

What to Expect in the Last Days or Hours of Life



PALLIATIVE CARE PROGRAM

This information in this booklet has been adapted from several resources including “The Last Hours or Days of Life” from the Temmy Latner Centre, Toronto and the Lunenburg Queens Palliative Program from their version of “Preparing for Approaching Death”.

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Introduction

This information package is designed to help you care for your loved one during the last hours or days of living. Your doctor or nurse has determined that only a little time remains. How long is not certain, but you and your family need to be prepared. When a person enters the final stages of dying it affects their body and mind. These changes are a normal part of the dying process. Knowing what to expect can help you and your loved one.

When a person's body is ready and wanting to stop, but the person is not finished with some important issue, or with some significant relationship, he/she may tend to linger in order to finish whatever needs finishing. On the other hand, when a person is emotionally-spiritually-mentally resolved and ready for this release, but his/her body has not completed its final physical process, the person will continue to live until the physical shut down is complete.

By being familiar with the normal process of dying we hope that this information will help you and your family and remove some fear of the unknown. Please ask any member of your health care team if you have any questions about any of this material.

People are unique and each of us live and die in our own way. The information in this package is meant to serve as guidelines.

The Physical Changes and Needs

Weakness and Sleepiness

Your loved one may feel weaker and much more tired. These changes usually happen over a few days but sometimes this happens very quickly over a few hours.

The person may now be spending all of his or her time in bed. If there is not already an electric-type bed in the home your doctor or nurse may suggest one. This kind of bed may make it easier to care for someone at home. You may place the person partly on their side, supported with pillows along the whole length of their body. Special soft, long body pillows are available at most department stores and can be very useful at this stage. You do not have to change the person's position more than every 6–8 hours. The person may lose control of urine and/or bowel matter as the muscles in that area begin to relax. Discuss with members of your Palliative Care Team what can be done to protect the bed and keep your loved one clean and comfortable. To make this time a little easier, your doctor or nurse may suggest using a urine catheter (a tube placed into the bladder) or protective undergarments.

The person may appear to be in a light sleep all the time and may be more awake at night. Plan to spend time with him/her during those times when he/she seems most alert or awake. You do not need to be quiet when around your loved one. Speak with normal voices. However, avoid very loud noises as they may startle and disturb the person and lead to some distress. Always talk to your loved one as if he or she can hear everything. The person may be too weak to respond or may not be able to speak but they may still be able to hear and understand what you say. Tell your loved one the things you want to say. Hug, touch and cry – all of these things are important to you and your family, as well as to your loved one.

Eating and Drinking

This is also a time when the person will eat or drink very little, if at all. At this stage, food or water will not help your loved one and it will not keep them alive longer. In fact, when the body's system slows down, food and water may not be processed properly. If you try to feed someone who is very sleepy it may cause the food or water to go down into the lungs, so be very careful.

If the person asks for water, raise the head of the bed a little and feed them ice chips or give them small amounts of water using a straw or a baby cup with a spout. If you hear the person cough or they have trouble breathing while you are giving them water, stop immediately.

Disorientation

The person may seem to be confused about the time, place, and identity of people surrounding him/her, including close and familiar people. This can happen due to many reasons. Identify yourself by name before you speak rather than ask the person to guess who you are. Speak softly, clearly, and truthfully when you need to tell them something important for their comfort, such as, "It is time to take your medication" and explain the reason for what you are doing, such as "So you won't begin to hurt".

Mouth and Eye Care

It is important that you help your loved one with mouth care. Often you may find the person is breathing through their mouth and is taking in very little fluids. The lining of the mouth and tongue can become quite dry, causing the person some discomfort. Frequent mouth care will help with this problem and products are available at the

pharmacy to moisten the mouth and protect the lips. Using these products and a sponge tip swab to clean and freshen the lining of the mouth, the gums and the tongue provides comfort. Sometimes the person may bite down on the sponge when you first put it in their mouth. This is a normal reaction to protect the mouth. If this happens, continue to hold onto the stick after a few moments the person will not bite it anymore. Mouth care should be done at least every few hours. Your Palliative Care Team can direct you on what products to use and how to provide mouth care.

For relief of dry eyes you can apply Artificial Tears or Lacrilube to the eyes. These are available at most drug stores. Your nurse will teach you how to do this and tell you how often.

Pain

Pain does not usually get worse at the end of life. Often as the body changes and the person becomes sleepier and moves around less, there may actually be less pain. Your doctor may need to adjust medications because of these changes. It is important not to stop giving pain medication to your loved one if they are not responding. They still require their regular medications for pain.

If the person can't swallow, the doctor 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 the mouth or under the tongue where it can be absorbed. It can also sometimes be given by suppository. Or, the person may receive pain medications by injection every 4 hours, using a special set-up called a butterfly that uses fewer needles. Your doctor or nurse will teach you about this too.

Sometimes you may hear the person moaning. This may happen when you move the patient from side to side or when they breathe out. This moaning is not caused by pain. However if you see the person's forehead scrunched up it could mean they are in pain, and you should give the extra breakthrough dose of pain medication as instructed by your Palliative Care Team.

Restlessness and Agitation

Sometimes your loved one can become very restless or agitated. Your Palliative Care Team will refer to this as Delirium. The person may make restless and repetitive motions, such as pulling at the bed linen or clothing. This can be due to internal body changes taking place or it can sometimes be due to a medication. Do not interfere with or try to restrain such motions. To provide a calming effect speak in a quiet, natural way, lightly massage the forehead, read to the person or play some soothing music. Other things which may be helpful in calming the person are to recall a favorite place the person enjoyed or a favorite experience, read something comforting, or play music, and give assurance that it is okay to let go. Medications can be helpful in easing restlessness when other things do not work. Your doctor may prescribe a medication that can be absorbed from under the tongue, at the side of the mouth or given by injection. This medication is a mild sedative that will quickly calm and soothe an agitated or restless person. At first you may need to give this medication every half-hour or hour, and it may take several doses before it helps. Your doctor or nurse will teach you how to do this.

Changes in Breathing Pattern

As your loved one gets weak, you may notice changes in their breathing patterns. The most common thing you will see will be 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 your loved one is gasping.. Other times the person's breathing, particularly near death, becomes more rapid, deeper and irregular. Oxygen will not help the person in either of these situations. Your loved one will not notice these periods and will not be upset by them.

Gurgling in the Throat and Secretions (a few hours or a day or two)

Very near death you may hear the person gurgle or make a snoring-like sound. During this time the person will be extremely drowsy and may not respond at all. These noises are the result of several things – small amounts of mucus in the throat, the jaw dropping back, or the tongue moving back due to the relaxation of jaw and throat muscles. Sometimes a soft short moaning sound with each breath out may accompany this. This will never result in suffocation or death from a blocked airway. Again, be reassured that your loved one is not in pain, but these sounds are due to relaxation of throat tissues.

The best thing to do is to put the person on their side and their head slightly raised. Make sure the person is well supported by pillows all along the back of the body. Doing this will often stop the noises. Sometimes the doctor will order an injected medicine or a medicine placed under the tongue to reduce these secretions. Oxygen will not help with this problem. Suction machines are very rarely needed and can potentially cause distress to the person.

Very Near the Time of Death

As your loved one comes very close to the time of dying their hands, arms, feet and/or legs may become increasingly cool to the touch, and the color of the skin may change. The underside of the body may become darker and the skin becomes discolored with a purple discoloration. This is a normal indication that the circulation of blood is decreasing to the body's limbs and being reserved for the most vital organs. Keep the person warm with a blanket but do not use an electric blanket. The person's eyes will often be open and not blinking.

Do not worry whether or not the nurse takes the person's blood pressure and pulse as they are not reliable signs that death is coming. Occasionally, someone who is unresponsive may suddenly become more alert as death approaches. This can sometimes be for minutes to hours prior to them becoming very sleepy then unresponsive again.

Emotional–Spiritual–Mental Signs and Symptoms

Vision–like Experience

As they are dying, some people see or speak with people who have already died. People generally find these experiences comforting. Just because you cannot see or hear it does not mean it is not real to your loved one. Affirm his/her experiences. If they frighten your loved one discuss this with members of your Palliative Care Team.

Social Withdrawal

As the process continues most people begin to withdraw from their friends and family. For example, a person who was very involved in the community may only want one or a very few people to whom they feel close at their bedside.

Spiritual Pain

Many of us are afraid to die. We worry whether our lives made a difference; we may be embarrassed about things that we have done in our lives, we may feel sad because we will miss those we leave behind or afraid of what comes after death.

These are concerns experienced by most people whether or not they were religious or attended church, it is part of the human experience. One of the things that we can do is to help people remind them of things that they did that made their life worthwhile.

If you feel that spiritual support would be helpful the Palliative Care team can help to facilitate a referral.

Giving Permission

A dying person may try to hold on, even though it brings prolonged discomfort, in order to be sure that those who are going to be left behind will be all right. Assuring them that it is alright to let go whenever they are ready, may be beneficial.

Other Important Information

This time can be one of both peace and distress for you and your family. It is the ending of a life and a relationship that is important to you. 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. We may wish for the dying process to end quickly which may evoke feelings of guilt. This is not an unusual experience.

- It is important for you to take care of yourself
- It is important to eat properly. We have a tendency not to want to eat or to eat fast food. It is a good idea to eat some fruits and vegetables every day.
- The tendency is to drink coffee and tea at this time. Please be sure to drink water too. This is especially true if your loved one is in the hospital which is a dry building.
- Take time to go outside if you can, If you cannot go outside be sure to move, walking up and down the hall or some form of exercise. This helps to relieve stress.
- Surround yourself with supportive friends and tell them how they can help you.
- Let your friends and family help you.
- Take caution if using sedatives, tranquillizers and avoid too much alcohol.
- Try and get some rest, if not some sleep.
- Ask your health care team members any questions, concerns or fears that come to mind.

This time can be one when there are mixed feelings: peace/relief and terrible sadness. Tears are important. Tears do not need to be hidden from your loved one or apologized for.

Children

Children have great imaginations and often what they imagine is worse than being at the bedside. Remember children and teenagers overhear everything, they will sense something upsetting is happening and if not told will invent an explanation for the family distress. If not told the children/teenagers will feel isolated.

Children and teenagers grieve differently than adults and often take breaks by playing or going out with friends. This does not indicate that they do not understand or lack compassion but are just taking a break from grief and getting replenished.

It is a natural inclination to try to protect the children. However, if they are prepared for what they will see it is generally comforting to all concerned. Children may misinterpret phrases such as "God is taking grandma", "we lost grandpa" or statements that indicate that death is like sleeping. Members of the Palliative Care Team are available to help you prepare the children, if you want. The Hospice Society has a lending library with resources that may be of help as well.

Pets

If your loved one is in hospital and would like to see their pet please check with the nursing staff to facilitate a visit.

The Death

Although you may be prepared for the death process you may not be prepared for the actual death moment. It may be helpful for you and your family to think about and discuss what you would do if you were present at the death moment. The death of a Palliative Care Patient is not an emergency. Do not panic and do not call 911. When your loved one dies there will be no breathing, no heartbeat and no response to stimulation. The eyelids will be slightly open and the eyes will be fixed on a certain spot. There will be no blinking. The jaw will be relaxed and the mouth slightly open. There also may be a release of bladder and bowel contents. Sometimes the process is so gradual that we are not really sure for awhile that our loved one has died.

There is no need to contact any one immediately, even the physician. The body does not have to be moved until you are ready. You and your family may wish to spend some time with your loved one following his/her death. When you are ready, call the VON Nurse or the Funeral Home if this has been previously arranged.

You may want to take some time to think about if you want to be present when your loved one is removed from home or hospital room by the funeral home. It is okay to stay or go to another room if you wish.

Grief

It is important to remember that grief is a natural process that accompanies loss. You and your loved ones may experience loss at various stages throughout the illness as well as after the death. Grief affects all aspects of life and requires support. Let your grief be expressed.

- Allow yourself to mourn
- Realize your grief is unique
- Talk about your grief with caring friends and relatives
- Expect to feel a wide range of emotions
- Allow for numbness
- Be tolerant of your physical and emotional limits
- Develop a support system
- Make use of ritual
- Embrace your spirituality
- Allow a search for meaning
- Treasure your memories
- Move toward your grief and heal
- There is no time limit on grief

Contact the Hospice Society at 893-3265 for the additional grief support of a friendly listener, a lending library and support groups.

Resources for You and Your Family

The Hospice Society

Colchester East Hants Hospice Society is a charitable community organization dedicated to providing care and support to families facing life threatening illness. Through a combination of professionals and trained volunteers, the Hospice Society is able to provide a wide variety of programs and services to support you:
 Volunteer Visitors: trained volunteers are available to visit in the hospital or in your home. A volunteer can provide a friendly listening ear, an opportunity to share in enjoyable activity, respite for the family members, assistance with errands, and much more.

Food From the Heart

The palliative team may refer families with limited financial resources to the Hospice Food From the Heart program, which provides \$100 in Sobey's gift certificates every two weeks for a period of up to three months.

Practical Support

Some families will have other needs including special equipment, supplies or other household needs and Hospice will consider these requests.

Hospice Wishes

A family may have a special activity or wish and Hospice will endeavor to assist in any way possible.

Lending Library

Many books and videos are available for your use.

Grief Support

Individuals with a life threatening illness and their loved ones will face many losses along their journey. Hospice provides a variety of programs geared to supporting

individuals and groups through this journey and through grief after the death of their loved one. These include: peer support (volunteer), lending library, bereavement follow up calls, book program, drop in Grief Walking Group, 6 week Grief Support Group, services of remembrance, and in the near future we intend to offer individual and family counseling

The Hospice Society also provides end of life education, public awareness, advocacy and system navigation support.

