HOME AND COMMUNITY CARE SUPPORT SERVICES Champlain



When Death Occurs at Home:

A Guide for Caregivers



Some people choose to die at home. People often have questions about what to expect when caring for someone going through the dying process. While everyone is different and will not experience end-of-life in the same way, this pamphlet will help you prepare.

Do Not Resuscitate

The *Do Not Resuscitate Confirmation*Form supports the wish for a natural death.
By signing this form, your Health Care
Team understands that CPR is not to be
performed. The signed form is kept in the
front of the Chart in the Home but you may
make copies. Should you have any questions,
please speak with your nurse, doctor or
Care Coordinator.

What To Do When You Notice the Following Signs

By being familiar with this information, you may better understand the dying process.



Longer Periods of Sleep and Difficulty Waking

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.

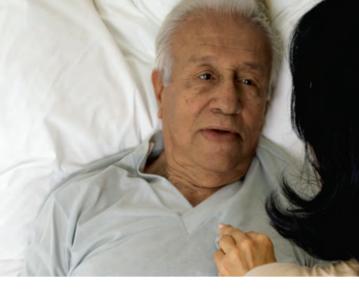
- Planning conversations when the person is more wakeful and alert
- Limiting the number of visitors
- Keeping visits short or encouraging visitors to sit quietly at the bedside
- Having a guest book at the bedside for visitors to write comforting notes (you can read these notes to the person at a time when he/she is awake)



Decrease in Appetite and Thirst

It is normal for a dying person to not be interested in food or drink. This is a natural part of the body preparing for death.

- Asking what they wish to eat or drink, and respect their choices
- Serving small portions of soft, light food or fluids
- Telling him/her that it is ok not to eat or drink if nothing tastes good or if their appetite is poor
- That if a dying person eats or drinks more than is wanted, this can cause nausea, vomiting and other problems



Mouth Care

Dry mouth is often mistaken for thirst. Frequent mouth care is very important to provide comfort. To keep the inside of the mouth moist, consider:

- Cleaning the mouth with a baby toothbrush and applying moisturizer to the lips to help with dryness
- Offering ice chips or small chunks of watery fruit, such as pineapple or watermelon

Difficulty Swallowing

A dying person may have difficulty or forget to swallow as weakness increases. Forcing the person to eat or drink may cause vomiting, choking or distress.

Consider:

 That foods and fluids with the consistency of yogurt are easier to swallow than thin water-like fluids

- Offering only small amounts of food or fluids but never insisting if refused
- Gently reminding the person to swallow
- Asking the nurse or doctor to suggest how to give medications when the person has difficulty or can no longer swallow

Confusion and/or Restlessness

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. Should you have any questions, please speak with your nurse, doctor or Care Coordinator.

- Identifying yourself
- Speaking calmly and naturally
- Keeping the room quiet and turning down the lights or using a nightlight
- Minimizing stimulation
- Offering reassurance about their safety and your presence
- Playing calm and soothing music
- Avoiding physical restraint
- Offering a gentle hand or foot massage
- Contacting the nurse or doctor if you have concerns

Changes in Breathing

Changes in breathing patterns are normal. There may be pauses between breaths of 10 to 30 seconds or longer. Breathing can also be noisy because of saliva collecting in the back of the throat. Usually the dying person is unaware of and untroubled by these changes.

Consider:

- Keeping the room well ventilated by adding a fan
- Repositioning the person
- That oxygen is typically not needed (unless it was required before)
- Talking to your nurse or doctor if you have any concerns
- Reminding yourself to breathe sometimes caregivers temporarily forget to breathe when focused on the dying person's breathing patterns

Response to Voices or Touch

- Speaking in a calm and natural way
- Sharing your emotions



Changes in Bladder and Bowel

Decreased urine output and bowel movements are normal at the end of life. Urine will become darker in colour and may have a strong odour.

Consider:

Asking the nurse for information about protective padding and whether a catheter is needed.

Changes in Skin Colour and Temperature

The person may feel unusually warm or cool to touch because the brain can no longer control temperature. This is a normal part of the dying process and the person usually does not feel these changes.

Consider:

Removing blankets or using cool cloths if warm

- Changing clothing and bedding when the skin is damp
- Adding blankets if skin is cold
- That skin, fingernails, hands and feet may become patchy, pale or bluish in colour

At the Time of Death

- DO NOT CALL 911. Emergency Medical Personnel may try to revive the person and may transport them to the hospital emergency department. This can be very distressing.
- There will be no response, no breathing, and no pulse/heartbeat
- The eyes may be open or closed
- There may be loss of bladder and/or bowel control
- Contact the nurse or doctor who has been identified to come and confirm death
- 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 at a time that is convenient for you. Anyone can assist you in doing this, if needed.

Saying Goodbye

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.

- Talking about shared experiences
- Offering or asking for forgiveness
- Remembering that tears are a natural and healing release of sadness
- Reminiscing and saying goodbye
- Reassuring the dying person that you and your family will be okay
- Choosing a funeral home if you have not already done so

After the Death

This final leave-taking can be a difficult time. Before the funeral home attendants arrive, you may want to bathe and/or dress the deceased or gather special objects or notes to send with him or her. You may prefer to choose the clothes you want the deceased 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 deceased to a stretcher in preparation for leaving. The deceased 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 deceased is removed. You may wish to remain with the deceased 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.

Key contacts

Complete the form below so you know whom to contact at all times:

Nurse:
Phone #:
Physician:
Phone #:
Funeral home:
Phone #:
Care Coordinator:
Phone #:
Family and other contacts:

For more information

Call us at **310-2222** or **1-800-538-0520** or visit us online at: **www.healthcareathome.ca**

Acknowledgement

The development of the pamphlet When Death Occurs at Home:
A Guide for Caregivers was significantly influenced by the work from Victoria Hospice

www.victoriahospice.org /i-am-caregiver/ preparing-death-guide-caregivers

About Us

If you, or someone you care about, needs health care services at home, at school or in the community, or if you are considering supported living programs or long-term care options, Home and Community Support Services Champlain can help.

Home and Community Support Services Champlain works with people of all ages to ensure they can make informed choices about their care, when and where they need it.

We also have useful information about local community support service agencies, and can link people to these providers to arrange services.

You can explore your care and support options through our website at **www.healthcareathome.ca**, or contact us at **310-2222** or **1-800-538-0520**.

For additional information on community services and educational resources please go to: www.champlainhealthline.ca.

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