

When Death Occurs at Home



Victoria Hospice

As a person is dying, their body will go through a number of physical changes as it slows down and moves toward the final stages of life. Many of these changes are normal and to be expected. Please remember that each person is different; all of these signs and symptoms won't occur for everyone. Although the following changes are presented in the order in which they usually appear, some variation is common.

When you notice changes, report them to your Home and Community Care Nurse (HCCN) or family doctor, who can make any needed adjustments in medications and offer practical suggestions. If you have questions or concerns at any time, please talk to the HCCN, family doctor or one of the Victoria Hospice palliative care team members.

We hope that this information will help you prepare for changes that are likely to happen. We include some practical advice and comfort measures to help you in your role as caregiver and advocate.

A dying person may...

SLEEP LONGER

A dying person may sleep for longer periods and sometimes have difficulty waking. Times of increased activity and communication may be followed by hours or days of deep sleep and unresponsiveness. *In the moments before death occurs, many people appear to be sleeping or comatose.*

- Plan visits for times when the person is more wakeful and alert.
- Encourage visitors to sit quietly at the bedside. Physical touch, such as holding hands, may be a good way to connect.
- Avoid overtiring the person. Limit the number and length of visits.

EAT AND DRINK MUCH LESS

It is normal at end of life for people to have very little appetite or thirst. A dying person not be interested in food or drink. This is a natural part of their body preparing for death.

- Allow the person to be your guide about what to eat or drink.
- Serve small portions of soft light food or fluids.

- Understand that when a dying person eats or drinks more than is wanted, this can cause nausea, vomiting and other problems.
- Clean the person's mouth with a damp cloth or mouth swab, and apply moisturizer to the lips to help with dryness.

BECOME CONFUSED AND/OR RESTLESS

A dying person may be unable to recognize familiar people or surroundings, may see things that you cannot see, pull at their sheets and clothing or reach into the air.

- Speak calmly, slowly and in a manner that is familiar to the person.
- Offer reassurance about their safety and your confidence in their care.
- Consider playing calm and soothing music, gently placing your hand on the person or offering a gentle hand or foot massage.
- Keep the atmosphere quiet and turn down the lights. Try to minimize stimulation.
- Give gentle reminders about the time, where they are and who is present in the room. Use caution when attempting to correct or discount what appears real to the dying person as this may increase distress.

- Ask the HCCN, family doctor or palliative care team if medications may help.

EXPERIENCE EMOTIONAL AND SPIRITUAL CHANGES

A dying person may talk about going somewhere, ask to go home, or see and speak to people you don't see. Strong emotions such as fear or anger may be expressed near end of life. Although not everyone will experience these responses, they are considered normal and expected.

- Continue to respond in your usual way.
- Realize the dying person may be working through important issues such as life review, saying goodbye and letting go.
- Accept that unusual language or references are not always signs of a problem and may hold helpful insights into the dying person's experience. This is explained in a book called **Final Gifts** (1993) by Maggie Callanan and Patricia Kelley.
- Ask for a Victoria Hospice Counsellor or Spiritual Care Coordinator or your own spiritual advisor to visit and discuss these changes.

A dying person may...

HAVE DIFFICULTY SWALLOWING

A dying person may forget to swallow or have difficulty swallowing as weakness increases. Foods and fluids with the consistency of yogurt are easier to swallow than thin water-like fluids.

- Give only small amounts of food and fluid. Too much may cause choking and/or vomiting.
 - Remind the person to swallow.
 - Ask the HCCN or family doctor to suggest how to give medications when the person can no longer swallow.
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HAVE IRREGULAR OR SHALLOW BREATHING

Rapid shallow breathing is common. There may be pauses between breaths of 10-30 seconds or longer. Changing breathing patterns are normal, and usually the dying person is unaware of and untroubled by these changes.

- Remind yourself to breathe. Sometimes caregivers forget to breathe when they notice changes in the dying person's breathing patterns.

DEVELOP WET-SOUNDING BREATHING OR MOANING

As the body weakens, saliva may collect at the back of the throat and cause wet-sounding breathing. This wet sound may also be caused by congestion deeper in the lungs. Moaning as the person breathes in or out may or may not be an indication of discomfort.

- Discuss what you are hearing with the HCCN or family doctor; there are medications that can decrease congestion or provide relief if pain is a concern.
 - Change the person's position, perhaps by turning him or her to one side, raising the head of the bed or using pillows to prop the person up.
 - Use prescribed medications to decrease congestion or provide relief if pain is a concern.
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BECOME UNRESPONSIVE

The person may no longer respond to voices, being touched or may seem to be sleeping with their eyes open.

- Continue to speak as you normally would. Your familiar voice is likely to be comforting. It is generally believed that people can still hear even when they cannot respond.

- Tell the person what you are going to do before you do it, such as a position change, personal care or giving medications.
- Ask the HCCN or family doctor if drops would be helpful to prevent drying of the eyes.

LOSE CONTROL OF BLADDER OR BOWELS

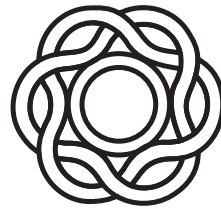
If the person has stopped eating and drinks very little, loss of bowel and bladder control may not be an issue. Decreased urine output and bowel movements are normal at the end of life.

- Ask the HCCN for information about protective padding and whether a catheter is appropriate.

HAVE A CHANGE IN BODY TEMPERATURE

The person may feel unusually hot or cool to the touch. If the temperature-regulating part of the brain is not working or a fever has developed, the person will feel hot to the touch. Conversely as circulation slows, the person's arms, legs, hands and feet may feel cool, and the skin may look patchy or bluish in colour. These changes are a normal part of the dying process. Typically, the person will not be feeling cold as this natural cooling occurs.

- Remove some blankets or place cool cloths on their forehead if the dying person is too warm.
- Use mouth swabs or damp cloths to prevent dryness in the mouth.



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Saying Good-bye

For many people, saying goodbye is an important part of the dying process. The person who is dying, as well as friends and family members, may wish to find ways to express their love, gratitude and sorrow to each other. Some people may choose to say goodbye through conversations, letters, trips and rituals, or simply by being together. Some dying people seem most comfortable with loved ones around, while others may be more at ease with quiet and privacy.

Usually the amount of stimulation and contact with others that people preferred when they were well is similar to what they desire near the end of life. A dying person may seem to choose the time to die, perhaps when particular people are present or when they are alone.

You may wish to:

- Talk about shared experiences, offering and receiving love.
- Offer or ask for forgiveness.
- Remember that tears are a natural and healing release of sadness.
- Reassure the dying person that you and your family will be okay.
- Give your permission for the person to die whenever he or she is ready.
- Choose a funeral home if you have not already done so.

At the Time of Death

You will notice that the person's:

- breathing and heartbeat have stopped
- eyes are not moving and may be open or closed
- mouth may fall or remain open as the jaw relaxes
- skin becomes pale and waxy looking

When Death has Occurred at Home

- DO NOT call 911, Police or Ambulance. Emergency Medical Personnel may try to revive the person and will transport them to the hospital emergency department. This can be very distressing.
- DO CALL Victoria Hospice, the Palliative Response Team, or the Home and Community Care Nurse. The phone numbers for Victoria Hospice and the HCCN are in the blue Hospice Home Chart. They will arrange for the most appropriate nurse or doctor to come to your home.
- DO CALL family members, friends or your spiritual advisor if you would like someone to be with you.

- SPEND as much time with the person who has died as you wish. Remember there is no need to rush. Take time to absorb the reality of death and say goodbye.
- Call the funeral home when you are ready, after the nurse or doctor has arrived to pronounce the death. If you have not chosen a funeral home, do so at this time.

After the Death...

This final leave-taking can be a difficult time. You may wish to spend time with the body of the person who has died, reminiscing and saying good-bye. Before the funeral home attendants arrive, you may want to bathe and/or dress the person or gather special objects or notes to send with him or her. You may prefer to choose the clothes you want the person to wear and give them to the attendants, or you can bring them to your meeting at the funeral home.

When the funeral home attendants arrive, they will move the body to a stretcher in preparation for leaving. The body will be placed in a special zippered bag made for the purpose of transport. Consider whether or not you wish to be present when the person's body is removed. You may wish to remain with the body or you may want to

- leave, go into another room or go for a walk while the stretcher is taken out. Memorial or funeral plans can be made or confirmed at an appointment with the funeral home the next day.

- Victoria Hospice Bereavement Services staff may keep in touch with family caregivers for a period of time. You will be given information about this service when the Hospice Home Chart is removed from your home. For more information, you can call the Victoria Hospice Bereavement Services office directly at (250) 370-8868 between 9:00 a.m. and 3:00 p.m. Monday to Friday (except for holidays).

- For more information, visit **www.victoriahospice.org**

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