




A Very Special JOURNEY



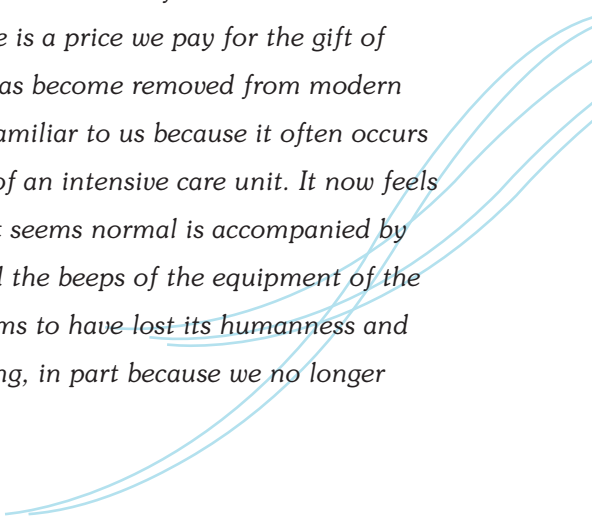
Hospice of
Palm Beach County



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

— Ambrose (c. 333-397) De bono mortis

*I*n 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 that 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.



CONTENTS

PHYSICAL SIGNS AND SYMPTOMS OF APPROACHING DEATH	3
Changes in Sleeping Patterns	3
Confusion or Disorientation.....	3
Changes in Body Temperature	4
Changes in Bladder and Bowel Functioning	5
Congestion and Changes in Breathing.....	5
Decreased Food and Fluid Intake	6
Agitation	7
EMOTIONAL AND SPIRITUAL SIGNS AND SYMPTOMS OF APPROACHING DEATH	8
Withdrawal From Everyday Life	8
Dream-Like Experiences	8
Saying Good-bye.....	9
WHAT HAPPENS WHEN DEATH OCCURS	10

The experience we call death occurs when the body completes its natural process of shutting down and the spirit completes its work of reconciling and finishing. The physical and emotional-spiritual symptoms of approaching death that follow are offered to help you understand natural things that may occur and how you can respond appropriately. It is important to understand that there is not a right or a wrong way to do this. Not all of these signs will occur with every person, nor will they occur in a particular order. Each person is unique and will experience death in his/her own way.

The team of caring professionals at Hospice of Palm Beach County want you to know what to expect as this event approaches, so that it seems less frightening. We want you to be prepared to respond in ways that will help your loved one accomplish this transition with support, understanding and ease. Hospice of Palm Beach County's team of professionals believe this is truly a very special journey and our goal is help you feel comfortable and capable during this challenging time as we work together to maintain your loved one's dignity and well-being.

Let us guide you on this journey as we look at what you can expect and what you can do. Your Hospice of Palm Beach County team includes many people who can assist you: nurses, certified nursing assistants, social workers, spiritual care counselors, volunteers, music, art and therapists, integrative therapists and bereavement counselors.



**WE'RE THERE
FOR YOU...**

to help in any way we can.

PHYSICAL SIGNS AND SYMPTOMS OF APPROACHING DEATH

There are many physical, emotional and spiritual changes during a patient's final stage of life. The physical symptoms include the following:

Changes in Sleeping Patterns

Your loved one may begin sleeping more and communicating less. At times, it may be hard to wake them. They may confuse day with night and awaken just when you are ready to go to sleep.

This is a normal part of the process. It results from the body naturally slowing down, as well as chemical imbalances that may occur at end of life or from medication.

You Can...

- ❖ Make the most of your time with your loved one when they are awake.
- ❖ Sit quietly with your loved one and just hold their hand.
- ❖ Try not to awaken them if they are sleeping or unable to respond.
- ❖ Speak normally, even if they don't seem to respond.
- ❖ Assume that your loved one can hear you.

Remember: the sense of hearing is usually the last sense that remains.

Confusion or Disorientation

Your loved one may not know where they are or what day it is. They may 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.

You Can...

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. Some of the ways to be helpful include:

- ❖ Identify yourself and remind the person of who you are when speaking to them such as, “Mom, it’s Mary. I’m here with you.”
- ❖ If you need to inform them of something, state clearly what you are doing and why, such as, “Dad, I’m going to change your position now so your skin won’t get sore.”
- ❖ Share your feelings with your Hospice team; we are here to listen. We know 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 someone else with whom you feel comfortable.

Changes in Body Temperature

The patient may go from being hot and sweaty to being cool and dry and then hot and dry. This occurs because changes in the body chemistry affect the brain’s “thermostat.”

You Can...

Try the following to make your loved one comfortable:

- ❖ Ask the Hospice nurse about administering medications, such as acetaminophen (Tylenol) to lower temperature.
- ❖ If your loved one is unable to swallow, ask about using a suppository.
- ❖ Lightly cover the patient with a sheet, rather than blankets.

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.

You Can...

- ❖ Keep your loved one warm with a blanket.
- ❖ Do not use an electric blanket or heating pad.

Changes in Bladder and Bowel Functioning

Your loved one may lose control of their bladder and/or bowel. This happens because the muscles in that area are relaxing as bodily changes take place. It can be extremely distressing for both the patient and the caregiver.

You Can...

Help make the patient comfortable and maintain their privacy and dignity. Some ways to do this are:

- ❖ Use protective covering for the bed, as well as adult diapers. Your Hospice of Palm Beach County nurse and team member can provide these for you.
- ❖ Use protective gloves and practice good hygiene. Again, your Hospice team can help obtain supplies and show you what to do.
- ❖ Ask the physician if a catheter is advisable (see Foley Catheter).

Your loved one may also stay dry for longer periods of time. If a catheter has been inserted, you may notice that the urine is darker in color 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 whole process of decline, which occurs as death approaches. Bowel movements may also become smaller and less frequent.

You Can...

- ❖ Understand that what is occurring is natural, and discuss any concerns or fears with your Hospice team.

Congestion and Changes in Breathing

You may hear gurgling or rumbling sounds in the patient's chest. These sounds can be quite loud. This occurs because the patient may not be able to swallow or cough up normal secretions.

You Can...

Keep in mind that these noises may be far more disturbing or

frightening to you than they are to the patient. Some helpful actions include:

- ❖ Elevate the head of the bed and gently turn the patient's head to the side, letting gravity drain the secretions.
- ❖ Wipe the mouth with a soft, moist cloth (suctioning would irritate the oral tissues and cause increased secretions).
- ❖ Discuss with your Hospice nurse medications that can reduce the amount of secretions. He or she can ask the physician if this would be appropriate for your loved one.

Sometimes the patient experiences periods of rapid breathing, possibly alternating with periods of no breathing (called apnea). This pattern is called Cheyne-Stokes breathing. The stimulus to breathe is not caused by lack of oxygen in our bodies, but by the build-up of carbon dioxide (CO₂). The brain of a terminally ill person is much less sensitive to this build-up. You may notice a period of apnea while the CO₂ 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 CO₂. There may then be another period of apnea. This pattern sometimes occurs while the patient is asleep but not while awake.

You Can...

- ❖ Remember that this is a natural breathing pattern for a dying person and does not generally cause discomfort.
- ❖ Be aware that administering oxygen at this point does not alter the pattern.
- ❖ Notify your Hospice team if your loved one appears in distress.

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 the patient may have difficulty swallowing and feel as if they are choking. This is because the body naturally conserves energy as body functions slow down. Physical changes

that affect brain can cause difficulty swallowing, while the chemicals released by certain tumors cause an appetite reduction.

You Can...

Keep in mind that because we associate food with life and love, it can be very difficult for you when your loved one no longer wants to eat. Some actions you can take include:

- ❖ Provide light meals with high caloric content if your loved one is still able to eat.
- ❖ Do not try to force the patient to eat or drink, and do not use guilt to manipulate the patient into taking nourishment.
- ❖ Remember that patients at this stage of life do not feel pain from having an empty stomach. In fact, dehydration actually has a pain-relieving and sedative effect at this stage, while giving fluids through the vein can actually cause discomfort.

Agitation

Your loved one may seem anxious, repeating tasks or movements such as “picking” at sheets, or tossing and turning in bed. The agitation may be severe, causing the patient to sit up or try to get out of bed. Some people become anxious because of a decrease in oxygen in the blood or other physical changes. The restlessness may also have an emotional cause, such as an unresolved issue that is disturbing to the patient.

You Can...

Be aware that it is not useful to try to restrain your loved one or prevent them from repeating the movements. It is helpful to:

- ❖ Speak quietly and calmly.
- ❖ Play quiet music, dim the lights, and create a soothing environment by decreasing the amount of noise in the room.
- ❖ Ask your Hospice of Palm Beach County team members how you can help your loved one let go of what is disturbing them.
- ❖ Discuss with your team the use of medication to relieve the agitation.

EMOTIONAL AND SPIRITUAL SIGNS AND SYMPTOMS OF APPROACHING DEATH

In addition to coping with physical changes, you will see other symptoms that may be upsetting to you. These, too, are a normal part of the dying process.

Withdrawal From Everyday Life

Your loved one may pull back from participating in family life or social activities. They may wish to spend time with only a few people or they may become unresponsive or in a coma-like state. This may be because your loved one is detaching from relationships and surroundings in preparation for releasing from this life.

Try not to feel rejection if you are not one of those that the patient wishes to spend time with. It does not mean you are not important to them. It simply means that you have accomplished the work that needed to be done. What your loved one needs at this time is support and permission to let go, as well as reassurance that it is okay to do so.

You Can...

- ❖ Speak quietly and calmly
- ❖ Touch the patient and say the things you know will help them let go.
- ❖ Allow your loved one to be in control of who they will spend their time with and how.

Dream-Like Experiences

Seeing people who have already died or “visiting” an especially beloved place are often shared by dying people. Some statements may seem bizarre or out of character. This is a part of preparing to make a transition from this life. Many believe that those who have already died but who were meaningful and loved in the patient’s life may appear to make the journey less frightening.

You Can...

- ❖ Take comfort in the fact that this is a natural and positive process and occurs to put the patient at ease with what is happening.
- ❖ Do not be afraid.
- ❖ Listen and believe your loved one when they tell you what they have seen. You may not be able to see these “guides,” but that does not make them less real to your loved one.

Saying Good-Bye

It is not unusual for someone at the end of life to hold on, even though they are suffering. This is especially true for those who have been authority figures or whose family is in conflict. In order to let go, your loved one needs to know that those they are leaving behind are going to be able to flourish without them.

You Can...

- ❖ Stay focused on giving one of the greatest gifts possible to your loved one – the security of knowing that you will be alright and that they have your permission and encouragement to let go. It is helpful to:
- ❖ Say good-bye, knowing that the patient – and you – may both need to hear this.
- ❖ Don't be afraid to cry. Tears are a natural part of the experience; they express your love. Don't try to hide them.
- ❖ Acknowledge that your loved one's absence will create a void in your life, but that you recognize their need to move on. You might say something like, “I will miss you, but I will be okay. It's time for you to let go.”
- ❖ Be aware that making your loved one feel guilty about leaving you can cause great distress, as can trying keep them from moving on in order to meet your needs.

WHAT HAPPENS WHEN DEATH OCCURS

We hope that your Hospice of Palm Beach County team, along with the information conveyed in this booklet, help to make the experience of the patient's death less frightening and anxiety-producing for you. We encourage you to involve us as much as you need so that we may help everyone involved handle this as smoothly as possible.

We cannot tell you when the moment of death will occur. Individuals who are very private, or who are afraid of causing their loved ones undue anguish, may choose to die when there is no one else in the room. Family members may feel guilty or rejected when this occurs, when the patient only wanted to spare them the distress of being present at the moment of death.

Most people who have never been present at a death still recognize when it occurs. A person who has died does not breathe or have a heartbeat. Their eyes may be slightly opened and there is no response to voice or touch. The skin may take on a pale or waxy look.

You Can...

Have a plan before the death occurs, so that you do not panic in the anxiety of the moment. Remember the following:

- ❖ A member of your Hospice of Palm Beach County team can be there to assist you with phone calls and other preparations. They will be as involved as you wish.
- ❖ Many people want the support of their own spiritual advisor or the Hospice of Palm Beach County chaplains. Still others want a Hospice staff member to be available but not actually there in the residence or at the bedside. We will try to accommodate you in any way possible.

- ❖ You may want to spend time with your loved one. The funeral home does not have to come right away, but will come when called. If at home, identify your loved one as a Hospice patient when calling them. You do not need to call the police.
- ❖ The Hospice of Palm Beach County nurse or team member will notify the physician.
- ❖ Be aware that your Hospice team is there to help you and that someone will be contacting you later at an appropriate time to see how we may support you in dealing with your loss.

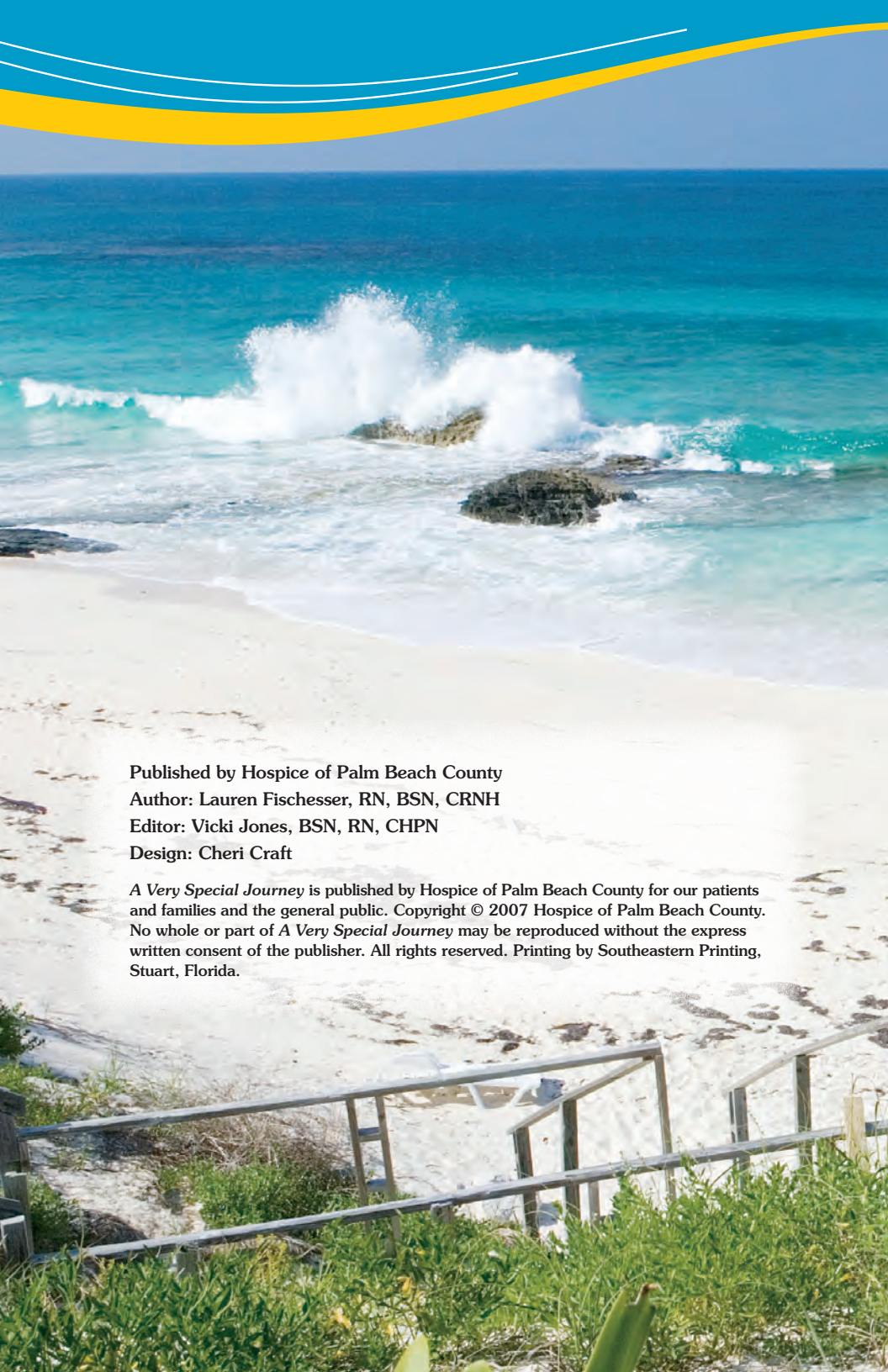


We at Hospice of Palm Beach County want you to know how privileged we feel to be involved in your care at this important time in your lives. We are here to walk the journey with you, support you and share with you what we have learned through our experiences. What we learn from you and from those who share the same path as you, goes beyond any practical knowledge we could ever convey.

Thank you for being our teacher.



**WE'RE THERE
FOR YOU...**
to help in any way we can.



Published by Hospice of Palm Beach County

Author: Lauren Fischesser, RN, BSN, CRNH

Editor: Vicki Jones, BSN, RN, CHPN

Design: Cheri Craft

A Very Special Journey is published by Hospice of Palm Beach County for our patients and families and the general public. Copyright © 2007 Hospice of Palm Beach County. No whole or part of *A Very Special Journey* may be reproduced without the express written consent of the publisher. All rights reserved. Printing by Southeastern Printing, Stuart, Florida.



*Quality of life
is our guiding objective.*



Hospice of
Palm Beach County

Licensed since 1981

We're there.

5300 East Avenue • West Palm Beach, FL 33407
(561) 227-5140 • (888) 848-5200 • www.hpbc.com

Accredited by The Joint Commission. 501(c)(3) not-for-profit organization
Jewish Accreditation by the Palm Beach County Board of Rabbis, Inc.

Copyright © 2007 Hospice of Palm Beach County