

A Very Special **Journey**



Hospice of Palm Beach County
Hospice by the Sea
trustbridge



It is not death therefore
that is burdensome,
but the fear of death.

— Ambrose (c. 333-392), *De bono mortis*



In earlier times, death, like birth, was seen as a normal part of life. Babies were born at home, the sick were nursed at home, and those who did not recover died there, as well. The advent of modern medicine dramatically changed how we experience the passage of our days. Technology has saved numerous lives that would have been lost prematurely and prolonged the lives of many others. It has worked countless miracles and we are indeed fortunate to live with such advances. But there is a price we pay for the gift of the miraculous. Death has become removed from modern culture. It is no longer familiar to us because it often occurs behind the closed door of an intensive-care unit. It now feels unnatural, because what seems normal is accompanied by the whirr, the clicks, and the beeps of the equipment of the critically ill. It often seems to have lost its humanness and can be terribly frightening, in part because we no longer understand it.

A Very Special Journey

*Familiarizing Yourself with
the End-of-Life Transition*

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A Letter from Trustbridge

Dear family and friends:

In earlier times, death was seen as a normal part of life. Like birth and illness, death occurred in the home, with the person surrounded by his or her loved ones and perhaps community members. While modern medicine and technology have saved or prolonged countless lives, it has also transformed death into an institutionalized experience that tends to be less connected to nature, creating an unnatural distance from the process of death.

At Trustbridge, we honor death as the natural part of life that it is. Our mission is to imbue the experience of dying with compassion and dignity, to make it possible for people who are approaching death to be surrounded by their loved ones as well as professionals who are trained to provide physical and emotional comfort to patients and families alike.

Our team of caring professionals believes this is truly a unique journey, and our goal is to help you feel comfortable and capable during this challenging time, as we work together to make your loved one's final days ones of comfort and well-being.

The information in this booklet is offered to help you better understand this end-of-life transition and guide you on how you can respond to the emotional, spiritual and physical signs and symptoms of approaching death. Let us guide you on this final journey as we look at what you can expect and what you can do. We want you to be prepared for what lies ahead so you can respond in ways that will help your loved one accomplish this transition with support, understanding and ease.

Your hospice team includes many people who can assist you: nurses, certified nursing assistants, social workers, spiritual-care counselors, volunteers, music therapists and bereavement counselors. Please reach out to us for support whenever you need it or just want to talk.

We're there for you . . . to help in any way we can.

When Death Approaches

The experience we call death occurs when the body completes its natural process of shutting down and the spirit completes its work. As the end of life approaches, your loved one will experience physical, emotional and spiritual changes; these are a normal part of the dying process. While these changes may be upsetting or confusing to you, rest assured that what your loved one is experiencing is a completely natural part of life's journey.

Familiarizing yourself with what may occur and how you can best respond can help prepare you to support your loved one as death approaches. It can also help ease some of your fear, anxiety and distress. This is not an easy time, but it can be a very meaningful and life-affirming experience for you. Even with the approach of physical death, emotional and spiritual healing is possible through expressions of love, joyful memories, forgiveness and reconciliation.

Remember that each person is unique and will experience death in his or her own way. Not all of these signs or symptoms will occur with every person, nor will they occur in any particular order. There are also varying degrees of decline toward the end of life, so some of these signs and symptoms may appear subtle at first and others may occur suddenly.

While it is completely natural for you to feel fear, sadness or any number of emotions, it is our sincere hope that the journey you are about to embark on with your loved one can also be one of great love, understanding, comfort, compassion and support.

Again, please remember that your loved one's present condition may or may not correspond to what you will read in the following pages. The information about these signs and symptoms is simply meant to be a guiding hand during this very unique and personal process.



Emotional & Spiritual Signs and Symptoms of Approaching Death

Withdrawal from Everyday Participation

It is completely normal for your loved one to pull back from participating in family life or social activities, preferring to be alone or with only a few people. This may be because the person is detaching from relationships and surroundings in preparation for releasing from this life.

At this time, your loved one may wish to spend time only with certain people. If you are not one of those your loved one wishes to spend time with, please try not to feel rejected or take it personally. It does not mean that you are not loved or that you are unimportant to the person; it means that you have accomplished the work that needed to be done in your relationship. If your presence is requested, use this opportunity to share and connect with your loved one and help him or her feel at ease.

In some cases, withdrawal may manifest in your loved one's becoming unresponsive or entering a coma-like state. This is a natural occurrence for some as death draws near. Keep in mind that even if your loved one seems unresponsive, it is likely that he or she can still hear you because the sense of hearing is often the last sense to remain. At this time, your loved one needs your support and permission to go, including reassurance that it is okay to do so. (See "When It Is Time to Say Goodbye" on page 9.)

Guidance for this sign:

- ♥ Allow your loved one to choose, when able, whom he or she will spend time with and how that time will be spent.
- ♥ Speak quietly and calmly to your loved one about both the ordinary and profound, as these naturally arise for you.
- ♥ Touch your loved one reassuringly and share messages you know will help him or her come to peace with letting go.

Dreamlike Experiences and/or Visions

When death nears, your loved one may see or have “conversations” with people who have already died. Some people believe that these experiences are, in fact, visits from people who were meaningful and loved in the person’s life to make this final transition easier. Your loved one may also speak as if he or she is somewhere else, such as a beloved place lived in or visited in the past. While such experiences may seem strange, unbelievable, or perhaps even frightening to you, understand that they are normal during the transition from this life.

Guidance for this sign:

- ♥ Take comfort in the fact that this is a natural, positive process and occurs to help put your loved one at ease with what is happening.
- ♥ Listen to your loved one if he describes what he has seen, and believe in the personal experience he or she is having. Though you may not be able to see these “visitors,” that does not make them less real to your loved one.
- ♥ If you are curious about your loved one’s experience, feel free to ask any questions that come naturally to you.



New Expressions and Special Requests

Your loved one may begin to say things that seem out of the ordinary or out of character, or may express regrets. The person may also make special requests or may urge you to make a promise. Listen attentively to what your loved one says. Allow him or her to express whatever is going on in her mind, whether or not you are able to make sense of it. Some people who were not religious or spiritual throughout their lives may become so at this time; this is not uncommon. Some may express their fears and anxieties over what is to come, even if they previously expressed none.

Guidance for this sign:

- ♥ If a special request or promise is something you can comply with, make an effort to do so.
- ♥ Listen to your loved one with a nonjudgmental attitude, even if he or she expresses something to you that you find disconcerting. You can process what the person has revealed later. For now, just try to be a compassionate, listening ear.
- ♥ Try to assure your loved one that he or she has done his personal best during his lifetime.
- ♥ Turn to your hospice team for support as needed to help your loved one resolve any special requests and concerns.
- ♥ Speak with the hospice chaplain to help with any of your loved one's desires regarding religious and/or spiritual matters.



When It Is Time to Say Goodbye

As difficult as it is, there comes a point in everyone's life when it's time to say goodbye. However, it is not uncommon for someone at the end of life to hold on. This can be especially true for people who were the caregivers or authority figures in their families or whose family is experiencing a conflict or issue. To let go, your loved one needs to know that the people being left behind will be able to flourish without the person in their life.

One of the greatest gifts you can give to your loved one is the security of knowing that you will be okay and that he or she has your permission and encouragement to let go when ready.

Be aware that trying to make your loved one feel guilty in an attempt to keep him or her from dying, as much as it comes from your heart, can cause your loved one distress. Try to accept that the person can no longer be with you and give him your permission to go. You can, of course, acknowledge that your loved one's absence will create a void in your life, but be clear that you recognize her need to move on. You might say something like, "I will miss you, but I will be okay. It's okay for you to let go."

When you feel it is time, say goodbye, understanding that your loved one—and you—may need to hear this. Allow yourself to cry; don't try to hide your tears. Tears are a completely natural part of the experience and express our love. If you don't cry because the tears aren't yet ready to come, that is okay, too. This is a personal experience for you as well.



Physical Signs and Symptoms of Approaching Death

Anxiety/Agitation

Your loved one may appear anxious and may be repeating tasks or movements such as “picking” at sheets or tossing and turning in bed. The agitation may be severe enough to cause your loved one to sit up or try to get out of bed. This anxiety may be caused by a decrease in oxygen in the blood or other physical changes. It is not useful to try to restrain your loved one or prevent the person from repeating the movements.

Guidance for this sign:

- ♥ If, due to this restlessness, you are concerned with your loved one's safety should he or she get out of bed or fall, speak with your hospice nurse.
- ♥ Play soft music, dim the lights and create a soothing environment by decreasing the amount of noise in the room.
- ♥ Speak quietly and calmly to your loved one.
- ♥ Discuss the use of medication to relieve this agitation with your hospice team to find out whether it would be appropriate.

Confusion/Disorientation

Your loved one may not know where he or she is or what day it is. The person may also be confused about who you or others are. This is because the body's metabolism varies in ways that cause chemical changes that affect the brain. Remember that this lack of recognition of you and others is not intentional; it is the result of the physical changes taking place in the body.

Guidance for this sign:

- ♥ Identify yourself and remind the person who you are when speaking to him or her. (For example, “Mom, it's Mary. I'm here with you.”)

- ♥ If you need to inform your loved one of something, state clearly what you are doing and why. (For example, “Dad, I’m going to change your position now so your skin won’t get sore.”)
- ♥ Share your feelings with your hospice team. Your team knows that it can be devastating for you to experience the confusion of someone who has been vital and in control. You may also wish to share your feelings with others you feel comfortable with.

Decreased Food and Fluid Intake

Your loved one may want very little or no nourishment, often refusing to eat or drink. Foods previously enjoyed may not taste the same, and your loved one may have difficulty swallowing and feel as if he or she is choking. Decreased food and fluid intake occurs because the body naturally conserves energy as body functions slow down. Physical changes that affect the brain can cause difficulty swallowing, while the chemicals released by certain tumors may cause an appetite reduction.

Because we often associate food with life and love, it can be very difficult for you when your loved one no longer wants to eat. Understand that this is a natural part of the process. People at this stage of life do not feel hunger. In fact, dehydration actually has a pain-relieving and sedative effect at this stage. Giving fluids through a vein can cause discomfort. Your hospice team knows how to respond to the situation.

Guidance for this sign:

- ♥ Provide light meals with high caloric content if your loved one is still able to eat.
- ♥ Do not try to force your loved one to eat or drink, and do not use guilt to manipulate the person into taking nourishment.



Illness-Specific Signs and Symptoms

Though we are sharing with you many of the general signs and symptoms of approaching death in this booklet, please keep in mind that depending on your loved one's illness, he or she may experience other signs and symptoms not included here that are specific to the person's particular situation. To better prepare yourself for what to expect, please speak with your hospice team and ask about anything that might be likely to happen with regard to the illness your loved one has.

Altered Sleeping Patterns

Your loved one may begin sleeping more and communicating less. At times, it may be difficult to wake the person. He or she may confuse day with night and awaken just when you are ready to go to sleep. Altered sleeping patterns result from the body's naturally slowing down, as well as chemical imbalances that may occur at end of life or from medication.

Guidance for this sign:

- ♥ Make the most of your time with your loved one while he or she is awake by spending time talking or reading to the person.
- ♥ Sit quietly with your loved one and just hold his or her hand if the person is asleep when you visit.
- ♥ Try not to awaken the person if he or she is sleeping or unable to respond.
- ♥ Speak normally, even if your loved one doesn't seem to respond. Assume that your loved one can hear you. Remember, the sense of hearing is usually the last sense that remains.
- ♥ When possible, try to adapt your sleeping pattern to enable you to rest while your loved one is resting.



Congestion and Changes in Breathing Patterns

You may hear gurgling or rumbling sounds coming from your loved one's chest. These sounds can be quite loud. They occur because your loved one may be unable to swallow or cough up normal secretions. Keep in mind that these noises may be more disturbing or frightening to you than they are to your loved one.

Guidance for this sign:

- ♥ Speak with your hospice nurse about medications that can reduce the amount of secretions. The nurse can ask the physician whether such medicine would be appropriate for your loved one.
- ♥ Elevate the head of the bed and gently turn your loved one's head to the side, letting gravity drain the secretions.
- ♥ Wipe the person's mouth with a soft, moist cloth.

Cheyne-Stokes Respiration

Sometimes your loved one may experience periods of rapid breathing, possibly alternating with periods of no breathing (called apnea). This pattern is called Cheyne-Stokes respiration.

The stimulus to breathe is not caused by lack of oxygen, but by the buildup of carbon dioxide. As death approaches, the brain is much less sensitive to this buildup. You may notice a period of apnea while the carbon dioxide accumulates to the level needed to trigger a breath. Your loved one may take several rapid, shallow breaths, which allow the body to "blow off" the carbon dioxide. There may then be another period of apnea. This pattern sometimes occurs during sleep but not wakefulness.

This is a natural breathing pattern for a dying person and does not generally cause discomfort. Administering oxygen at this point does not alter the pattern. Understand that this is a symptom your loved one may experience, but notify your hospice team if your loved one appears to be in distress.

Fluctuations/Changes in Body Temperature

Your loved one may go from being hot and sweaty to being cool and dry and then hot and dry. This occurs because changes in body chemistry affect the brain's "thermostat."

Your loved one may also develop coolness in the hands and arms and/or coolness in the feet and legs. At the same time, the lower part of the body may become darker and look blotchy or mottled. This happens because the brain is shutting down circulation to the hands and feet so that blood is reserved for the vital organs.

Guidance for this sign:

- ♥ If your loved one's body temperature is high, ask the hospice nurse about administering medications, such as acetaminophen (Tylenol) to lower temperature. If your loved one is unable to swallow, ask your hospice team whether using a suppository might be necessary.
- ♥ If the person is warm, you can use a sheet, rather than a blanket, to cover your loved one.
- ♥ If your loved one develops coolness in the extremities, keep the person warm with a blanket. Do *not* use an electric blanket or heating pad.

Changes in Bladder and Bowel Function

Your loved one may lose control of his or her bladder and/or bowel. This happens because the muscles in that area are relaxing as bodily changes take place. While this can be extremely distressing for both you and your loved one, try to understand that it is a normal part of the process. You can take steps to help your loved one feel comfortable and maintain his or her privacy and dignity; ask your hospice nurse and team for guidance.

Your loved one may also urinate less frequently. You may notice that the urine is darker and that smaller amounts are present than before. This is, in part, because your loved one may be drinking fewer fluids. Another reason for a decrease in the amount of urine is that the kidneys may be shutting down as a result of the dying process. Bowel movements may also become smaller and less frequent.

Guidance for this sign:

- ♥ With a loss of bladder or bowel control, use protective covering for the bed as well as adult diapers. Your hospice nurse and team can provide these for you.
- ♥ When assisting your loved one, use protective gloves and practice good hygiene. Your hospice nurse and team can help obtain the supplies you need and show you what to do.
- ♥ Discuss any concerns or fears with regard to bladder and bowel functioning and any changes you notice with your hospice team.



When Death Occurs

It is our hope at Trustbridge that your hospice team, along with the information conveyed in this booklet, helps to make the experience of your loved one's death less frightening, confusing and anxiety-provoking for you. We encourage you to involve your hospice team as much as you need to so that we may help everyone involved handle this transition as smoothly as possible.

During this time, many families want the support of their spiritual advisor or a hospice chaplain. Still others want to know that a hospice staff member will be available. We will try to accommodate you in any way possible.

There is no way to know for certain when the moment of death will occur. People who are very private or who do not want to cause their loved ones anguish may choose to die when there is no one present in the room. Family members may feel guilty or rejected if this occurs, but as this is a personal journey for your loved one, please try not to take it personally if you are not present.

In other cases, family members and friends may be present at the time of death. Those in attendance may choose to spend time at their loved one's bedside, praying, meditating, sitting in silence, speaking to the loved one who has passed on, speaking to and comforting one another, and so on. As your loved one's transition was for him or her, this is a personal experience for everyone involved.

You may want to spend time with your loved one before contacting the funeral home. Funeral attendants do not have to come right away, but they will come when called. If your loved one has died at home, identify your loved one as a hospice patient when calling the funeral home. You do not need to call the police.

A member of your hospice team can be there to assist you with phone calls and other preparations. Express your wishes to the team member; he or she will be as involved as you wish. A member of your hospice team will notify the physician.

How Will I Know When My Loved One Has Died?

Most people who have never been present at a death will recognize when it occurs, although it may not be immediately obvious. Because the breaths become fewer and farther between as the time of death approaches, it may take a few minutes to recognize that breathing has ceased. A person who has died does not breathe or have a heartbeat. The eyes may be slightly open. The skin may take on a pale or waxy look. There may be some muscle twitching or bodily sounds; if this occurs, understand that it is normal.

Please know that our support at Trustbridge does not stop with your loved one's death. Someone from your hospice team will contact you at an appropriate time to ask you how we may support you in coping with the loss of your loved one. You can also call us when you feel ready, if we have not yet reached out.



Questions and Answers

The answers to the following questions, which have been asked by others who have walked this path previously, may help you prepare:

Whom can I ask for assistance with funeral arrangements?

You may certainly contact your hospice team's chaplain or social worker for direction and assistance. Keep in mind, too, that your chosen funeral home can assist with the burial arrangements. Your local place of worship, or even friends, can assist with planning for the services. You may also contact your hospice team for assistance with poems, prayers, etc., to use for the service and burial.

How do I place an obituary in the newspaper?

Funeral homes often assist families in placing obituaries in their local newspapers. However, many families contact their local papers themselves. Each newspaper has its own obituary department and a service representative can lead you through the process. Costs vary from newspaper to newspaper and are often based on length.



How do I write an obituary?

An obituary can be a beautiful way to memorialize your loved one. There are some practical aspects to the obituary, as well; it can be a way to make others aware of the funeral arrangements.

The amount of detail written in the obituary is your choice. Be comfortable with your decision. You may simply choose to write your loved one's name, date of birth, date of death, and the funeral arrangements. It is your decision. The obituary can include some or all of the following:

- ♥ Name, age, town of residence, place of death
- ♥ Cause of death
- ♥ Immediate survivors (still living), or a beloved predeceased person as desired
- ♥ Summary of life (i.e., place and date of birth, education, military career, employment history, hobbies, civic and volunteer activities, etc.)
- ♥ Funeral service arrangements (time and place)
- ♥ Donations (sometimes in lieu of flowers)
- ♥ Special thanks to certain individuals or agencies

My loved one wants to be buried in his home state. How do I go about making arrangements for this?

Contact your funeral home director for details. The director will assist you with the arrangements and will often make all the calls necessary to the funeral home in the state in which your loved one will be buried. You may also contact your hospice team's chaplain or social worker for direction and assistance.

We do not have the finances to pay for a funeral. Whom can I contact for assistance?

Palm Beach County has an assistance program for families needing support with funeral arrangements. For help, call Funeral Service Consumer Assistance at 800.662.7666. You will need to meet criteria set by the Palm Beach County Burial Assistance program. Local funeral homes are also usually able to help you in working with the county program. Sometimes, the funeral homes may even assist with the necessary paperwork. There are private companies that can help you find a funeral home that best suits your needs.

We did not belong to an organized place of worship, but I would like some kind of spiritual memorial service. What do I do?

You can contact your hospice team's chaplain, who can assist with these arrangements. One of our chaplains may be able to conduct the service. Also, most religious institutions will be pleased to assist you with some type of memorial service. We recommend you call the ones in your general area and inform them of your needs. Also, keep in mind that one of your friends or family members may know a member of the clergy or faith leader who would be willing to provide this type of support.



What organizations do I need to contact to notify them of my loved one's death?

Some immediate organizations that would need to be notified include the following:

- ♥ Social Security office
- ♥ Loved one's employer
- ♥ Any insurance companies that you may have policies with that are in your loved one's name
- ♥ Any financial institutions (e.g., banks, stockbrokerage firms)

If you require copies of the death certificate, your funeral home may be able to give you copies. In most states, however, you will need to contact the Office of Vital Statistics for your particular city.

Is it appropriate for children to attend the funeral?

Whether or not a child attends the funeral should be decided according to the parents' beliefs as well as the child's wishes. A simple way to know if it is appropriate is simply to ask the child. If attending the funeral is not an option, the child can still be part of the memorialization by other means, such as writing a letter or drawing a picture. Above all, please know that children are incredibly resilient. Providing support, choices and love will be the most important intervention any parent or guardian can provide to a child.



We at Trustbridge want you to know how privileged we feel to be involved in your care at this important time in your lives. We are here to walk the journey with you, support you, and share with you what we have learned through our experiences. What we learn from you and from those who share the same path as you goes beyond any practice or knowledge we could ever convey. Thank you for being our teacher so that we can better help those who follow.

**We're there for you . . .
to help in any way we can.**





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Direct inquiries to Marketing at 561.848.5200

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call CareConnection
888.441.4040

For 24/7 New Patient Admissions
call **844.422.3648**



5300 East Avenue • West Palm Beach, FL 33407

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