

## WHAT TO CONSIDER WHEN CARING FOR SOMEONE WHO IS DYING AT HOME

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*This is written for families and caregivers of the person who has made the choice to die at home.*

Changes that occur as a person dies will vary from one person to the next. Some changes may be unsettling and are usually more difficult for you to watch than for the person to experience. The more families and friends understand what is happening during the dying process, the better you will be able to handle the situation and manage caring for your loved one at home. An important goal when death is near is to do what the person with an advanced terminal illness would choose. Ideally, he or she knows what is happening and has participated in making decisions about how to live and prepare for death. Discussing these wishes with you, your family, and your physician is important. If this has not happened, you should aim to do what this person would want. Following the wishes of the person who is dying may mean making decisions that are different from what you would choose for yourself.

### WHAT YOU CAN DO TO HELP

#### ***Help with comfort and rest***

Continue giving medicine for pain on a regular basis as ordered by the physician. If a person cannot tell you about pain, watch for tense body posture, clenched fists, frowns, restlessness, moaning, or attempts to turn over. Soft music can be very soothing, even when a person is not conscious. Turn the patient every few hours and rearrange his or her position with pillows (ask the physician or nurse to show you how if you are unsure or worried about how to do this). Give back rubs and maintain skin moisture with lotion. Try to avoid using bright lights. Moisten the patient's eyes, using a warm damp cloth and their lips with lip balm to prevent dryness. Talking and touching are comforting to both you and the patient, although s/he may often not respond.

#### ***Prepare for physical and emotional changes***

As people die, they become extremely tired and weak. Swallowing fluids and taking medication gets harder. Breathing changes and becomes noisy and irregular, the person may even periodically stop breathing at times and sound as though they are gasping, which can often be frightening. The person will gradually respond less and less to you but continue to keep talking and holding hands for comfort. Discuss any symptoms that you are concerned about—such as pain, difficulty swallowing, noisy breathing or general anxiety and discomfort, with the physician or nurse. Medications can be ordered to help keep your loved one comfortable and are often available in a variety of different routes for administering. Prescriptions will need to be filled through your local pharmacy.

#### ***Avoid calling 911 or an emergency team***

When you or someone else calls 911 or the emergency number in your area, you need to remember that the paramedics will arrive expecting to save a life or give "aggressive" treatment in an attempt to restore life—they may even move the person from the home to the hospital. Have an emergency plan in place and a network of people to call, such as phoning a family physician or palliative care specialist first. Keep phone numbers of physicians, home care nurses, palliative care team staff and other people you may need to contact readily available. Know who to call when worried or concerned.

#### ***Prepare a list of people to call near the time of death***

Decide who you and your loved one would want to visit the home near the time of death—to say a final goodbye. Also make a list of people who want to be notified when the person dies. Decide who would be most helpful to you at this difficult time and have them come over to help with phoning and anything else that you may need. Ask certain adults to be "on-call" to help with any younger children if this is needed. Decide if clergy or a bereavement counselor should be called before or at the time of death.

#### ***Prepare for the funeral home ahead of time***

Select a funeral home and inform them that you expect a natural death at home in the near future. The funeral home staff can tell you and your loved one about the costs and different kinds of services available so that you can both be thinking about what you would like and afford. Some families prefer to make these arrangements early so that the person with an advanced illness can help in the planning. Others make these arrangements just before death occurs. The doctor or nurse who confirms that death has occurred will usually call the funeral home for you. This does not need to be done immediately.

### WHAT TO ANTICIPATE AND RECOGNIZE WHEN THE END OF LIFE IS NEAR

No matter how much you prepare for this moment, death arrives in its own time and in its own way. The experience of dying is different for every person and for every family. What is important is to do whatever is felt to be of help and comfort during this time. The moments around the time of death are often full of emotion for many reasons, and you may need help from a home care nurse or other health care professionals at this point—in order to keep your loved one comfortable.

At the end of dying is death itself. You will know this has happened because the chest will not rise and you will feel no breath from the person's nose. The eyes may be glassy (if they are open). You will not feel any pulse in the places where you felt it before. When you realize someone has just died, it is a very "still" and quiet moment. After your loved one has passed on, take as much time as you need to say your goodbyes. The attending physician or nurse will need to see your loved one and sign a death certificate, of which you will later need to obtain a copy from the funeral director. Medications will also need to be discarded appropriately; ask your physician or nurse what to do with these. Either the physician or the nurse will call the funeral home for you and arrange to have them respond when you are ready to have them come to your home.

#### **WHAT IF CARING FOR YOUR LOVED ONE AT HOME DOES NOT WORK?**

Helping someone to die at home is hard work, and you may need to take the person you are caring for somewhere else to live out the final days of his or her life. Periodically ask yourself if the person you are caring for is comfortable and if his or her wishes are being followed. Also ask yourself if you have the physical and emotional strength to give the care that is needed. If not, it is important that you speak with the doctor or nurse. You can still help to give care for your loved one in the hospital, palliative care unit, nursing home, or hospice—having a sense that the person is comfortable and that you are meeting their needs in this way is important for you and your family to know.

#### **HELP for YOU and YOUR FAMILY**

Remember that you are not alone, there are many people ready to help when a family is preparing for an expected death-at-home. Consider discussing the following with your physician or home care nurse, in order to connect you with some helpful resources in your community—so that you can reach them when you are ready and need to.

#### **RESOURCES to consider contacting in your community:**

**Spiritual Support Services -**

**Grief Counseling and Bereavement Services for Family and Caregivers -**

##### **Website Resources:**

**The Canadian Cancer Society** <http://www.cancer.ca/english/index.asp>

**The Canadian Hospice Palliative Care Association** <http://www.cPCA.net>

**Alberta Palliative.net – A Caregivers Guide** <http://www.albertapalliative.net/APN/CGG/CGGIdx.html/>

**American College of Physicians Home Care Guide for Advanced Cancer**

[http://www.acponline.org/public/h\\_care](http://www.acponline.org/public/h_care)

**Caring for Your Loved One at Home: P.E.I. Guidelines for Managing the Expected Home Death**

[http://www.gov.pe.ca/photos/original/hss\\_homedeadth.pdf](http://www.gov.pe.ca/photos/original/hss_homedeadth.pdf)

**Preparing for An Expected Death at Home. Nova Scotia Department of Health Publication.**

[http://www.gov.ns.ca/health/downloads/preparing\\_at\\_home.pdf](http://www.gov.ns.ca/health/downloads/preparing_at_home.pdf)

#### **IMPORTANT PHONE NUMBERS:**

**FAMILY PHYSICIAN:**

**PHARMACY:**

**HOME CARE NURSE:**

**CLERGY/SPIRITUAL SUPPORT:**

**PALLIATIVE CARE TEAM:**

**FUNERAL HOME/DIRECTOR:**

**RESPIRE SERVICES:**

**LAWYER:**

**OTHER CONTACT NUMBERS (friends, family, community services):**

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1. The American College of Physicians Home Care Guide for Advanced Cancer. The American College of Physicians is not responsible for this adaptation. To view the complete original document visit: [http://www.acponline.org/public/h\\_care/index.html](http://www.acponline.org/public/h_care/index.html)
2. Preparing for An Expected Death at Home, Home Care Nova Scotia, 2000 <http://www.gov.ns.ca/health/>



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