

Understanding the Last Weeks, Days, and Hours of Life

Contents

Physical changes.....	2
Weakness and sleepiness	2
Eating and drinking.....	3
Mouth care.....	3
Eye care.....	3
Pain	4
Restlessness and agitation	4
Changes in breathing.....	5
Gurgling in the throat and secretions	6
Other changes	6
Confusion	6
Vision-like experiences	7
Social withdrawal.....	7
Spiritual pain.....	7
Cultural, spiritual, and religious considerations	8
In the last days	8
Very near the time of death	9
At the time of death	9
Talking to children about death	10
Pets	10
Caring for yourself.....	11
Grief	11
What can help with grief?	13
Grief supports.....	13
Important phone numbers	14

Understanding the Last Weeks, Days, and Hours of Life

The information provided in this pamphlet is to help you understand the changes that happen to someone during the last weeks, days, and hours of life. It is not possible to predict exactly how much time is left, but there are some physical changes that may tell you that the time of death is getting closer.

When a person is dying, both the body and mind are affected. These changes are a part of the dying process. Knowing what to expect may help you feel less afraid and less worried about what you may see. Knowing what to expect may also help you begin to understand the changes as they happen.

When a person's body begins to shut down, there are natural biological processes that happen. These processes are unique to that person and may look different from anything you have experienced before.

If you are caring for a dying person at home and they have symptoms that you are not prepared for, or feel you are not able to cope, you may need to call for help or reassurance:

- › If this happens, call the health care team contacts listed on page 14.

If you cannot reach them:

- › Consider calling 811, to talk to a registered nurse. This service is available 24 hours, every day.
- › **In an emergency, call 911.** If the person is registered with the Emergency Health Service (EHS) Special Patient Program (SPP), give the dispatcher their registration number.

This pamphlet was originally developed with Nova Scotia Health Cancer Care Program and several other partners, including patients, family members, and health professionals. This pamphlet is possible thanks to the Colchester East Hants Hospice Society, who granted permission to adapt their resource, *What to Expect at End of Life*.

Physical changes

Weakness and sleepiness

- As an illness gets worse, a person will feel weaker and much more tired. These changes usually happen over time, but can sometimes happen very quickly over a few hours.
- The person may now be spending all of their time in bed. If there is not an electric-type bed in the home, your health care team may suggest one or request one for you.
- To make them more comfortable, consider placing them partly on their side, supported with pillows along the entire length of their body. Special soft, long body pillows are available at most stores and can help at this stage.
- You can change the person's position every 6 to 8 hours if it is comfortable to do so. Talk with members of your health care team about what can be done to keep the person clean and comfortable.
- Your health care team may suggest using a urine catheter (a tube placed into the bladder) or protective undergarments (incontinence underwear).
- The person may appear to be in a light sleep all the time and more awake at night. Plan to spend time with them during those times when they seem most alert or awake.
- You may find the person likes the room light or dark. Either is OK.
- You do not need to be quiet when you are around them. Try to avoid very loud noises, as these may startle or upset them.
- Use your normal voice. **Do not** talk louder than usual.
- Always talk as if they can hear everything. They may be too weak to respond or not able to talk, but they may still hear and understand what you say.
- Sometimes, someone who is not responsive may suddenly become more alert as death gets closer. This can sometimes be for minutes to hours before getting very sleepy and then not responsive again.

Eating and drinking

- There will be a time when the person will eat or drink very little, if at all. As the body slows down, food and water are not needed and will not keep them alive any longer.
- If you try to feed someone who is very sleepy, it may cause food to go into their lungs. This can be dangerous. **Before trying to feed the person, please talk to your health care team.**
- If the person asks for water, raise the head of the bed a little and feed them ice chips or give them tiny amounts of water using a straw or a cup with a spout. If you hear the person cough or have trouble breathing while giving them water, stop and talk to your health care team.

Mouth care

- You may find the person is breathing through their mouth and is taking in very little fluid. The lining of their mouth and tongue can become dry and cause discomfort. Frequent mouth care will help keep their mouth moist. Mouth care should be done at least every few hours.
- Over-the-counter products are available at the pharmacy to moisten the mouth and protect their lips. Using these products and a sponge tip swab to clean and freshen the lining of their mouth, gums, and tongue, can provide comfort.
 - › Sometimes the person may bite down on the stick part of the swab sponge when you first put it in their mouth. This is a common reaction to protect the mouth. If this happens, continue to hold onto the stick, and after a few moments the person will stop biting on it.
 - › Your health care team can give you advice about what products to use (like lip balm or moisturizer) and how to provide mouth care.

Eye care

For relief of dry eyes, you can apply artificial tears (saline drops) to the eyes. These are available over-the-counter at most pharmacies. Your health care team can teach you how to do this and explain how often this is needed.

Pain

- Pain does not usually get worse at the end of life. As the body changes and the person becomes sleepier and moves around less, there may be less pain. Medications may need to be adjusted because of these changes.
- **Do not** suddenly stop giving pain medication if the person is not responding. They still need regular pain medications.
- If the person cannot swallow, your health care team will change the way the pain medication is given.
 - › You may be asked to give pain medication by mouth, by placing it against the lining of their mouth or under their tongue where it can be absorbed.
 - › The person may also need to receive pain medications through a butterfly. A butterfly is a small tube inserted by a team member under the person's skin. It has a small port on the outside that the medications go through. Your health care team will talk to you about this, if needed.
- Sometimes you may hear the person moaning. This may happen when you move them from side to side or when they breathe out. Often, this moaning is not caused by pain.
 - › If this happens, tell a member of your health care team.
- If they are in pain, they may need an extra breakthrough dose of pain medication. If you have given 3 extra doses of medication in a short period of time and their symptoms are not getting better, talk to your health care team.

Restlessness and agitation

- Sometimes the person can become very restless, confused, or agitated. Your health care team may call this **delirium**. These moments can be upsetting for everyone.
- The person may be restless or make repeated motions (like pulling at the bedding or their clothes). This may be a side effect of their medication or a symptom of their illness. If this happens:
 - › **Do not** stop or try to restrain them.
 - › Try to remain calm and **do not** argue with them.
 - › Offer reassurance and comfort by:
 - › talking in a quiet, natural way.
 - › playing soothing music.
 - › lightly massaging their forehead.
 - › talking about a memory or recalling a favorite place or experience they enjoyed.
 - › reading to them.

- Medications may help ease restlessness when other things do not work. Your health care team may prescribe a medication that can be absorbed under the tongue, at the side of the mouth or given using a butterfly.
 - › This medication is a mild sedative that will help to calm and soothe them. Your health care team may tell you to give this medication every 30 to 60 minutes. It may take several doses before the medication helps. Your health care team will teach you how to do this and talk with you about what to do if it is not working.

Changes in breathing

- As the person gets weaker, you may notice changes in their breathing. The most common thing you will see are short periods of time when the person stops breathing.
- The time between breaths may get longer as they get closer to death. It may seem like the person is gasping. At other times the person's breathing, particularly near death, becomes faster, deeper, and irregular. Oxygen is not needed, and it will not help the person in either of these situations. The person will not notice these periods and will not be upset by them.
- It might be stressful for you to watch the person's breathing change. It is important that you know it is OK to ask your health care team questions about these changes.
- It is important to watch your own breathing when you are with a dying person. Sometimes you can start to breathe in the same way as the dying person. This can make you dizzy or feel lightheaded. If you notice this, sit down and take a few slow deep breaths.

Gurgling in the throat and secretions

- Closer to death you may hear the person make gurgling sounds or start to make new snoring-like sounds. During this time, the person will be very drowsy (sleepy) and may not respond. These noises are because of:
 - › tiny amounts of mucus in their throat
 - › their jaw dropping back
 - › their tongue moving back as their jaw and throat muscles relax
- Sometimes you may also hear a soft, short moaning sound with each breath out. This will not cause suffocation or death from a blocked airway. Please know the person is **not** in pain and these sounds are caused by the relaxation of their throat tissues.
- When this happens, put the person on their side with their head slightly raised, if possible. Make sure the person is well supported by pillows all along the back of the body. A slight change in position will often help this noise.
- Sometimes medications may lower secretions.
- Giving oxygen will not help lower secretions.
- Suction machines are only needed in rare cases. Using suction can sometimes upset the person and only help lower the secretions for a short time.

Other changes

Confusion

The person may seem to be confused about the time, place, and who the people surrounding them are, including close and familiar people. This can happen for many reasons. It can help to:

- Tell the person your name before you talk, instead of asking them to guess who you are.
- Talk softly, clearly, and truthfully when you need to tell them something important for their comfort.
 - › For example, say, “It is time to take your medication”. Explain the reason for what you are doing, say, “so you won’t have pain or have trouble breathing.”

Vision-like experiences

- Some people see or talk to people who have already died or who they have not seen in many years. These experiences can be comforting to the person.
- Just because you cannot see or hear it, does not mean it is not real to the person. If these experiences are frightening, talk to a member of your health care team.

Social withdrawal

- Some people begin to withdraw from their chosen family and friends.
 - › For example, a person who was involved in the community may want only 1, or a few people with whom they feel close, at their bedside. It is important to respect these wishes as part of providing a comforting and calm environment.

Spiritual pain

- Some people are afraid to die:
 - › They may worry whether their lives have made a difference.
 - › They may feel guilty about things that they have done or not done.
 - › They may struggle with who they leave behind or be afraid of what comes after death.
- These are concerns experienced by people whether they consider themselves religious or not. It is part of being human.
- Depending on your relationship with the person and your own situation, sometimes it can help to remind them of ways they have made a difference and how they will be remembered.
- Spiritual care is available. For more information, talk to your health care team.

Cultural, spiritual, and religious considerations

- Many people have values and beliefs about:
 - › Dying and death
 - › Talking about dying and death
 - › What causes illness, including how pain is experienced and expressed
 - › The meaning of human life and the afterlife
 - › How a person's body should be treated leading up to death and afterward
 - › Rituals, funeral practices, and rites
- Your health care team wants to make sure your culture and traditions are respected. Please talk about any rituals, practices, or rites that are important during the last days.

In the last days

- A dying person may live longer than you expect. There are many reasons this happens. Depending on your relationship, you may choose to tell them it is OK to die. This may be hard for you, but it may be a meaningful or important conversation you choose to have.
- How you do this will reflect your unique relationship with the person. For some people it may be writing a letter, playing music, reminiscing, lying with the person, holding their hand, or saying everything you need to say. Other ways of saying goodbye include creating videos, sharing memories, or passing along keepsakes.
- It is common to have many different emotions at this time. This is natural. Everyone's experience is different.
- It is important to know that people will die in their own way, so even though you may feel there is nothing left to be done, the body still shuts down in its own way and time.

Very near the time of death

- As the person comes close to the time of dying, their hands, arms, feet, and/or legs may be cool to the touch. Their skin may look purple or bluish in colour. Less blood is reaching the body's limbs and instead is going to the body's most vital organs.
 - › You may use a blanket to help warm them, but **do not** use an electric blanket.
- The person's eyes may be open and not blinking.
- The health care team no longer needs to take the person's blood pressure, oxygen levels, or pulse. These are no longer reliable signs of how much time is left. The health care team will keep caring for the person and helping to make them comfortable.

At the time of death

- Although you may feel prepared for the dying process, you may not be prepared for the actual death. It may help for you to think about and talk about what you would do if you were present at that moment.
- **The expected death of the person is not an emergency. You do not need to call 911.**
- Sometimes, a person has died and we do not realize it at first. This is common. When the person dies there will be no breathing, no heartbeat, and no response when you touch them. Their eyelids can be slightly open, and their eyes will be fixed on a certain spot. They will no longer blink. The jaw will be relaxed and the mouth slightly open. There also may be a release of bladder and bowel contents.
- Know that their body does not have to be moved until you are ready. You may wish to spend some time with the person after their death. This is OK.
- When you are ready, call a member of your health care team or the funeral home (if this has been arranged).
- It is important to decide if you would like to be present when the person is picked up by a funeral home. Some people find comfort in being present during this moment, while others prefer to step away or be in another room.

Talking to children about death

- It is natural to try to protect children from painful feelings and experiences. Research and experience have shown that children benefit from honest, age-appropriate information.
- Children have great imaginations and often what they imagine is worse than being at the bedside of the dying person. Children may misinterpret phrases like, “God is taking grandma”, “We lost grandpa”, or referring to death as sleeping.
- Remember that children and teens may overhear your conversations. They can sense something upsetting is happening and if not told, may invent an explanation.
- If children and teens are not included in important conversations, they can feel isolated and alone.
- Talking to children honestly about illness, death, and grief, helps them to learn about this natural part of life. This conversation should be with someone they trust.
- Tell your child or teen’s teacher so they are aware of what is happening and can make accommodations if needed for missed work or assignments.
- Remember, children and teens grieve differently than adults. They often take breaks by playing or going out with friends. This does not mean that they do not understand or that they do not care, they may just need time and space away from their grief.
- Members of your health care team are available to help you talk to children and teens about death.

Pets

If the person is not at home and would like to see their pet, please check with your health care team to see if a visit from the pet is possible.

Caring for yourself

- This time can be one of both connection and stress for you and those involved. It is the ending of a life and a relationship. As death approaches, it can be a time of fear, it can be seen as an end to suffering, or it can be seen as a time of hope and healing.
- Many people want the dying process to end quickly. This may cause feelings of guilt. This is a common emotional reaction. Your health care team is available to talk with you about this.
- During this time, it is important for you to take care of yourself. The following suggestions are offered for you to consider:
 - › Eat healthy meals regularly. When you are stressed, you may lose your appetite (not feel hungry) or look for quick, convenient options for meals. Try to eat some fruits and vegetables each day.
 - › Remember to drink plenty of water to stay hydrated.
 - › Take time to go outside. If you cannot go outside, be sure to move around inside, walk around, or take time to stretch. This can help to relieve stress.
 - › Surround yourself with chosen family and supportive friends and let them help you.
 - › If you are using alcohol, sedatives, or tranquilizers, be careful you are not relying on them to be able to cope.
 - › Try to rest and sleep if you can.
- Ask your health care team about any questions, concerns, or fears that you may have.

Grief

- Grief can be one of the messiest and most painful experiences we have as human beings. It is our natural response to loss of any kind and can affect our whole being.
- For some people, grief can be both overwhelming and exhausting.
- You may find that you are so focused on caring for the person that your grief is not fully realized until the days and months after their death.
- Many caregivers feel guilty or blame themselves for their person's illness and wonder if they did enough to support them. **Remember, their death is not your fault.**

- Your experience of grief will be as unique as your relationship is with the person. No one grieves the same way and there is no right or wrong way to grieve. Grief does not follow simple stages or timelines.
- Please be gentle with yourself. Remember to treat yourself as you would with any good friend who is going through something similar, with understanding, compassion, and empathy.
- As humans, we will experience loss at some point in our life. Loss can include the loss of a relationship or something important in our lives.
 - › Loss of any kind can be grieved.
 - › Grief is personal, universal, and natural.
 - › There is no wrong way to grieve.
 - › Grief does not just “stop” but it can change over time.
 - › Letting yourself experience grief can honour your loss.
 - › Cultural traditions and beliefs can play an important role in grieving.
- You may feel a mix of these emotions, or no emotions at all. You may also feel more than 1 emotion at the same time.
- **Grief can affect:** Physical, emotional, mental, social, cultural, spiritual, and financial wellbeing.
- **Grief can cause:** Trouble sleeping (more or less than usual), trouble focusing, upset stomach (belly), chest pain, trouble breathing, dry mouth, tightness in the throat, lack of energy, aches and pains including headaches, anxiety, worry, and depression.
- **Grief can feel like:** Sadness, shame, worthlessness, guilt, anxiety, relief, hope, joy, loneliness, anger, fear, numbness and shock. You may feel a mix of emotions at the same time or none at all. You can also feel more than one emotion at the same time.
- **Grief can bring about:** Questioning your place in the world, intrusive thoughts, loss of routine, difficulty thinking things through, and other complex thoughts and emotions.

Remember, there is no right or wrong way to grieve. It is not a physical or mental illness to experience grief. When a person experiences loss, it is common to grieve.

What can help with grief?

It may help to make a grief care plan for yourself and your chosen family and friends. If you are feeling overwhelmed and are not sure how to cope with your grief, it may help to write down a plan.

Think about other losses you have experienced and ask yourself:

- › Did someone say or do something that you found helpful? What was it?
- › Did someone say or do something that you found did not help? What was it?
- › Is there anyone you would like to reach out to?
- › What do you need?
- › What helps to improve your mood when you feel down?
- › What are your favourite distractions?
- › What helps you feel safe and mindful?
- The answers to these questions can help your chosen family and your health care team support you.
- You may wish to talk with someone about your grief, like:
 - › A trusted member of your health care team
 - › A chosen family member or friend
 - › A leader from a faith community
 - › A hospital chaplain

This can help to lower the loneliness caused by grief.

We are here to support you. If you have questions, please ask a member of the health care team.

Grief supports

- › <http://nshealth.ca> (search “grief”)
- › <http://ns.211.ca> (search “grief groups”)
- **Halifax Hospice Grief & Bereavement Support**
 - › <https://hospicehalifax.ca/programs/>
- **Nova Scotia Hospice Palliative Care Association**
 - › <https://nshpca.ca/>
- **Canadian Virtual Hospice**
 - › <https://mygrief.ca/>
 - › <https://kidsgrief.ca/>

Important phone numbers

Contact

Phone number

Primary health care provider

Health care team (during the day)

Health care team (after hours)

EHS SPP identification (ID) number

Delegate (SDM)

Funeral home

Lawyer

Executor

Contact

Phone number

Bank

Other phone numbers

Other supports
