotional, and physical energy for the duration of the end-of-life process can be overwhelming. It can be challenging to witness confusion or delirium at the bedside and possibly not even be able to have a “familiar” conversation as the end of life draws nearer.

We invite you to consider the ways that you can allow and ask others to help you with your responsibilities, so that you can be present at the bedside if this is what you desire. In light of the many losses you are experiencing every day, you may choose to:

- ◆ intentionally ask yourself what you need so that you can carry on,
- ◆ reflect on what it is like to observe the many changes, and/or
- ◆ seek support from your healthcare team or other support people, as it may help you to share your thoughts and feelings with another.

The continuing journey of grief through bereavement is a transition that can bring ongoing sorrow and a flood of memories. Everyone experiences and expresses grief uniquely. Over time, we are more able to remember that a life lived is so much more than the circumstances surrounding a person’s death.

There is no right or wrong way to move towards healing. Finding a safe place to express your grief is important and people have different approaches: some connect emotionally to others to help them cope with their grief; others take action to create meaning from their loss.

Funerals, celebrations of life, and memorials are all rituals that help us to acknowledge and honour the death of someone who mattered to us. People often find that ongoing rituals on anniversaries and at holiday celebrations aid them to keep their memories alive. Remembering or sharing stories of that person also contributes to building and enriching the next chapter of our lives.

May your healing come on gentle wings.



Your Best Gift

Let me be that sweetness, that calm three-in-the-morning breeze.

*That ocean sound, that remarkable scent, that endless bounty.
When you think about it, it cannot be possessed.*

*Who possesses sweetness? Who harnesses the breeze?
Who has laid claim to the sound of the ocean and sealed it in a jar?
Who can deposit a fragrance, with a signature, in a bank account
to be withdrawn at will?*

None. None can. Not ever.

*These are owned by no one, yet are given away freely by all
who will open their hands. Love too, cannot be owned.
It spoils if kept. It must be given away. So too, with all that I am,
frail, fading, full of love and dying. Give me away.
Offer me as a gift with your hands open.
As the taste of sweetness, a breeze across the field.
The sound of the ocean, and the sweet smell
of the kindness of fond memory.*

*Don't possess me. Don't cling to the way you held me before,
since time itself began its long journey, a journey of love between
you and me.*

*Let me now become a wave arriving on the senses
of your sister and your brother, your fathers, your mothers.
A sweet taste, a felt breeze, a calm sound, a pleasing aroma.
Not just today, while I am here.
But tomorrow especially, when I am gone.*

*It will be the place that you and I meet, the new way of our embrace.
Above all else, this will honour me and be my favourite gift.
A final one. Given by you, to me, freely
From your heart of love.*

T. Cain


Resources & Support

Please enquire through your home, hospital, or hospice care teams about additional supports.

If you live in or near to Calgary, Hospice Calgary can offer support or counselling and information for you and your family, including children who may be facing this journey with you. We can provide this service to you at any convenient location.

For more information and to access this service, call us at 403-263-4525.

hospicecalgary.ca – here at our website, you will find additional resources on advanced care planning, palliative and hospice care that may be useful to you regardless of your geographical location.



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