

# Body & Spirit

A Big Bend Hospice Guide  
to Transition and Passage



**Big Bend  
Hospice**

*your hometown hospice, licensed since 1983*

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[WWW.BIGBENDHOSPICE.ORG](http://WWW.BIGBENDHOSPICE.ORG)

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## ***Dear Family and Friends,***

Though we all know that one day every life will end in death, it is rarely easy to face the end of our own lives or the end of the life of someone we love. Although we prefer not thinking about death, our lives can be richer and our deaths more meaningful if we can find the courage to plan for our dying and for the dying of those we love.

This booklet is offered as a guide for what to expect as your loved one approaches the final phases of life. We hope that knowing what to expect will give comfort and a sense of safety as a caregiver, family member or friend. While no one can be certain of how long it will take for someone to die, having some milestones will give you greater confidence in where your loved one is on the journey and will enable you to focus on making the most of the time that is left with your loved one.

One way to make the most of this time is to take the time to say the things that you want to say and to ask to hear the things you would like to hear. This might be a time to give or receive forgiveness, express or receive gratitude or express or receive love. For some the time left is best spent realizing a last wish to go to the beach or make one more fishing trip. Some enjoy eating their favorite foods whenever they wish, listening to their favorite music or savoring the pages of a family album. Your hospice team can help you find creative ways to realize a last wish.

Some choose to plan their funeral or life celebration. Some enjoy having someone read or sing to them. Others wish to simply rest for the journey from life through death into what is beyond death. There is no proper way to die. What is appropriate is whatever makes the one who is journeying toward death as comfortable and peaceful as possible.

Like birth, death has identifiable stages. Sometimes these stages are only recognized in retrospect. When a person's health has been declining over a long period of time, the changes may be so gradual they are difficult to detect. Often the person who is dying may be the one who is most aware that the time is approaching, but out of concern for family and friends is hesitant to discuss it. Creating a safe space for the dying to talk about their approaching death can be a courageous gift.

Death is the natural outcome of life and comes to us all. It is a passage made sacred by the very nature of the mystical passing from this life into the beyond. We hope that knowing more about this sacred passage will enable you to explore the opportunities during such an important time of life.

**Your Big Bend Hospice Team**

# SETTING A PEACEFUL TONE

## *Honoring your loved one's wishes*

Caring for those who are dying is a sacred privilege and a great challenge. One of the most courageous acts is honoring what your loved one wants in terms of their care at the end of life. When we have the wonderful gift of knowing what someone we love wants, we should do our best to honor their decisions. It may be very hard for us not to insist that our loved one eat when they are no longer hungry or resist the urge to rush them to the hospital when they have clearly stated that they do not want any more aggressive measures. It is perhaps the most difficult thing you will ever do, but it is the right thing to do to honor the plans your loved one has communicated. Your hospice team is available to help you if needed.

## *Is it okay to talk about death?*

Most often people who are dying know they are dying and want to talk about it. While it may be difficult to address this topic, it is usually very helpful. One way to start the conversation is to ask, “*What do you think or feel is happening to you?*” If you need help with this your hospice team can assist you. Remember that in the long run, talking about death will reduce fears and regrets and foster stronger emotional bonds between you and your loved one.

## ***When eating or drinking is no longer helpful***

As death comes closer, the body no longer needs the calories it once relied upon and the desire to eat lessens. If it is safe to do so, a person can still be offered food and fluids but may not want them. Hunger is usually not experienced and thirst can be relieved with frequent mouth care and possibly ice chips. As a body weakens, very often a person's ability to swallow decreases, and food and liquids could actually be harmful. Artificial hydration (IV fluids) and nutrition (tube feedings) show no evidence of helping someone who is dying, and can actually cause an increase in discomfort. A dying person's needs change from physical (food, mobility) to emotional and spiritual (love, acceptance, forgiveness, connection to spiritual being). Although it may be difficult to see your loved one not eating or drinking, it is a natural part of dying.

## ***What about giving routine medications?***

As the body changes, routine medications may no longer be necessary. For example, a blood pressure medication might be discontinued if someone now has low blood pressure due to losing weight or a decrease in fluid intake. The hospice nurse will review each medication with the physician to determine if it is still necessary. Closer to death, the medications that are most important to take are the ones that can provide comfort. These medications can be given in many different ways if a person can no longer swallow.

## ***Balancing pain relief and sleepiness***

The goal of pain management is to increase a person's comfort level to what is acceptable to them. Sleepiness can be a side effect of many medications, although other factors could cause a person to sleep more. Sleeping usually increases as one gets closer to dying. One may sleep for a prolonged period of time after having pain relief from the medications, due to the fact that they are now comfortable enough to sleep, when in the past, they may not have been. Our goal at Big Bend Hospice is to promote one's comfort by finding the best balance between pain relief and sleepiness and to evaluate the effects of all medications.

## ***Special requests at the time of death***

Your loved one may make special requests as they near the time of death. These requests may be recorded in your loved one's Five Wishes or other advance directives. These requests may be about seeing or not seeing certain family and/or friends. They may center around who or what they want present as the time of death nears or may even be for a special meal or type of food. Even if the request seems unusual to you it may be very important to your loved one. As long as the request will not harm them or cause undo stress it may be a great gift to attempt to accommodate your loved one's wishes. If you have questions or concerns speak to a member of your hospice team for guidance and support.

## ***Funeral arrangements & memorial planning***

Making funeral arrangements is never easy but is easier if handled before death. Your hospice social worker or chaplain can assist you in discussing these important questions:

- *Has a funeral home been selected?*
- *Has burial or cremation been decided?*
- *Has a location for burial or placing ashes been made? If the location is out of the area, have arrangements been made?*
- *Should the casket be open or closed?*
- *Is a viewing desired?*
- *Has the obituary been written?*
- *Has the outfit for burial been selected?*
- *Has the funeral home been paid?  
(Social Security contributes around \$250.00 toward expenses.)*
- *Is a life insurance policy available to pay for the funeral and if so, where is it?*
- *If a veteran, do you have military papers to obtain a flag and to inquire about any military burial benefit?*

If a funeral service is desired, local clergy and/or a hospice chaplain can assist in preparation and conducting the service. When possible, conversations with the person who is dying about how he or she would like to be remembered and any desires regarding the funeral service are helpful and often very meaningful.

## ***Children and death***

You may wonder if it is appropriate for a child to be in the presence of one who is dying. If the relationship is significant to the child or the patient it may do more harm than good to keep the child away. Every child is unique. Be honest that death is normal and that while most people who get sick get better with the help of doctors and medicines, sometimes people get so sick they cannot get better. Reassure them that death is not a punishment, not their fault and not contagious. Answer questions simply, lovingly and honestly while being aware of the child's age and ability to understand. Be honest about your own feelings of sadness, fear, guilt or anger. This gives the child permission to express feelings he or she may be having. If the child acts upset or stressed in the presence of the patient, encourage involvement in other ways like making cards, writing letters or drawing pictures that you can share on their behalf.

## ***Common questions regarding children***

Answering, *"What does dead mean?"*

When someone dies their body stops working. They do not need to eat, sleep, breathe, talk, laugh or cry. They do not feel pain and cannot move.

*Anything that is mentionable is manageable.*  
~ Fred Rogers of Mister Rogers Neighborhood



## ***Should my child attend the funeral service?***

If these events are planned, talk to your child about whether or not they want to attend. Describe for them what they will see, what people might be doing and what the environment will be like. If they choose to go, ask an adult that the child is comfortable with to leave with the child if needed. If the child does not want to attend, explore other ways they can be involved: send a photo, write a letter or draw a picture to be placed in the casket or have someone take pictures at the funeral for the child to look at later.

## ***My child seems upset one moment and fine the next. Is this normal?***

Children grieve intermittently, that is, they need to take frequent breaks from the intensity of grieving. They may be crying one minute and off playing the next. This does not mean the child does not care about the person who is dying or is not affected by the experience. Take the lead with the child and do not be afraid to ask them about how they are feeling. If adults remain open, children will let them know when they are ready to talk. Also, remember that teens may share their feelings more readily with peers. Whatever their age, young people need available, safe, caring adults to help support them when someone they love is dying.

PHASE	SYMPTOMS
<p><b>Preliminary Phase</b> TWO TO THREE MONTHS OUT</p> <p>Sleeping more Eating less Focus on completing tasks Focus on "What is next?" Withdrawing more from socializing Talking more of the deceased</p>	<ol style="list-style-type: none"> <li>1. Falls</li> <li>2. Decreased interaction and increased sleep</li> <li>3. Decreased appetite</li> </ol>
<p><b>Preparation Phase</b> TWO TO THREE WEEKS OUT</p> <p>Asleep more than awake Less interest in what was once enjoyed Confused more Less able to communicate Weaker, less interest in eating Loss of muscle control</p>	<ol style="list-style-type: none"> <li>1. Increased weakness*</li> <li>2. Loss of bowel and bladder control*</li> <li>3. Difficulty swallowing*</li> </ol> <p>*these symptoms may present earlier.</p>
<p><b>Passage Phase</b> DAYS OUT</p> <p>Unable to eat or drink Less aware of surroundings Other possibilities include: Increase in discomfort Breathing pattern changes Hands and feet cooler and darker Talking to or seeing people/things that are not there Agitation, restlessness, increased confusion</p>	<ol style="list-style-type: none"> <li>1. Discomfort</li> <li>2. Changes in breathing patterns, gurgling sounds from the throat; irregular breathing, cool hands and feet - not bothersome to your loved one</li> <li>3. Engaging unseen people or things</li> <li>4. Fever and skin temperature changes</li> </ol>
<p><b>Death</b> MINUTES OUT</p> <p>Slight mouth movement may be noted as the last breaths are taken A final cough or odd sputter is sometimes heard with final breath</p>	<ul style="list-style-type: none"> <li>• No longer breathing</li> <li>• No heart beat</li> <li>• Unresponsive</li> <li>• Pupils dilated and fixed</li> </ul>

**REMEMBER THAT NOT EVERYONE WILL EXPERIENCE EVERY**

	<b>COMFORT MEASURES</b>
	<ol style="list-style-type: none"> <li>1. Safety precautions; affirmation of worth though unable to get around or be productive.</li> <li>2. Permission to not engage; assurance of love; comfortable bedding; encourage rest; quiet presence with your loved one.</li> <li>3. Allow to decline food; nourish the spirit through readings, music or interaction that your loved one appreciates.</li> </ol>
	<ol style="list-style-type: none"> <li>1. Safety precautions; encouragement to rest and allow others to help.</li> <li>2. Support dignity; encourage use of diapers or catheter to conserve energy for other things.</li> <li>3. Thickened liquids; pureed food; ice chips; mouth swabs; nurse can discuss swallowing techniques; may decrease unnecessary medicines and how medicine is given may change.</li> </ol> <p><i>Contact family and friends to say goodbye</i></p>
	<ol style="list-style-type: none"> <li>1. Listen for moans, look for grimaces or furrowed brow that might indicate discomfort; gentle repositioning sometimes helps; comfort medications and prayer as appropriate.</li> <li>2. Assure them of your presence and love; mouth care may comfort; soothing touch, words or music; loving presence.</li> <li>3. If not distressing, support them; if they seem distressed, report to hospice nurse.</li> <li>4. Cool cloth, lighter clothes, coverings; cool room.</li> </ol> <p><i>In any way you are comfortable, give permission for loved one to die; receive their blessing, if offered.</i></p>
	<p>Call Big Bend Hospice at (850) 878-5310. <b>PLEASE DO NOT CALL 911.</b></p> <p>Big Bend Hospice staff will assist in bathing the body and will call the funeral home.</p> <p>Spend time with loved one if comforting to you.</p>

**EVERYTHING DISCUSSED, SO LOOK FOR WHAT APPLIES TO YOU.**

# AS DEATH DRAWS NEAR

## *Phases of the dying process*

In the next pages you will find a description of the phases of dying and what you can do to help create the best environment for the journey through that stage. Remember that not everyone will experience everything described in the following phases. And know that your hospice team is here to help you. Please call us if you need us at (850) 878-5310.

### *The Preliminary Phase*

In the preliminary phase, two or three months prior to death, you may find your loved one sleeping more. Because they are not as active, they do not burn as many calories and may find their appetite is not as hearty. Your loved one may find their attention is more drawn to completing tasks or settling financial and relational matters. They may care less about the affairs of the world and even of their own circle of family and friends as they contemplate what is ahead. While they may love people deeply and regret having to leave them, your loved one may be realizing and even accepting that the end of life is approaching. As family and friends, you may notice that your loved one seems to be withdrawing and perhaps begins speaking more of loved ones who are deceased. This is not a reflection of the person's love for you, but for some, a necessary

part of letting go and moving on. You may experience many emotions like anger, guilt, sadness and hopelessness. Your hospice team can help you understand these feelings.

## ***The Preparation Phase***

In the preparation phase, one to two weeks prior to death, your loved one may sleep eighteen to twenty-two hours a day and have limited interest in those things that at one time they found enjoyable. They may feel and seem more confused, have difficulty finding words and not be able to communicate thoughts and feelings. They may be increasingly weaker and have very little interest in or desire for food and drink. They may lose muscle control leading to risk of increased falls, loss of bowel and bladder control and swallowing difficulty.

As family, friends and caregivers, you may find it hard to bear these changes. You may feel a strong urge to encourage your loved one to eat or drink, to stay awake, to fight. Allow your loved one to guide you. As you are able, it is a compassionate gift to focus your love and attention on the one who is dying, making the transition as smooth and peaceful as possible.

*Dying and death are not a medical event. They are a human event, a family event, a personal event that each one of us will have the privilege to experience only once.*  
~ Alexander Peralta, Jr.

## *The Passage Phase*

The passage phase is the actual dying process when breathing may become irregular, hands and feet may become cooler and change color, and eyes may become fixed in a distant stare. You may hear a gurgle due to excess fluid that your loved one is no longer strong enough to expel. Your loved one may have a temperature or may pick at the bed linens. They may talk with or seem to interact with someone you do not see. These changes do not seem to be bothersome to the dying as their body's natural dying mechanism takes over. The hospice team will assist you in doing all that is possible to keep your loved one comfortable.

This passage phase may take hours to days and is a time when you, as family, friends and caregivers, can create the best environment for the one you are caring for to cross the threshold of death. You will want to keep the environment around your loved one peaceful and calm. You may wish to offer gentle touch, soothing music and encouraging words if these are things that matter to your loved one. You may want to soften the lighting and pay close attention to the comfort level of your loved one. If you are able, you will want to tell your loved one how much they are treasured and will be remembered always. You may want to call in those whose presence is important. Place phone calls to those who cannot be present and allow them to talk to your loved one, even if it seems that they are not aware.

You may grant your loved one permission to go without rushing them to do so. Let them know that you are with them and if you are able, tell them that they are loved. Death is a passage, a crossing over that can in itself be a sacred moment. If it seems helpful, call on your hospice chaplain or your clergy person to be with you. Music therapists, social workers and vigil volunteers are also able to bring comfort and support. You may wish to have a nurse present for some of this time. You may access these services by contacting (850) 878-5310 and either your hospice team (*during business hours*) or on-call hospice staff (*after hours*) can help meet your needs.

## **WHEN DEATH HAS COME**

### ***Making the moment sacred***

In the moment that your loved one dies, there may be a sense of your world shifting. While death happens to countless numbers of people every day, everywhere, there is something deeply personal and unique about your loss. Be respectful of your feelings. You may want to offer a prayer. You may want to mark the moment with attentive silence. You may want to cry, to pour out your soul. You might feel anger or relief, helplessness or peace. You may want to place flowers on your loved one or cover them in their favorite blanket. You may want to assist the hospice nurse in bathing your loved one. You might

play a favorite song or read a favorite poem or scripture. Know that just as there is no proper way to die, there is no proper way to respond to the moment of death. Take the time you need to find some level of peace.

When you are ready, if the hospice nurse is not yet present, please call (850) 878-5310 and report that your loved one has died. A nurse will come as quickly as possible, night or day, to bathe your loved one, if desired, and to take care of details related to medications and medical equipment. Your nurse or other hospice team members will call the funeral home. If you wish to have a chaplain or social worker with you at this point, call (850) 878-5310 and someone will respond at any time. Chaplains can help you mark the time of passing as a holy moment, help you sort through your questions or pain as they listen attentively, and assist with funeral preparations and services. Social workers can assist with emotions you are having at this time.

### ***Honoring your own needs***

Though the moment of death is anticipated, it is never easy, no matter how prepared you think you may be. Be gentle with yourself as you allow the funeral home to take your loved one, prepare for the funeral and memorial service, if there is one, and share the news with others. There is no proper way to handle the details to be tended to after the death of your family member or friend. Allow others to help



you if they offer. Don't be afraid to ask for help if needed. Allow yourself time to grieve before making any major decisions about your property, mementos or finances. Know that a counselor trained in helping those who grieve will be calling you from Big Bend Hospice to offer assistance and emotional support. You do not have to wait for this call. If you would like to talk with a grief counselor call (850) 878-5310 and ask for the Bereavement Services Department. Please know you are not alone. Though the absence of your loved one may be painful, their presence in your heart is eternal.

### ***When things do not turn out as planned***

While no description of the journey toward death is ever fully accurate, it is possible your experience may be vastly different from this description. Maybe death is coming much sooner than expected. Maybe, for a number of reasons, symptoms are not fully controlled and you have concern regarding the well-being of your loved one and the loss of your own opportunity to make the transition smooth. We hope that you will call us at (850) 878-5310 as soon as you realize your need so that we can do all that is possible to assist you. We believe that through your own inner strength and the help of others, your faith or whatever nurtures your spirit, you will make it through this journey. We hope that you will feel peace knowing that you tried your best under difficult circumstances. Our Big Bend Hospice grief and loss counselors are specially trained in helping you work through the feelings you may have in these particularly difficult situations.

# RESOURCES

## YOU MAY FIND HELPFUL

### *Words you may hear and what they mean*

**Advance Directives** • Describes two kinds of legal documents: living wills and health care surrogates. Advance directives allow a person to give instructions about future medical care to another person should s/he become unable to speak for him or herself. One such document is the Five Wishes and includes personal, emotional and spiritual needs as well as medical needs.

**DNRO** • Stands for “*Do Not Resuscitate Order*.” This is an order signed by the doctor and family/patient and is the only legal document kept with the person. It means that when the heart stops and breathing stops, there is to be NO medical intervention (*CPR, breathing tubes*) to artificially keep the person alive.

**Dysphagia** • Difficulty swallowing

**Dyspnea** • Shortness of breath

**Edema** • Swelling in any part of the body

**Imminent** • Hours to days before dying

**Incontinent** • Loss of bowel and/or bladder control

**Mottling** • Changes in color that usually start in the hands and feet, but also can be seen on the face before dying. Color may vary from bluish-gray to pale white depending on patient’s skin tone.

**Pain** • Any unpleasant/uncomfortable sensation that is expressed. Can be physical, spiritual or emotional and therefore can be relieved in many different ways including medications, music therapy, gentle touch, spiritual and emotional support.

**Palliative Care** • Comfort measures for spiritual, physical and emotional needs.

**Terminal Agitation** • Restlessness, possible hallucinations and “*extra energy*” that may not seem comfortable to the person at the end of life. This can be managed in different ways including medications, music therapy, spiritual and emotional support.

**Transitioning** • Coming closer to dying; death occurs usually within days to weeks.

## ***Hospice Care Guide references***

When your loved one was admitted to Big Bend Hospice you received a [Hospice Care Guide](#). Besides the sections of the book identified by your team, you might find these pages helpful as your loved one approaches the last months and weeks of life:

**Questions and Answers**

**Information on Advance Directives**

**Making the Most of this Time**

**Children and Death**

**Symptoms and Spiritual Pain**

**Anticipating Loss**

**Grief Support After Death**

## ***Books***

Ira Byock, *[Dying Well & The Four Things that Matter Most](#)*

Maggie Callanan and Patricia Kelley, *[Final Gifts](#)*

Henri J.M. Nouwen, *[Our Greatest Gift](#)*

Marc Brown and Larry Brown, *[When Dinosaurs Die](#)*

Maggie Callanan, *[Final Journeys](#)*

## ***Websites for children:***

THE DOUGY CENTER

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

NATIONAL ALLIANCE FOR CHILDREN'S GRIEF

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

## ***Websites for adults:***

211 BIG BEND (*RESOURCES FOR BIG BEND AREA*)

[www.211bigbend.org](http://www.211bigbend.org)

AGING WITH DIGNITY

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

BIG BEND HOSPICE

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

CARING INFO

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

HOSPICE FOUNDATION OF AMERICA

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

# SACRED MOMENTS

*The moments of our lives, sometimes too quickly gone  
It may seem life's end is rushing upon*

*We may not know when the time is for us to depart  
And these times of reflection can be sacred to the heart*

*We can laugh, we can cry, say "I love you" and "goodbye"*

*We can touch, be still, be present and even pray  
And know the time we're still here can be a sacred day  
Our hopes may change – the hope of fear and pain relieved  
And oh how we know it is not easy for us to grieve*

*Each "I love you" is a promise, each touch is a gift  
The words we may wish to speak, our hearts could lift  
With the stress of this time, it can feel like years  
When each day is long, but not enough ....it appears*

*Although we may not want to, we can say "goodbye"  
It's a gift we can give to both you and I  
We can share these sacred moments of earthly release  
And may all who are touched find a sense of sacred peace*



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