

# Guide for Caregiving

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The logo for Eventide Hospice features a blue wavy line above the word "eventide" in a bold, orange, lowercase sans-serif font. Below "eventide" is the word "Hospice" in a smaller, blue, uppercase sans-serif font.

# Togetherhness

Death is nothing at all—I have only slipped away into the next room. Whatever we were to each other, that we are still. Call me by my old familiar name, speak to me in the easy way which you always used to. Laugh as we always laughed together. Play, smile, think of me, pray for me. Let my name be the household word that it always was. Let it be spoken without effort. Life means all that it ever meant. It is the same as it ever was; there is absolutely unbroken continuity. Why should I be out of your mind because I am out of your sight? I am but waiting for you, for an interval, somewhere very near just around the corner. All is well. Nothing is past; nothing is lost. One brief moment and all will be as it was before—only better, infinitely happier and forever...

— Author Unknown

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# Life is a Journey—A Wonderful and Sometimes Unsure Experience



Entering the phase near the end of life is a time when everything we encounter is new. Facing death is never easy, but you are not alone. Our hospice team is here to assist you and your loved one with compassion, comfort and care.

In this booklet, you will find information on the physical, emotional, mental and spiritual changes commonly faced as death approaches. These changes are a normal, natural way in which the body prepares for death. Usually, these changes are not medical emergencies and are better cared for in a comforting, supportive manner. It is our hope that you will find these tools helpful in caring for your loved one.

## How Do I Say Goodbye?

One of the most complex issues around death is being able to say goodbye to one who means so much. Saying goodbye seems impossible.

We wonder what death will be like. We struggle with what to say or not to say. We want to find answers to difficult questions like, “How do I tell you what you’ve meant to me?” and “What will my life be like without you?”

We want to say, “I love you for \_\_\_\_\_; I thank you for \_\_\_\_\_. I want to affirm who you are and how you have contributed to my life and to the lives of others.”

This time of reflection, the sharing of memories and the meaning of a life, is a time of personal growth. It is a time when we see the connectedness of ourselves to one another, a time when we can give voice to all that is in our hearts.

While these discussions are tearful and emotional, families rarely report regretting having the talk or saying what matters. Some are blessed to be given enough time to create legacies for future generations: assembling photo books, recording audio or digital footage, or writing words of advice for a future bride, groom or grandchild.

For others, the time or circumstances only allow for sharing thanks, love and forgiveness. For all, death signals the end of our loved one’s physical presence with us. We hope that through sharing, you are able to gain an understanding of how your loved one will live in you for eternity.

WHAT CAN I EXPECT?

## What Comfort Can I Provide?



While no one can pinpoint the exact time death will occur, there are signs that become visible as death gets closer. We have listed several symptoms that may be seen, but it is important to remember that not all signs and symptoms will occur with every person, nor will they occur in any particular order.

Some signs will occur a few hours to minutes before death, and some a few months or days prior to death. We have also provided suggestions for what you can do as these signs occur. Remember, your hospice team is always available to help you with any questions or concerns you may have.

## Fatigue

Often fatigue is one of the first symptoms experienced. It is a feeling of being extremely tired or weary. It may be the result of metabolic, respiratory or circulatory changes. It also may be the result of emotional concerns or depression.

### What You Can Do

Encourage your loved one to take frequent rest periods and use energy conservation techniques, such as using appropriate assistive devices as needed (i.e., commode, wheelchair or walker). Your hospice team can arrange for a home health aide or a volunteer to assist you.

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## Sleeping

As death gets near, your loved one will gradually spend increasing amounts of time sleeping. At times he or she may be uncommunicative or unresponsive and difficult to awaken. This change is normal, as the body systems gradually slow down as a result of advancing disease.

### What You Can Do

Let the person sleep. It is more important to just be with your loved one. Sit and hold his or her hand. Speaking loudly or shaking him or her will not awaken your loved one from this deep sleep. Make the most of the time your loved one seems most alert or awake. Do not talk about the person in his or her presence as though he or she is not there. Speak to your loved one directly as you normally would, even though there may be no response. Never assume he or she cannot hear; hearing is known to be the sense that remains the longest with a person who is dying.



## Urine Decrease

Your loved one's urine output normally decreases and may become dark colored, referred to as "concentrated urine." This may be the result of decreased fluid intake or decreased kidney function.

### What You Can Do

Your hospice team will assist you to determine what should be done. Often, there is nothing that should be done differently.

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## Incontinence

Your loved one may lose control of bladder and/or bowel functions as the muscles begin to relax.

### What You Can Do

Change your loved one as needed to keep them clean and comfortable. The hospice nurse can teach you how to provide personal care. Protect the mattress by using Chux or waterproof padding over the mattress.

## Disorientation (Mental Confusion)

Your loved one may seem confused about the time, place and identity of people, including those close and familiar. This is due in part to the slowing of organ functions, causing smaller amounts of oxygen to reach the brain.

### What You Can Do

Identify yourself by name before you speak, rather than ask your loved one to guess who you are. Remind your loved one of the time of day, where you are and who is present. Speak softly, clearly and truthfully when communicating important information, such as, “It is time to take your medication.” Then explain the reason for the communication, such as, “So you won’t begin to hurt.” You may find yourself repeating the same explanations. While it can be frustrating, it is normal for your loved one to quickly forget or have difficulty following instructions.

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## Coolness

The person’s hands, arms, feet and legs may be increasingly cool to the touch. At the same time, the skin color may change. The underside of the body may become darker or blotchy looking. This is called “mottling,” and is a normal indication blood circulation to the body’s extremities is decreasing and being reserved for the most vital organs.

### What You Can Do

If your loved one complains of being cold, you can offer a warm blanket. Never use an electric blanket, as it may cause burns. Some families have found warming a blanket in the dryer to be helpful.

## Congestion

You may hear gurgling sounds coming from the chest as your loved one breathes through his or her mouth. These sounds may become very loud. This may be due to an inability to cough up secretions. At times, it is due to a very thin layer of secretions covering the voice box. Though it may bother you, generally it is not uncomfortable or distressing to your loved one.

### What You Can Do

If a feeding tube is present, reducing or stopping the amount often reduces congestion significantly. If secretions drain from the mouth, you may gently wipe the mouth with a moist cloth. Elevating the head off the bed with pillows or turning your loved one onto his or her side may help temporarily. Ask your hospice nurse about medications that may also relieve congestion. The sound of congestion does not indicate difficulty breathing or the onset of severe or new pain.

## Breathing

You may notice breathing patterns changing to an irregular pace; there may even be 10- to 60-second periods with no breathing. These are referred to as periods of “apnea.” This is very common and indicative of a decrease in circulation and buildup in body waste products. There may be a moaning sound with each breath.

### What You Can Do

Elevating the head or turning your loved one to the side may make breathing easier. Moaning may not indicate pain, but rather the sound of air passing over the relaxed vocal cords. Holding your loved one’s hand and speaking gently may offer comfort.

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## Pain or Discomfort

If your loved one experiences pain, know that your hospice team are experts in pain management and will assist you in treating the pain.

### What You Can Do

Your hospice team will let you know what non-verbal signs and symptoms to watch for, such as facial grimacing, rigidity or a furrowed brow. Using medications as needed and directed by your loved one’s physician and hospice team will help. Using and repositioning pillows under the arms and legs may provide comfort; distractions and a gentle massage may help as well.

## Socializing

As your loved one's physical changes become greater, his or her world may become smaller and the desire to socialize may become less.

### What You Can Do

Just being there for your loved one is most important. You can do this by sitting quietly and holding his or her hand. Honor your loved one's wishes as to whom he or she would like near.

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## Letting Go

Your loved one may seem unresponsive, withdrawn or in a comatose state. It may seem as though he or she has given up. Your loved one may even refuse your attempts to make him or her more comfortable. However, your loved one is preparing for release, detaching from surroundings and relationships, and beginning to let go.

### What You Can Do

Say what you need to say to help your loved one with the letting go process. Share that you will miss your loved one. Recall fond memories. What you say to your loved one will help him or her to die in peace and may also help you in your grief process.



## **Fear and Anxiety**

**Your loved one may perform repetitive or restless tasks, such as picking in the air or at bed linens. This restlessness may be due in part to the decrease in oxygen circulating to the brain.**

### **What You Can Do**

Do not interfere with or try to restrain such motions. Prevent your loved one from falling if he or she tries to get out of bed. Reassure your loved one that he or she is not alone, that he or she is loved and that there is nothing to fear. Speak in a calm voice. Playing or singing soft, familiar music, or reciting familiar prayers or scripture may have a calming effect. Touch is a lasting sense and often the greatest need to be fulfilled. Touch can range from a gentle holding of hands to a compassionate embrace. Please be aware that at times touch may be painful or irritating. Gently experiment with touch. Do not be hurt or offended if your loved one rejects your touch. Encourage him or her to talk about anything on his or her mind. Listen to what your loved one would like or need, and try to meet that desire.



## Vision-Like Experience

Your loved one may speak or claim to have spoken to individuals who have already died. He or she may see or have seen places not presently accessible or visible to you. This does not indicate a hallucination or a drug reaction. Your loved one is beginning to detach from this life and is being prepared for the transition, so it will not be frightening.

### What You Can Do

It is best not to contradict, explain away, belittle or argue about what he or she claims to have seen or heard. Because you cannot see or hear these experiences does not mean they are not real for your loved one. Affirm those experiences by encouraging your loved one to talk about what he or she has seen or heard. If these experiences frighten your loved one, visit with your hospice nurse. A visit from your own clergy or the hospice chaplain may help.

## Saying Goodbye

When your loved one is ready to die and you are able to let go, then is the time to say goodbye. Saying goodbye is your final gift of love; it achieves closure and makes the final release possible.

### What You Can Do

It may be helpful to lie in bed, take your loved one's hand and say everything you need to say. It may be as simple as saying, "I love you." It may include recounting favorite memories, places and activities you shared. It may include saying, "I'm sorry for whatever I contributed to any tensions or difficulties in our relationship." It may also include saying, "Thank you for \_\_\_\_\_." It may include just being there. Tears do not need to be apologized for or to be hidden from your loved one. Tears express your love and help you to let go. Do not hesitate to tell your loved one you will miss him or her.



The signs and symptoms of approaching death are as unique as the person. Not everyone experiences these symptoms on the same timeline. Contact your hospice nurse with any questions.

## One to Three Months Before Death Occurs

### Emotional

- > Withdrawal from people and interests
- > Decreased communication
- > Limited activity
- > Desire to fulfill end-of-life wishes

### Physical

- > Changes in pain or symptoms
- > Decreased appetite
- > Frequent sleeping
- > Overall weakness; feeling tired or heavy
- > Irregular respirations
- > Congestion

## Weeks Before Death

### Emotional

- > Increased mental confusion/disorientation
- > Increased anxiety or agitation
- > Vision-like experiences
- > Saying goodbye; making amends

### Physical

- > Decreased blood pressure
- > Changes in pulse rate
- > Body temperature: hot or cold
- > Incontinence (loss of bladder and/or bowel control as muscles relax)
- > Not eating; taking little fluids

## Days or Hours Before Death

### Emotional

- > Surge of energy
- > Restlessness or no activity

### Physical

- > Cannot be awakened
- > Eyes glassy, tearing, half-open
- > Irregular breathing: stop/start
- > Gurgling respirations
- > Jaw relaxes, breathes through mouth
- > Pulse weak and hard to find
- > Decreased urine output
- > Increased perspiration
- > Purplish knees, feet, hands; blotchy skin



## **When Death Occurs**

**Death occurs when the body completes its natural process of shutting down and when the spirit completes its natural process of reconciling. These two processes need to happen in a way appropriate and unique to the values, beliefs and lifestyle of the dying person.**

**The journey is just beginning. At the time of death, breathing stops. There is no heartbeat. There may be loss of control of the bowel and bladder as these muscles relax. You may note the eyelids remain slightly open and the eyes are fixed on a certain spot. The mouth may fall open slightly as the jaw relaxes.**

## **What You Can Do**

**There is nothing you have to do. You and your family can just be with your loved one. When you are ready, contact your hospice nurse to assist you. The nurse will make a home visit to be with you and will assist with calls to your clergy, physician and funeral home.**



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