

Preparing for Death:  
A Guide  
for Caregivers



Victoria Hospice

**A**s 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 or have any questions or concerns please talk to the Home and Community Care Nurse, family doctor or one of the Victoria Hospice palliative care team members. They can make any needed adjustments and offer practical suggestions.

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...

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### **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 may not be interested in food or drink. This is a natural part of their body preparing for death.

- Ask what they wish to eat or drink.
- Serve small portions of soft, light food or fluids.

- Understand that if 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.

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## EXPERIENCE EMOTIONAL AND SPIRITUAL CHANGES

A dying person may talk about going on a trip, ask to go home, or speak to people you don't see. Strong emotions such as fear or anger also 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 that 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 with you.

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## BECOME CONFUSED AND/OR RESTLESS

A dying person may be unable to recognize familiar people or surroundings, 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 presence.
- 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 their distress.
- Ask the nurse, doctor or palliative care team if medications would help.

# A dying person may...

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## **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 nurse or 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 to 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 temporarily forget to breathe when focused on the dying person's breathing patterns.

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## **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 nurse or 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.

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## **BECOME UNRESPONSIVE**

The person may no longer respond to voice or touch or may seem to be sleeping with their eyes open.

- Continue to speak to the person. 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 (e.g. a position change, personal care or giving medications).
- Ask the nurse or doctor if drops would be helpful to prevent eye dryness.

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## **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 nurse for information about protective padding and whether a catheter is appropriate.

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## **HAVE A CHANGE IN BODY TEMPERATURE**

The person may feel unusually warm or cool to the touch. When the temperature-regulating part of the brain is not working or a fever has developed, the person will feel hot. Conversely as circulation slows, their arms, legs, hands and feet may feel cool, and the skin may look patchy or bluish in colour. This is a normal part of the dying process and, usually, people do not feel these changes.

- Remove 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.

## What About You?

At this time, you may find you are so busy being a caregiver that you are not looking after your own health. Remember, it can be difficult to care for another when you don't care for yourself.

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## **SELF CARE SUGGESTIONS**

- Ask for and accept help with care, household and other tasks (e.g. phone calls, shopping).
- Find ways to handle updates and enquiries (e.g. use email, designate a friend).
- Notice what gives you comfort or pleasure (e.g. time with others, reading, nature).
- Remember to breathe, to eat and to sleep.
- Set limits and say no when you need to. Let others know how you are doing.
- Don't ignore the humour and beauty in life.
- Share stories and memories.
- Acknowledge this is a difficult time. Remember that everyone (including you) is doing their best.
- Do anything that feels like self care (e.g. massage, haircut, nap, walk, sit quietly, cry).
- Maintain your spiritual and religious practices.
- Sing, play or listen to music that comforts or uplifts you.

## Saying Good-bye

For many people, saying goodbye is very important. The person who is dying, as well as friends and family members, may wish to express their love, gratitude and sorrow to each other. Some people may say goodbye through conversations, letters, trips and rituals, or simply by being together. Some dying people are most comfortable with having people around, while others are more at ease with quiet and privacy. Sometimes a person seems to choose the time to die, perhaps when alone or when particular people are present.

### **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.
- 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 (HCCN). The phone numbers for Victoria Hospice and the HCCN are in the blue *Palliative Care at Home* binder. They will arrange for a nurse or doctor to come to your home, as required, to pronounce the death.
- 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 to say goodbye.
- Call the funeral home when you are ready, after the nurse or doctor has arrived. 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** team are able to keep in touch with family caregivers for a period of time. You will be given information about this service when the *Palliative Care at Home* binder is removed from your home or when you leave the inpatient unit. For more information, you can call the Victoria Hospice Bereavement Services office directly at 250-370-8868 Monday through Friday (except holidays) or visit **[www.victoriahospice.org](http://www.victoriahospice.org)**



## Victoria Hospice

Richmond Pavilion, 1952 Bay Street  
Victoria, BC V8R 1J8

250-370-8715

**[www.victoriahospice.org](http://www.victoriahospice.org)**