



**ALONG THE
FINAL JOURNEY**

*A Guide
for families
and caregivers*

TABLE OF CONTENTS

STARTING THE JOURNEY	2
ALONG THE JOURNEY	3
<i>Physical/Emotional Symptoms and Appropriate Comfort Measures</i>	
Diminishing Appetite	3
Decreased Socialization	4
Sleeping	4
Changes in Pain Level.....	5
Incontinence	5
Disorientation.....	6
Restlessness and Agitation.....	6
Coolness and Skin Color Changes.....	7
Breathing Pattern Change	7
Congestion	8
Fever.....	8
Withdrawal	8
Vision-like Experiences.....	9
Surge/Rally	9
Unusual Communication	9
THE FINAL JOURNEY	10
Giving Permission	10
Saying Goodbye.....	11
SUMMARY OF WHAT TO EXPECT	12
SUMMARY OF GUIDELINES	13

HOSPICE CARE THAT HONORS EACH LIFE

From all of us at Compassus, thank you for entrusting us with hospice care for your loved one. Our mission is to bring comfort, dignity and honor to the end of life's journey. To patients, we offer relief from pain and symptoms. To families and caregivers, we provide support before and after the death of a loved one.

We recognize that caring for someone you love during the final days can be a difficult experience. We created this caregiver's guide to help make the hospice experience more comfortable for both you and your loved one.

Remember that you are not going through this alone. You can call on your hospice team at any time with questions or concerns. Together, we can make the final chapter of your loved one's life worthy of all that has come before it.

STARTING THE JOURNEY

During the final journey, the mind and body will experience two different, dynamic stages that are closely intertwined. The physical stage is the body's process of shutting down. In the emotional and spiritual stage, your loved one may want to complete unfinished business or begin to withdraw and let go.

The members of your hospice care team will help you understand these stages, as well as the signs and symptoms of impending death, and show you how your support can bring comfort and even peace during this time.



ALONG THE JOURNEY

Physical/Emotional Symptoms and Appropriate Comfort Measures

Following are physical and emotional symptoms that naturally occur during the dying process, plus ways that you can provide comfort. These signs and symptoms will not occur with every person, nor will they occur in any particular order.

DIMINISHING APPETITE

A body that has begun the dying process does not experience hunger and thirst in the same way that a healthy body does. As a result, it is natural for your loved one to have a decreased appetite, to say food no longer tastes good or to have no interest in eating meals. Typically, meats are the first food groups that are no longer appealing, followed by fruits and vegetables. A person's diet may eventually be limited to soft foods and then liquids only. Although a loss of appetite may be one of the most difficult things for family members to accept, don't be concerned if the patient does not want to eat. In fact, eating may increase discomfort.

How you can provide comfort:

- Do not force food and fluids.
- Offer small, frequent snacks of the foods the patient requests.
- Sponge swabs moistened with cool water or a favorite beverage can keep the mouth and lips moist and comfortable.

Remember that appetite is the best indicator of what the body needs and can tolerate. Let your loved one's appetite guide you.

DECREASED SOCIALIZATION

Your loved one may want to be alone, or with just a few friends or family. This is natural when someone is growing weak and tired and preparing for the separation that death brings. The important thing is to understand what he or she wants.

How you can provide comfort:

- Limit visitors to those your loved one wants to see.
- Recommend short visits.
- It is not always important to talk — holding a hand can be all that is needed.
- Keep lights soft; bright lights may be uncomfortable.

SLEEPING

Your loved one may spend an increased amount of time sleeping and appear uncommunicative, withdrawn or unresponsive.

How you can provide comfort:

- Plan to spend time with your loved one when he or she is most awake.
- Hold hands — touch can bring comfort.
- Speak normally, even though there may be no response.

Do not say anything you would not want your loved one to hear. Even in an unresponsive state, he or she may be able to hear you.

CHANGES IN PAIN LEVEL

Your loved one may experience an increase or decrease in pain, or no change at all. As the body changes, so does the way it perceives pain. Watch your loved one for complaints or signs of pain. Do not change any pain medication without the direction of the nurse.

How you can provide comfort:

- Call your hospice nurse for help. Our hospice professional staff will offer medications to alleviate symptoms of discomfort such as pain, nausea, agitation and labored breathing. Our goal is to keep patients comfortable.

INCONTINENCE

Incontinence and an overall decrease in urine output are normal and expected. While troubling for some loved ones, it is not uncommon for the patient to lose control of the bowel and/or bladder as muscles relax. Your hospice team can help you and your loved one deal with this issue with dignity.

How you can provide comfort:

- Reassure your loved one that this experience is normal and that you are there to help.
- Talk to your hospice nurse about the best ways to keep your loved one clean and comfortable.

DISORIENTATION

Your loved one may be confused about the time, place and identity of people.

How you can provide comfort:

- Identify yourself by name before you speak.
- Speak softly, clearly and truthfully. For example: “It is time to take your medication, so you won’t have pain.”
- Do not try to force or trick your loved one into taking medications, even if you believe it is in the patient’s best interest. Trust between your loved one and caregiver is too important to jeopardize.

RESTLESSNESS AND AGITATION

Your loved one may make restless or repetitive motions or appear agitated. Though they may occur frequently, do not interfere with or try to restrain these motions.

How you can provide comfort:

- Establish a calm atmosphere; eliminate bright lights.
- Speak in a quiet, natural way.
- Try other calming strategies — gently rub the back, stroke the arms or forehead, read aloud or play soothing music.
- Give assurance that you are there and will remain with your loved one.

COOLNESS AND SKIN COLOR CHANGES

Your loved one's face and extremities may be cool to the touch, or the skin may start to pale, become discolored or appear blotchy. These are normal signs that circulation to the body's extremities is changing.

How you can provide comfort:

- Keep your loved one lightly covered.
- Avoid using an electric blanket.
- Socks may keep the feet warm.

BREATHING PATTERN CHANGE

It is common for the regular breathing pattern of your loved one to change. During some periods, breathing may stop for several seconds.

How you can provide comfort:

- Elevate the head with a pillow or blanket.
- Turn your loved one on the side — this may also be more comfortable.
- Hold hands, speak gently and be reassuring.

CONGESTION

Gurgling or rattling sounds coming from your loved one's chest or throat are normal and often due to an inability to clear or cough up secretions. Congestion is distressing to listen to but may not indicate discomfort for the patient.

How you can provide comfort:

- Elevate your loved one's head and gently turn it to the side, allowing gravity to drain secretions.
- Mouth care may be given as instructed by your nurse.

FEVER

Your loved one may have a temperature, which is not uncommon.

How you can provide comfort:

- Place a cool, damp washcloth on the forehead or under each arm.
- Call your hospice nurse to discuss other comfort measures that could be used.

WITHDRAWAL

Your loved one may seem withdrawn or in a coma-like state, which signals that death is near.

How you can provide comfort:

- Since the sense of hearing functions until the end, speak to your loved one; he or she may hear you.
- Spend time together and hold hands.

VISION-LIKE EXPERIENCES — NEARING DEATH AWARENESS

Your loved one may speak to people who already have died and speak of seeing places not visible to you.

How you can provide comfort:

- If you cannot gently re-orient him or her, validate the experiences; do not contradict or explain away these events.
- If these experiences frighten your loved one, explain that they are normal.

SURGE/RALLY

After being inactive, disoriented or confused for a time, your loved one may suddenly become energized and alert, request a favorite meal or ask for visitors. This can be normal during the dying process.

How you can provide comfort:

- Give your loved one your utmost attention, since this surge of energy may not last long or return.

UNUSUAL COMMUNICATION

Your loved one may make an out-of-character statement or gesture that may indicate he or she is ready to say goodbye and to test you to see if you are ready.

How you can provide comfort:

- Accept this moment as a beautiful gift: kiss, hug, hold, cry and take the opportunity to share love and forgiveness.
- Be calm, and be guided by your loved one's needs.

THE FINAL JOURNEY

GIVING PERMISSION

Giving permission to your loved one to let go can be difficult. A dying person may try to hold on, which shows his or her concern and love for those left behind.

How you can provide comfort:

- Releasing your loved one from this concern and assuring him or her that it is all right to let go is one of the greatest gifts you can give at this time.



SAYING GOODBYE

The moment your loved one is ready to die, letting go is an important part of achieving closure.

How you can provide comfort:

- The moment may include giving and receiving forgiveness, recounting favorite memories, holding hands and sharing unexpressed love.
- Your loved one may wish to know that he or she made a difference in your life and will be remembered.
- Tears and emotions are normal and natural — don't apologize for your feelings or try to hide them.

The impending death is not a medical emergency. You and your hospice team will have worked together to allow your loved one to die in familiar surroundings without painful or extraordinary treatments. Nothing must be done immediately.

The signs of death may include no breathing, no heartbeat, release of bowel and bladder, eyelids slightly open or fixed on a certain spot, no blinking, jaw relaxed or mouth slightly open.

After death, contact your hospice nurse, who will coordinate final arrangements.

SUMMARY OF WHAT TO EXPECT

- Your loved one's need for food and drink may decrease.
- Your loved one may want to be with few friends, family or just you.
- Periods of sleep may increase during the day.
- It may be difficult to wake or rouse your loved one from sleep.
- Your loved one may be more restless or may pick or pull at the bed linen.
- Your loved one may have more anxiety, restlessness, fear and loneliness at night.
- Loss of control or incontinence of urine and bowel matter may occur.
- Urine may become darker in color and decrease in amount.
- Your loved one may express the need for spiritual care.
- Arms and legs may feel cool to the touch.
- Your loved one's temperature may be elevated or subnormal.
- Your loved one may be confused about time, place and people.
- Breathing may be irregular.
- Breathing may stop for several seconds at a time.
- Mucus in the throat may increase.
- Vision may become blurry or dim.
- There may be profuse sweating, and the skin may feel cold and clammy.
- Your loved one may tell you that people who have died are present.
- Skin on the arms, hands, legs and feet may deepen in color and appear blotchy.
- Your loved one may have a sudden burst of energy and rally.
- The pulse of your loved one may be weak and difficult to find.

SUMMARY OF GUIDELINES

The dying process is unique to each individual. People may show any of the symptoms listed below during the time leading up to death.

ONE TO THREE MONTHS BEFORE DEATH:

- Withdrawal from people and activities
- Less communication
- Eating and drinking less
- Increase in sleep

ONE TO TWO WEEKS BEFORE DEATH:

- Disorientation and confusion
 - Agitation
 - Talking to others not present in the room
 - Picking at clothes
 - Use of symbolic language (“I want to go home”)
- Physical changes
 - Increase or decrease in pulse
 - Decrease in blood pressure
 - Change in skin color: pale, bluish
 - Increased perspiration
 - Irregularities in breathing
 - Congestion
 - Sleeping but responding
 - Not eating, taking in little or no fluids
 - Complaints of being tired or the body feeling heavy
 - Changes in body temperature: hot, cold

DAYS TO A WEEK BEFORE DEATH:

- Sleeping most of the time
- Surge of energy
- Further decrease in blood pressure
- Restlessness or no activity
- Difficulty swallowing
- Further discoloration of skin: purplish, blotchy knees, feet, hands
- Ongoing changes in breathing (long pauses between breaths)
- Weak pulse
- Eyes glassy, tearing, half open, no longer able to close completely
- Decreased urine output or no urine
- May wet or soil the bed

HOURS TO DAYS BEFORE DEATH:

- Shallow breaths with longer pauses
- Mouth opened
- Unresponsive, cannot be awakened

Please visit our website, compassus.com, for more information and a current list of all our locations around the nation.



compassus.com

© 2016 Compassus. All Rights Reserved.
128AFJ0416