

WHAT TO EXPECT DURING

# End of Life

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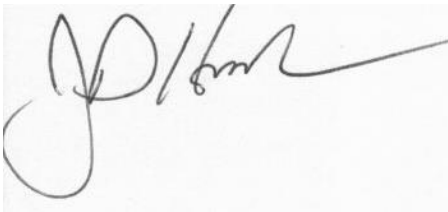
*Providing care and support to those  
facing life threatening illness and grief*

## Forward

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I have had the great privilege of meeting and working with many remarkable individuals during my many years as a Palliative Care Physician. Most patients and families have expressed that they found having clear and accurate information about what to expect, despite how difficult it is to hear at the time, to be tremendously empowering. Having this information reduced the many fears of what might happen, enabling the family to focus on relationships and the emotions we go through when someone is dying.

We hope this publication will help you and your family to understand the normal process of dying. Please don't hesitate to ask your health care team to clarify or elaborate on any of the information you have read in this booklet.

A handwritten signature in black ink, appearing to read 'D Henderson', written on a light-colored background.

**Dr. David Henderson, MD, CCFP, FCFP, ABHPM**  
Hospice Society Board of Directors,  
Medical Director, CEHHA Palliative Care Program



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## **Introduction**

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The Hospice Palliative Care team has designed this booklet to help you understand what happens to someone during the last weeks, days and hours of life when your care team has determined that little time remains. Predicting exactly how much time is impossible to determine, but there are some changes that may be occurring physically to the person that indicate death will happen soon. Preparing for this time is important for all involved and we have been told that understanding what is going on during the process has been helpful. When a person enters the final stages of dying both body and mind are affected. These changes are a normal part of the dying process and knowing what to expect helps address fears and concerns that you may have at this time.

When a person's body is ready and preparing to stop there are natural biological processes that start to happen. Each person is unique and so too will be their dying. Some have spiritual and/or emotional processes that are important as well, and others may focus more on relationships and tasks they feel need to be completed. The Hospice Palliative Care team provides a comprehensive approach to meeting you where you are in this process to help guide you in resolving and addressing the issues of personal importance wherever possible. Body, mind and soul will be uniquely involved. There can be a lot of fear at this time. So much about death and dying remains unknown. Many people tell us they find having this information to be helpful in reducing these fears.

This edition of our booklet was made possible through the generous financial support of, United Way, Colchester County, Atlantic Compassion Fund and the Federal Government of Canada. It is provided free of charge to Hospice Palliative Care patient families in the Colchester East Hants region. Hospice is a registered charity funded through donations. Thanks to the support of our community, Hospice has helped to give the families of Colchester and East Hants the best end of life care programs available in Nova Scotia today.

We receive many expressions of thanks for our programs of support and the care provided by our staff and volunteers. We are grateful for the support of our donors who provide the funding that makes our programs possible. Please consider making Colchester East Hants Hospice Society your charity of choice.

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## **Physical Changes and Needs**

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### **Weakness and Sleepiness**

As an illness progresses, your person may feel weaker and much more tired. These changes usually happen over a few days but can sometimes happen very quickly over a few hours.

The person may now be spending all of their time in bed. If there is not already an electric-type bed in the home your doctor or nurse may suggest one or you can request one. This kind of bed may make it easier to care for someone at home. To increase their comfort, you may want to 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. It's a good idea to change the person's position every six to eight hours if it is comfortable to do so. Discuss with members of your Palliative Care Team what can be done to protect the bed and keep your person 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 of the time and may be more awake at night. Plan to spend time with them during those times when they seem most alert or awake. You do not need to be quiet when you are around them. Speak with normal voices. However, avoid very loud noises, as these may startle and disturb the person and lead to some distress. Always talk to the person as if they 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 them 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 the person who is dying.



## **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 them 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 when doing so and consult with your palliative care team members for how to do this safely.

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 cup with a spout. If you hear the person cough or they have trouble breathing while you are giving them water, stop immediately.

## **Mouth and Eye Care**

It is important that you help your person with mouth care. Often you may find the person is breathing through their mouth and is taking in very little fluid. 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, and 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 (saline tears) to the eyes. These are available at most drug stores. Your nurse can 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 the person if they are not responding. They still require their regular medications for pain.

If the person can't swallow, the team 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. The person may also need to receive pain medications through a butterfly. This is a small tube that is inserted by the team under the person's skin. It has a small port on the outside that the medications go through. Your team will teach you about this.

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 is scrunched up, it could mean they are in pain, and you could give an extra breakthrough dose of pain medication as instructed by your Palliative Care Team.

## **Restlessness and Agitation**

Sometimes the person 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 produce 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 talking about a memory, or recalling a favorite place or experience they enjoyed. Medications can be helpful in easing restlessness when other things do not work. Your team may prescribe a medication that can be absorbed from under the tongue, at the side of the mouth or given by butterfly. 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 team will teach you how to do this.

## **Changes in Breathing Pattern**

As the person one gets weaker, 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 the person is gasping. At 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. The person will not notice these periods and will not be upset by them. It might be distressing for you to watch the person's breathing changes. It's important that you know it is ok to ask questions to your team about these changes. They can help you to understand what you are seeing.

## **Gurgling in the Throat and Secretions**

Very near death (anywhere from a day or two to a few hours before) you may hear the person gurgle or make snoring-like sounds. 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 not result in suffocation or death from a blocked airway. Again, be reassured that the person is not in pain and these sounds are due to relaxation of throat tissues.

The best thing to do is to put the person on their side with their head slightly raised. Make sure the person is well supported by pillows all along the back of the body. A slight change in position will often help this noise. Sometimes the doctor will order medicine through a butterfly or a medicine placed under the tongue to reduce the secretions. Oxygen will not help with this problem. Suction machines are only needed in rare cases and can potentially cause distress to the person.

## **Very Near the Time of Death**

As the person 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 can take on a purplish discoloration. This is a normal indication that the circulation of blood is decreasing to the body's limbs and is 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 at this time.

It is not necessary for the nurse to take the person's blood pressure, oxygen levels and pulse. These 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 and then unresponsive again.

## **Emotional-Spiritual-Mental Signs and Symptoms**

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### **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 for 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". Explain the reason for what you are doing, such as "so you won't begin to hurt".

### **Vision-like Experiences**

As they are dying, some people see or speak with people who have already died or who they have not seen in many years. People generally find these experiences comforting. Just because you cannot see or hear it, does not mean it is not real to your person. Affirm their experiences. If they frighten the person, discuss this with members of your Palliative Care Team.

## **Social Withdrawal**

As the dying process continues, some 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 select few people with whom they feel close, at their bedside. It's important to respect these wishes as part of providing a comforting and calm environment for them.

## **Spiritual Pain**

Some people are afraid to die. They worry whether their lives have made a difference; they may feel guilty about things that they have done; they may feel sad because they will miss those they leave behind or afraid of what comes after death.

These are concerns experienced by some people whether or not they are religious or attend church: it is part of the human experience. As a friend/family member, one of the things that you can do is to help remind them of ways they have made a difference in your life and how they will be remembered.

If you feel that more specific spiritual support would be helpful, the Social Worker or another member of the Hospice Palliative Care Team can facilitate a referral to a religious and/or spiritual representative.

Excerpt from "Helping Yourself Live When You are Dying" by Dr. Allan Wolfelt;  
Hospice Net, [www.hospicenet.org](http://www.hospicenet.org)

## **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 all right

to let go whenever they are ready, may bring much needed spiritual peace. As difficult as this may be, it is one of the greatest gifts you have to give your person at this time. It may be helpful to lay in bed with or hold the person, or to take their hand and then say everything you need to say.

Tears are a normal and natural part of saying goodbye. Tears do not need to be hidden from them or apologized for. Tears can express your love and help you let go.

Excerpt from “How Do I Cope”, Hospice Greater Saint John

## **The Moment of Death**

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Although you may be prepared for the dying process you may not be prepared for the actual death moment. It may be helpful for you to think about and discuss what you would do if you were present at that moment. The death of a Palliative Care Patient is not an emergency. Do not panic and do not call 911. When the person dies there will be no breathing, no heartbeat and no response when you touch them. The eyelids can 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 death can occur and at first you may not realize or be sure that the person has died.

There is no need to contact anyone immediately, even the physician. The body does not have to be moved until you are ready. You may wish to spend some time with your person following the 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 the person is picked up by the funeral home from

home or the hospital room. It is all right to stay or go to another room if you wish.



## **Other Important Information For Caregivers**

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This time can be one of both connection and distress for you and other people involved. It is the ending of a life and a relationship. 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. It is common to wish for the dying process to end quickly, this may cause feelings of guilt. This is a perfectly normal emotional reaction that can happen. This is something your team is available to talk with you about.

### **It is important for you to take care of yourself**

- Continue to eat properly. During stressful times, we may experience a loss of appetite or seek out quick, convenient options for meals rather than focus on nutrition. It is a good idea to try to eat some fruits and vegetables every day.
- The tendency is to drink increased amounts of coffee and tea at this time. Try to drink water to stay hydrated.
- Take time to go outside if you can. If you cannot go outside be sure to move around, such as walking up and down the hall doing some form of exercise, or just have a stretch. This helps to relieve stress.
- Surround yourself with supportive friends and let them help you.
- Take caution if using alcohol, sedatives or tranquillizers and avoid relying on substances to cope.
- Try and get some rest, if not some sleep.
- Ask your health care team members about 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. You do not need to hide your tears from the person or apologize for them.

## **Time to Say What You Need to Say**

Knowing the person's death may be imminent offers you an opportunity to say good-bye. If you feel you are able, consider how you will say good-bye. You might set aside time to talk to the person to help identify if there is anyone they would like to see or talk with. Other ways of saying goodbye include writing letters, creating video, sharing memories or passing along keepsakes.

## **Children**

Children have great imaginations and often what they imagine is worse than being at the bedside. Remember that children and teenagers overhear everything. They will sense something upsetting is happening and if not told, will invent an explanation. If efforts are not made to include children/teenagers in important conversations, they can feel isolated and alone.

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 may just need a time-out from their grief and some space and time away from what's happening.

It is a natural inclination to try to protect 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 Hospice Palliative Care Team are available to help you prepare children and youth. The Hospice Society has a lending library with resources that may be of help as well. You may want to notify the school so they are aware of the situation.

## **Pets**

If the person is in hospital and would like to see their pet, please check with the nursing staff to see if a visit can be arranged (not every pet meets the NSHA visitation criteria).

## **Grief**

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It is important to remember that grief is a natural process that accompanies loss. You may experience loss at various times throughout the illness as well as after the death. Grief affects all aspects of life and may require support. It's important to express your grief.

Allow yourself to mourn.

This will look different for each of us. It may involve crying, sharing memories and stories, having alone time, making a scrapbook, avoiding activities we shared with the person, developing ways to remember.

Realize that your grief is unique.

Sometimes there can be a tendency to compare our experience of loss to others'. Other family members or friends may be grieving differently, which can lead us to think we are doing it "wrong". Your grief now may be different than grief you have experienced in the past. Remember, no one can tell you how to grieve. Grief is something we feel in our own way in our own time.

Talk about your grief with friends, relatives or hospice volunteers. While many of us prefer to keep our feelings private, it can be helpful to find a few people with whom you can share how grief is impacting you. Don't be afraid to tell people what you would like

in response. For instance, “I’m having a hard day and I don’t need you to fix it, I just need someone to listen.”

Expect to feel a wide range of emotions.

Obviously we tend to associate grief with sadness and that’s certainly a huge part of grieving. But grief can also involve a lot of mixed feelings such as anger, guilt, relief, loneliness, anxiety, love, disbelief and many more.

Allow for numbness.

At times, you may experience periods of “no feelings”, or numbness. This too is a natural reaction to emotional pain. We can in essence “shut down” temporarily as a way to process loss and grief.

Be tolerant of your physical and emotional limits.

Grieving can affect our level of energy, both physical and emotional. We may find it difficult to do everyday tasks and duties that we used to perform easily. Be patient with yourself and know that it is ok to set limits around what you can and cannot do.

Maintain a support system.

This can be emotional support, but also may involve accessing support for practical considerations, like shopping, child care, or household maintenance. Support may also involve just hanging out with people and not talking about your grief.

Make use of ritual.

Funerals and memorials are a type of ritual that can be a part of grieving, but we may also want to develop ones that are just for us like lighting a candle, setting an extra place at the table, or looking at a photo or an item that belonged to the person.

### Embrace your spirituality

Many people struggle with big questions when faced with death. Allow for these struggles and questions – they may not have answers. You may find comfort in spiritual traditions. It's ok to discuss these ideas.

### Allow a search for meaning.

When something painful happens in our lives, we might question what does this mean for me and who I am? So often our identity as a mother, brother, daughter, grandson, wife, partner, friend shifts when someone we love dies. You may feel shaken, lost, and like life has lost its meaning. This is a normal reaction. Give yourself permission to feel these things and try to seek out people with whom you can share these concerns.

### There is no time limit on grief.

Often we get strong messages that we should be “over” a loss by a specific time. This sets up unrealistic expectations. Grief is not a straight line where we move from hurting to healing. It ebbs and flows, comes in waves, often when we least expect it, and sneaks up on us from around corners. Know that grief shifts and changes over time, but there is no set timeframe that defines “normal” grieving.

Contact the Hospice Society at 893-3265 for additional grief support.

## Hospice Resources

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Colchester East Hants Hospice Society is a charitable community organization dedicated to providing a safe and accessible space for those in our communities to Understand and navigate grief.

Our team is here to help and can be reached at:

902-893-3265

[www.cehhospice.org](http://www.cehhospice.org)

[info@cehhospice.org](mailto:info@cehhospice.org)





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