

# What to Expect in the Last Hours of Life

Information for Caregivers



# Let's Talk About It .....

In this pamphlet you will learn about:

- How you can take care of your loved one
- How you can take care of yourself during this time



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## What can I expect as my loved one is dying?

It is our priority to make sure that your loved one receives the highest quality of care that is consistent with their values and desires. Our goal is to make sure your loved one is as comfortable as possible in their final hours.

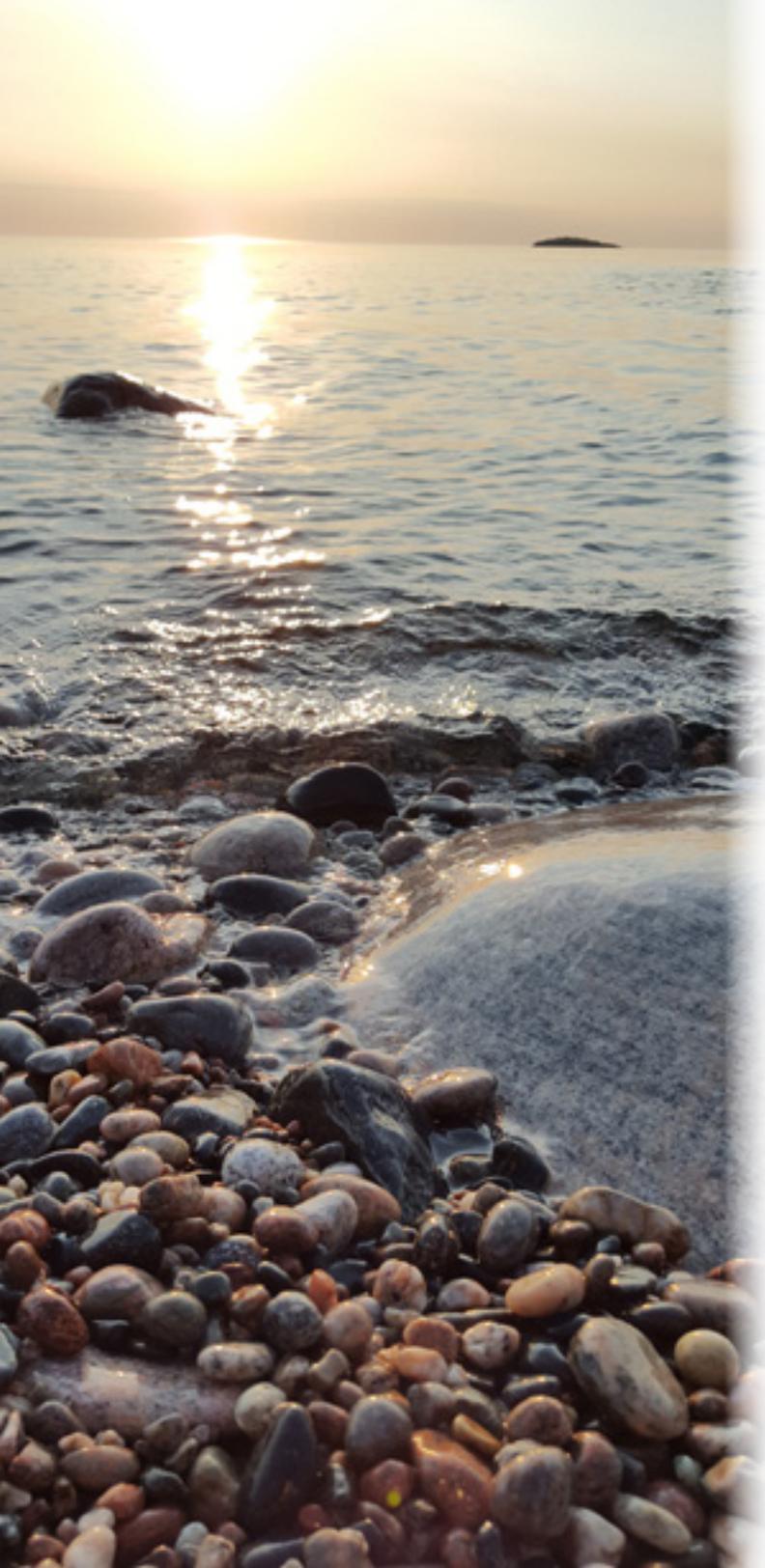
Dying is a natural part of life, but many people do not have experience caring for their loved one in their last hours or days of life.

- It is normal to feel many emotions when someone you love is dying.
- People from the same family or other loved ones may cope in different ways. Some individuals may not agree about the treatments being given or the goals of care.
- It is common to have questions about all parts of your loved one's care:
  - What caused this?
  - Was something missed?
  - Could we have done something differently?

Each person's dying experience is unique and no one can fully know exactly when or how it will occur. We hope this information will help you care for your loved one through their last hours or days of life. This information is meant to guide you through the physical and emotional needs of a dying person and to answer questions you may have at this time.

- At this point, blood tests, X-rays, and other tests will be stopped and will only be done if the tests can help with the management of symptoms.
- Things like watching for heart rate and blood pressure will be stopped. Instead the healthcare team will do a "comfort assessment", which includes looking at your loved one's level of pain, agitation or their breathing.





## Is my loved one in pain?

- Ensuring that your loved one is not in pain is an important part of end-of-life care.
- Your loved one's pain may stay the same or change.
- Your care team may need to adjust the medications to help with these changes.
- If your loved one cannot swallow, the team will give the pain medication through a special device that goes under their skin but does not cause discomfort.
- At times you may hear your loved one moan or seem as if they are in distress.
  - This may happen when your loved one is moved from side to side or when they breathe out.
  - Sometimes it can be hard to know if the moans or sounds are caused by pain, restlessness or agitation.
  - If you see signs of frowning, eyebrow wrinkling or tightness around the mouth it is often a sign of pain and pain medication will be given.
- Pain medications given at the end-of-life will not make your loved one's heart stop or cause them to stop breathing.



## Is my loved one having trouble breathing?

- When a person is near the end-of-life their breathing rate and rhythm may change.
- Breaths may become shallow and slower.
- There may even be short periods of time when your loved one will stop breathing for a few moments and the time between breaths may get longer as they come closer to death.
- You may see your loved one use the muscles in their neck and chest more to breathe.
- These changes in breathing are part of the dying process. They can make family and friends worry or feel upset however these are not signs that your loved one is uncomfortable.
- When a person is near the end-of-life you may hear them gurgle or make snoring-like sounds with each breath. This may sound like they are choking.
- These noises happen because the person swallows less. Small amounts of fluid will collect in the throat or the tongue will move back due to the relaxation of the jaw and throat muscles. Your loved one will not be aware that this is happening.
- Deep suctioning is discouraged, but the nurse may suction the mouth. The nurse may also move your loved one to try and stop or make this symptom better. A medication may be given to dry up the secretions and lessen the sound.

## My loved one is so sleepy.

### What can I do?

- It may be common for your loved one to pull away from friends, family and the world around them as part of their dying process.
- You may see changes in their energy level. They may be more weak, tired, and they may sleep more than usual. These changes will usually happen over a few days, but this can happen very quickly, even over a few hours.
- Your loved one's position in their bed does not need to be changed a lot at this time because it might make them uncomfortable. If your loved one is short of breath, they may be turned partly on their side as this will help them to breathe.
- Your loved one may not respond and may seem to be in a coma-like state. This is more like a deep sleep and does not cause any pain or distress.
- Touching your loved one or sitting quietly in silence might be the most comforting thing you can do.





## Can my loved one hear me?

- No one knows what your loved one might hear in this state, but we believe their awareness is greater than their ability to respond.
- Speak to your loved one like he or she can hear everything. They may be too weak to respond or may not be able to speak, but they may still be able to hear and understand what you say.
- Speak with normal voices. Do not say anything in front of the person that you would not say if he or she were awake.
- Tell your loved one anything you need or want to say. Hug, touch, show your feelings, express love and thanks. Feel free to cry. All of these things are important for you, your family, and your loved one. Your being with them, your words and your touch can give comfort.
- If you can, surround your loved one with people, children, pets, music and sounds they would like. Let them know they can let go and pass away by using words that give them comfort.
- Take part in activities to create memories. Some ideas include: stories and photos, family reunions and celebrations, letter writing, creating audio or video tapes, gift giving and saying good bye.
- Some people feel comfortable lying in bed next to their loved one and saying parting words. Others may want to simply hold hands.
- If music, chanting, or prayer is used to help the dying, make sure it is comforting and familiar.
- A dying person's body language will let you know if these sounds are soothing.

## Is my loved one hungry?

- When a dying person stops eating and drinking, families may think their loved one is starving, dying of thirst, or giving up. When a person is nearing the end of their life, it is natural for them to stop eating and drinking.
- Loss of appetite is a normal part of the dying process. At this time, your loved one may not want food or water. Some may even find it makes them feel sick to their stomach. As their body systems slow down, the body cannot take in food in the usual way. Feeding a person with feeding tubes can cause harm and does not make them live longer.
- What is eaten should be guided by what and how much your loved one wants to eat and when they want it.
- Respect your loved one's wishes if they do not want to eat or drink.
- Your loved one may bite the spoon, clamp their teeth closed, turn their head, or spit food out to let you know they do not want to eat.
- If your loved one is very sleepy or has trouble swallowing and you try to feed them, the food or fluid may go down into the lungs, which can cause them to choke, cough, or have trouble breathing.
- For your loved one's safety always check with your nurse before feeding or offering fluids.



## Urine and bowel changes

- When your loved one is nearing the end of their life the amount of urine they make is less and their urine color turns darker.
- If your loved one has trouble passing urine, a urine catheter (a tube placed into the bladder) may be put in. There may be a few seconds of discomfort while it is put in but often they will not know the catheter is being put in.
- A loss of control of the bladder and bowels may occur as the muscles of the lower body relax. Incontinence pads may be used to keep your loved one clean, dry and comfortable.
- If your loved one is constipated and seems to be uncomfortable, laxatives or an enema may be given to help pass stool.
- If your loved one asks for water you may give water but please give it slowly and carefully.

## Is my loved one thirsty?

- Raise the head of the bed a little or support your loved one's head and offer ice chips or small sips of water using a spoon. If the fluid causes coughing or trouble breathing stop right away.
- If your loved one asks for water, but cannot drink or your care team feels it is unsafe for them to drink, good mouth care will keep their mouth and lips moist and give comfort. It is also a way to nurture your loved one.
- The use of intravenous fluid is not recommended (given by a needle in a vein). The solutions used in the intravenous have salt in them or sugar and water and they do not give any nutrition. The intravenous fluid does not give comfort and may have a bad effect like build up of fluid which will make your loved one feel worse. When fluid builds up in the body it can cause shortness of breath and increased secretions.





## Providing mouth care

- Some of the medications used for comfort may also cause dry mouth. Mouth care products may be used to help with this symptom. It helps to do mouth care often.
- Moisturize and clean your loved one's mouth and lips frequently. The nurse can teach you how to provide mouth care.
- If the nurse gives you a sponge tip swab to help with mouth care, dip it in water and squeeze out extra moisture before you use it in the mouth, along the cheeks and over the tongue.
- You may put on a soothing lip balm (any brand) to protect their lips. Try not to use lip balms with a scent in them as they may bother the skin.

## Providing eye care

- At this time some people cannot keep their eyelids closed all the way during sleep or they blink less often.
- To help with dry eyes you can use artificial tears or eye gel which the nurse can bring to you.



## Why is my loved one restless or agitated?



- When a person nears the end of their life they may get confused, restless, disoriented or agitated. Sometimes arrangements are made for a family member or other person to stay at the bedside to keep them calm and safe.
- When managing any type of restlessness or agitation it is important to note there are no rules for what is right and wrong. What works for one person may not work for another. If you find something that calms your loved one, then you should keep doing it, and if you see something that makes them worse then it should be stopped.
- Often when a person is agitated they will need some type of medication to help control this symptom.

## What can I do to help with the restlessness or agitation?

- It may help to give your loved one calming words or comforting strokes. This tells them you are there and that you will take care of them and keep them safe.
- Speak slowly and calmly with normal voices.
- Try not to make loud noises.
- Try reading something hopeful or playing soft music.
- Holding their hand or a light touch may give your loved one comfort.
- It may help to bring in a beloved pet.
- Some people find comfort in sharing memories about special occasions, holidays, family gatherings or a favourite place.
- Please speak to your care team about visiting hours, the number of visitors that come at one time, and bringing in personal things and photos.
- Your loved one may talk about seeing people who have died before them. Try not to tell them they are confused as what they see may give them comfort.



## What happens as a person gets closer to death?

- In the last hours before dying a person may become very alert or active. This may be followed by a time of being unresponsive.
- You may see blotchiness and feel cooling of the arms and legs.

## No one can know exactly when death will happen.

- Their eyes will often be open and not blinking.
- Some people die surrounded by loved ones while others take their last breath when they are alone. At this time family members may get some peace and relief, feel sad or have a release of grief.
- It is often a time when silence can have great meaning and when words may not do justice in the moment. Being physically present with one another is an important support.
- Everyone has a different experience and a personal sense of loss. Even if dying has been expected for some time you will not know how that feels until the moment of loss. It may be felt as an end to suffering, or it may be seen as a time of healing and hope.
- The people closest to a dying person may choose not to be in the same room as their loved one. The decision to try and be present at the moment of death depends on many things. Do not judge others if they choose not to be present around the time of death.



## Saying goodbye

- Many people have questions about saying goodbye and ask if they should do so. Some people are worried that it will make their loved one's death come faster or make them feel badly. When and how to say goodbye or even giving permission to let go is a decision each person must make and there is no right or wrong way to do it.
- When your loved one is ready to die and you are ready to let them go it is time to say goodbye. Saying goodbye is not easy but can be a final gift of love. It may help to give you and your loved one closure.
- You may want to lie beside your loved one, hold him or her or take his or her hand. This is a time to say whatever you want or need to say. It may be "I love you", "Thank you for ...", "I'm sorry for ...". You may want to recall special memories.
- Tears are a normal and natural part of saying "Goodbye". You do not need to hide your tears or say sorry. These are normal ways to show your love and sadness.
- Please know that each time you leave your loved one it may be the last goodbye. If you need more information or would like to talk more about your feelings and concerns, please feel free to approach any member of the care team.
- A dying person may seem to "hold on" in order to be sure that those who are left behind are going to be all right or to say goodbye to someone close to them. Giving your loved one permission to go, and telling them that you will be all right, may bring peace and release.
- People who are dying often want "permission to die" from those they love.

They often want to know 5 key things:

- Things they are or have been responsible for will be taken care of
  - The survivors will go on without them
  - All is forgiven
  - Their life had meaning and they mattered
  - They will be remembered
- Saying goodbye is not easy. It is important for the dying person and their loved ones to do so.



## What happens right after a person dies?

- Once death happens, spend as much time as you need to say goodbye. Touch, hold and kiss the person, as you feel comfortable. Complete the rites and rituals you would like.
- Once your loved one has died let the care team know of any personal, cultural, and religious traditions, prayers, rites, and rituals that need to happen. Please let the healthcare team know how your loved one's body is to be handled and when and how their body can be moved.
- There may be cultural or family norms that guide how children are included. Our staff is available to help you with ways to talk about death with children and tell you about resources for children who are grieving.
- Please let our care team know if there is anything we can do to help you during this time.

## Taking care of yourself as you take care of your loved one

- Try and get some rest and sleep.
- If you are too exhausted, you may not be able to help your loved one or your family during this time.
- Make sure you eat and drink.
- Allow yourself some time away from the bedside of your loved one.
- Accept as much help from the nursing and support staff as can be given.
- Surround yourself with friends and family if this helps you.
- Take some time for yourself (eg. a walk, meditation or prayer).
- Take part in any personal, spiritual, cultural, or religious traditions, rites, rituals or ceremonies that may give you comfort.
- If you feel you need help coping with your grief, please ask to speak to our social worker or chaplain or ask for a visit from your clergy.
- Try not to take sedatives, tranquillizers, or too much alcohol as they may make your ability to cope worse.
- Don't be afraid to talk about your fears with your care team.







No night without

*There is no night without a dawning  
No winter without a spring  
And beyond the dark horizon  
Our hearts will once more sing...  
For those who leave us for a while  
Have only gone away  
Out of restless, care worn world  
Into a brighter day.*



**Comfortable End-of-Life Journeys**

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