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THE FINAL JOURNEY

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peace.

Levine & Dickson  
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**Kids Path**

*“You matter because  
you are you,  
and you matter  
to the last moment  
of your life.*

*We will do all we can  
not only to help you  
die peacefully,  
but also to live  
until you die.”*

*- DAME CICELY SAUNDERS, M.D.  
FOUNDER OF THE MODERN  
HOSPICE MOVEMENT*

*1918-2005*

# *The Final Journey*

## **UNDERSTANDING & SUPPORTING THOSE APPROACHING THE FINAL STAGES OF LIFE**

Caring for a loved one who is entering the last phase of his/her life can be both overwhelming and challenging for you and your family. The clinical teams of Hospice & Palliative Care Charlotte Region, Hospice & Palliative Care Lake Norman, Hospice & Palliative Care Lincoln County, Hospice & Palliative Care Palmetto Region, Hospice Cleveland County, Kids Path®, Levine & Dickson Hospice House - Huntersville, Levine & Dickson Hospice House at Aldersgate, Levine & Dickson Hospice House at Southminster, the Testa Family Hospice House, and the Wendover Hospice House have compiled this information to help you and your loved one prepare for, and cope with, the symptoms of approaching death.

It is our hope that you will learn and benefit from our experiences with others who have died under our care. We also want you to know that, by choosing to participate in this experience, you can truly make a difference in the last months, weeks, and days of your loved one's life.

The information on the following pages describes how the body prepares for the final journey. Some individuals experience all of these symptoms, while others do not. It has been our experience that each patient's journey is unique. Death will come in its own time and in its own way. However, you may take comfort in knowing that your presence throughout this process will provide enormous reassurance to your loved one.

Our teams are here to assist and support you in any way that we can during this time. After you have reviewed the information in this booklet, please contact a member of your care team with any questions you may have.

# The Seven Fears of Dying

We all have general fears about dying. Patients living with a terminal illness, however, have more time to think about the concept of death and may have specific worries. Your loved one will most likely experience many of the following seven fears, identified in *Hospice: A Caring Community* by Theodore H. Koff.

## **FEAR OF THE DYING PROCESS**

Hospice patients are often anxious or frightened about death. They worry that it will be painful. They are often concerned about their body image, as physical changes take place when death approaches. This fear may be especially true with patients who experience weight loss and other signs of physical decline.

## **FEAR OF LOSS OF CONTROL**

Terminal illnesses gradually make people more dependent on others. As the disease progresses, they are often thrust into a healthcare system which makes them and their family feel more helpless and less able to make decisions about themselves and their future.

## **FEAR OF THE LOSS OF LOVED ONES**

Hospice patients are often greatly concerned about what will happen to the loved ones they leave behind. Will there be sufficient money to put their children through school? Will their spouse be able to return to work? Will their families get along well in their absence?

## **FEAR OF OTHERS' REACTIONS TO THEM**

This fear is perhaps best explained by the quotation, "I never knew what fear was until I saw it in the eyes of the people taking care of me."

## **FEAR OF ISOLATION**

Hospice patients are often fearful of dying alone. They feel increasingly isolated if friends and family, and some healthcare professionals, visit less frequently and begin to withdraw as death approaches.

## FEAR OF THE UNKNOWN

Hospice patients wonder what they can expect in the way of physical suffering. End of life is also the time when they may begin to question their personal system of faith. They may wonder if there is life after death, and, if there is, what it is like.

## FEAR THAT LIFE MAY HAVE BEEN MEANINGLESS

It has been said that death is “the time when the mind’s own camera is forever turned upon oneself.” It is a time of intense self-examination as a patient seeks to evaluate the course of his/her life and whether or not it has been meaningful. The results of such self-examination can greatly affect your loved one’s emotional reactions and the capacity to cope with death.

*“The brochures, suggestions, and instructions (you provided) helped the family help her. Knowing what to expect, and having help to meet the challenges, made a very difficult time endurable. I don’t think I could have done it without your help, but with it, my mom was able to die as she wished – at home.”*

# *What to Expect in the Final Months*

## **WITHDRAWAL**

Some changes will begin to occur one to three months before death. Your loved one may begin to withdraw from friends and family and become less outgoing. It takes considerable energy to begin the process of dying; at this time, patients frequently begin to reserve their energy for “the trip” and for themselves. They may be less interested in the newspaper, television, or family activities. Often, those faced with a terminal illness will gradually separate from those they love, since it might be too difficult to do suddenly, without preparation. They will spend time reflecting on their lives and how they have lived. They may wonder, “Was my life worthwhile? Have I contributed something?”

A life review may help your loved one know how much they mean to you; that you appreciate everything they did on your behalf. You might want to offer him/her the following words: “I’m sad that you are experiencing this, but I want you to know I will be here for you. If there is anything I can do to help you feel more peaceful, I will do it.” Often hospice patients like to “finish business” before they die – perhaps letting you know their wishes for funeral arrangements or how to distribute their possessions. Try not to discourage the conversation or deny their feelings; instead, encourage them to share more with you.

In the final months, your loved one will begin to sleep more during the day. Though he/she will appear to be just sleeping, important “work” may be going on at a level which we cannot define. You may feel more helpless and might struggle with your loved one becoming more distant from you. In fact, this distance or “time away” may increase your sense of sadness and loss. That’s because we are never ready to let go of our loved ones. The months before death are also a time of reflection. You will evaluate how your life will be different when your loved one is no longer with you. And it is also a time of preparation for the person who is dying.

### **What you can do:**

- Let the patient rest and sleep.
- Try to accept that he/she does not have the desire or the energy to do more.
- Spend time with your loved one. That is more important than doing unnecessary things for them.
- Promote a peaceful environment with less noise and activity around the patient.

## NUTRITIONAL NEEDS

When we are healthy, we eat to nourish our bodies and give ourselves energy. When our bodies begin to prepare for death, however, it is perfectly natural for eating to slow or stop. Unfortunately, this occurrence is difficult for families to accept because our lives revolve around eating; it is a way in which we socialize and come together as families.

For patients who have a terminal illness, food may not taste the same, and the appetite they once had is gone. To help, we suggest that you make small portions available and offer frequent, small snacks. There may be times when your loved one will crave a certain food. After you have spent time cooking it, however, they may no longer be able to eat what you have prepared. That's because the smell of food cooking may be offensive for someone who has little appetite. At this time, liquids may be preferable to solids. You need to understand that it is normal when your loved one does not want to eat. This behavior is the body's way of slowing down. A different kind of energy is needed that food cannot supply. Energy from within, emotional or spiritual, will help sustain your loved one now.

Offer, but do not force, food, liquids, and medications. Do not try to manipulate the patient into eating or drinking. Jell-O, ice cream, or yogurt is easier for patients to swallow than water or thin liquids. Small chips of ice, soft drinks, ginger ale, juice, and/or popsicles may be refreshing to the patient's mouth. Your primary nurse can give you information on liquid food supplements which may also be helpful.

As your loved one's condition declines, liquids alone may be sufficient. At some point, most patients will be unable to take anything by mouth. If the patient becomes unable to swallow, fluids may be given in small amounts by syringe. Your nurse can provide guidance with this. Lip balm can be applied to relieve dry lips. Moistened swabs can help keep the patient's mouth and lips comfortable. A cool, moist washcloth on his/her forehead or mouth can also provide comfort.

### **What you can do:**

- Offer, but do not force, food, liquids, and medications.
- Try not to say, "If you don't eat or drink something, you won't get stronger."
- Provide very small amounts of food or liquid at a time.
- Offer foods with the consistency of Jell-O, soft ice cream, or yogurt, which may be easier to swallow than water or thin liquids.

## DEHYDRATION

It may be helpful to understand what happens to the body of a hospice patient when dehydration occurs. With an advanced terminal disease, it is normal to see a fluid deficit with reduced circulation to all body systems.

As the electrolytes or chemicals in the body change, nausea, vomiting, muscular twitching, and increased restlessness may be experienced. There will be a decreased level of consciousness. Patients will begin to sleep more and may become confused or disoriented while awake.

The medical community continues to research and learn more about ways to comfort a dying person who no longer desires food or liquids. During the end stage of life there are benefits to not having intravenous (IV) fluids or additional tube feedings. The decision about continuing fluids and feedings is an individual one for each person and family.

As the body begins to shut down, eating and drinking become less important. This is nature's way of beginning the dying process. Your loved one may drink less due to difficulty swallowing, loss of appetite, low energy level, or emotional withdrawal. When your loved one is no longer able to tolerate fluids, more pronounced changes are likely to occur within the next eight to ten days.

This time may be the most difficult for you. It is important to remember that if your loved one were able to eat or drink, he/she would. But at the end of life's journey, our bodies are just not able to take in food or drink. In fact, in some instances, it can even cause more discomfort. It is helpful at this time to let your loved one know that it's okay if he/she does not eat or drink. Many patients live for days to weeks without eating or drinking. Understand that it is most likely more bothersome to you than it is to your loved one. He/she can still remain comfortable without food or liquids.

Decreased body fluids and chemical changes cause a natural state of anesthesia within the central nervous system. As the level of consciousness decreases, a person's perception of suffering also decreases. There are two questions you should ask yourself: "Are IV fluids making my loved one's discomfort and suffering last longer?" and "What symptoms are being relieved because my loved one is receiving IV fluids?" IV fluids do not moisten the mouth; however, other measures can be taken to provide that comfort (see page 5). Please remember that we will work with you to make your loved one's death a comfortable and peaceful one.

**Some positive effects of dehydration:**

With decreased fluid intake, there will be:

- less urine output. A bed pad or incontinence briefs may be used instead of a bedpan.
- less gastrointestinal fluid buildup. Nausea and vomiting is reduced, especially in patients with a bowel obstruction.
- fewer secretions in the lungs and upper airway, reducing cough and congestion.
- increased ease in swallowing secretions. Choking or drowning sensation will be relieved.
- less swelling or edema of the ankles, feet, and abdomen. Often the swelling around a tumor may also be reduced, providing some comfort.

*“(The nurse) stayed with us  
and gave us all the information we  
needed and answered any questions we had.  
She was calm and offered to stay  
as long as we needed her.”*

# *What to Expect One to Two Weeks Before Death*

## **COMMUNICATION**

In the last few weeks, your loved one will be sleeping most of the time. While awake, he/she may become confused, agitated, or seem disoriented. He/she may talk with people who are not really present or have “conversations” with loved ones who have already died. You should not be alarmed; these conversations may provide great peace and offer company for the patient on the journey ahead. Your loved one may tell you that he/she wants to “go home” even if he/she is already at home. This can be a difficult time for families and others close to the patient. You begin to understand that your loved one will be leaving you for a place to which you cannot go.

We encourage you to listen very closely to what your loved one is saying. These final moments of communication often hold important meaning for those who are leaving as well as for those remaining. If we listen carefully, we may hear them asking for our permission to die, or witnessing something of which we cannot be a part. Not only is it essential to listen with complete attention, but you must also let your loved one know you are listening. It is important to validate what he/she is experiencing.

### **What you can do:**

- Try to sit quietly with your loved one. A calm, reassuring approach is helpful.
- Pay special attention to safety measures.
- Provide a quiet, restful environment, and consider having fewer visitors (other than immediate family).
- Respond in ways which tell the person that you accept whatever they say or “see,” by saying “Tell me more about that.”
- Respond to what they say in a gentle way. Ask questions and offer sensitive insights which might encourage them to keep talking.
- Encourage the patient to repeat or clarify statements if necessary. Don’t be afraid to say, “I’m not sure I follow you. Can you explain that a little more?”
- Offer support. For instance, if the patient is having difficulty letting go, do not deny the problem. Acknowledge it and offer to help. “Tell me what I can help you with right now.”
- Be prepared to say things like:
  - “I love you.”
  - “Remember when ... ”
  - “I am sorry for ... ”
  - “Thank you for ... ”
  - “You have truly made a difference ...”

- Try not to push the patient in any way. If your loved one does not feel like talking, or cannot talk, offer your support and acceptance. Family members share so much together during their lives. Final moments together can also be a time of sharing if the environment is supportive.

### **Additional communication techniques:**

- Maintain a calm, accepting approach.
- Use yes/no questions. Avoid complicated choices.
- Give simple, short explanations.
- Encourage reminiscing since long-term memory is often still intact.
- Look at photo albums together.
- Try to understand the feelings that are being conveyed.
- Speak quietly and slowly.
- Be aware of your body movements. Make an effort to slow down and relax. Convey a sense of peacefulness.
- It is appropriate to sometimes just sit quietly with your loved one.

## **PHYSICAL CHANGES**

In the last few weeks, your loved one will experience physical changes.

- His/her blood pressure often lowers.
- The patient's heart rate may greatly increase or decrease.
- As the body's temperature changes, a fever may occur or the patient's arms/legs may be cold.
- There may be increased perspiration or clamminess.
- As skin color changes, your loved one may appear flushed or pale.
- The patient's feet and hands will often become pale, or blue in color, due to the heart's inability to maintain a normal flow of blood throughout the body.
- The rhythm and rate of breathing will change. You may notice pauses occurring between breaths or the rate varying between six to forty breaths each minute.
- Congestion may cause a rattling sound in the upper throat and lungs. Certain medications or changes in position may reduce this pooling of secretions.

# What to Expect Days or Hours Before Death

## COMMUNICATION

Occasionally, your loved one may have periods of wakefulness. He/she may be alert and able to talk with you. Your loved one may even be able to eat something or sit up and visit with family. This phase is another part of the transition.

During this time, the physical changes you noticed before will become more pronounced. Restlessness may increase due to lower oxygen levels in the blood. Breathing will become more shallow and irregular. Congestion will also increase. The patient's hands and feet may become purplish and blotchy.

As your loved one becomes more unresponsive, his/her eyes may be open but he/she may not be able to focus or see. Know that your loved one can hear you as you speak, even if you receive no response or answer.

Our experiences with patients who are dying have taught us how important it is to give a loved one permission to die. This is often the final gift that only you can give; it allows the patient to finally rest and let go. You might simply whisper, "I'm going to be all right. If you need to go on now, then it's okay – I want you to let go and rest." These words may bring tremendous relief and peace to a person who is dying. You, and only you, will know when you can share that message with your loved one.

Finally, when it seems that the last breath has occurred, it may be followed by several sporadic breaths. There will be no blood pressure, heartbeat, or pulse. Your loved one will have completed his/her life's journey.

*“Hospice experience –  
generous, giving, caring,  
devoted, loving, sympathetic –  
not only to the hospice patient,  
but to the whole family unit involved.  
There aren't enough words that  
can describe my  
hospice experience.”*

## *Tasks to Complete After Your Loved One's Death Occurs*

- Decide on the time and place of a funeral and/or memorial service, if desired.
- Notify immediate family, close friends, and business colleagues of your loved one's death.
- If you choose to have memorial gifts designated to charities that were important to your loved one and your family (e.g. community of faith, school, hospice, or other charities), make those determinations.
- Write an obituary. You may include age, place of birth, cause of death, occupation, schools and degrees, memberships held, military service, outstanding work and/or life accomplishments, list of survivors in immediate family, time and place of service(s), and memorial designation(s). The funeral home will communicate this information to the newspapers for you.
- Select pallbearers and notify them. Avoid choosing individuals with heart or back difficulties, or designate them as honorary pallbearers.
- Plan for distribution of flowers following the funeral.
- Notify insurance companies, lawyer, and/or executor of the patient's death.
- Arrange for members of the family or close friends to take turns answering the door or phone, while keeping a record of contacts.
- Coordinate gifts of food.
- Arrange appropriate child care, if necessary.
- Consider special needs of the household and tasks that might be done by friends.
- Arrange hospitality for visiting relatives and friends.
- Prepare a list of distant persons to be notified by phone, letter, email, and/or printed notice, and compose a copy for each.
- Prepare a list of persons to receive acknowledgments of flowers, to receive a call, etc.

*Some of these tasks may be addressed before the death, if desired.*

# Summary of the Journey and How to Help

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## MONTHS BEFORE DEATH

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### Symptom

Withdrawal from world and loved ones

Decreased food intake

Sleeping more and communicating less

### Response

Allow peace and quiet.

Offer food but do not push.  
Give permission not to eat.

Provide comfort and reassurance.

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## WEEKS BEFORE DEATH

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### Symptom

Restlessness, agitation, confusion,  
and disorientation

Loss of bladder/bowel control

Talking to people who aren't there

Physical changes: change in vital signs  
and skin color, congestion, and breathing

Behavioral changes: not eating or drinking,  
sleeping a lot, awake at night, or sleeping  
during the day

### Response

Provide a safe environment; speak  
with the nurse about "rest medicine."

Use a catheter or incontinence briefs,  
as needed.

Provide support through gentle  
reassurance.

Provide comfort measures that  
include scheduled medicines and  
mouth care.

Provide comfort measures that  
include ice chips, back rubs, quiet  
music, or just sitting with your  
loved one.

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## DAYS OR HOURS BEFORE DEATH

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### Symptom

Physical symptoms increase, urine output  
decreases, breathing becomes more  
uneven, congestion worsens, and vital  
signs are weak

### Response

Continue comfort measures and just  
be there to offer gentle, quiet support  
and reassurance.

Give permission to let go.

**WHEN YOU THINK DEATH HAS OCCURRED, PLEASE CALL US.**

Hospice & Palliative Care Charlotte Region . . . . .	704.375.0100
Hospice & Palliative Care Lake Norman . . . . .	704.375.0100
Hospice & Palliative Care Lincoln County. . . . .	704.732.6146
Hospice Cleveland County . . . . .	704.487.4677
Hospice & Palliative Care Palmetto Region . . . . .	833.772.0556
Hospice & Palliative Care Palmetto Region - Laurens County. .	864.833.6287
Kids Path® . . . . .	704.375.0100
Levine & Dickson Hospice House - Huntersville . . . . .	704.375.0100
Levine & Dickson Hospice House at Aldersgate . . . . .	704.375.0100
Levine & Dickson Hospice House at Southminster. . . . .	704.375.0100
Testa Family Hospice House . . . . .	704.751.3918
Wendover Hospice House . . . . .	704.487.7018

*“We could not have asked for  
better care. My mother died with dignity,  
surrounded by her loving family, in her own bed.  
You made that all possible for her –  
thank you.”*

## REGIONAL LOCATIONS

### North Carolina

**Hospice & Palliative Care Charlotte Region**  
7845 Little Avenue • Charlotte, NC 28226

**Hospice & Palliative Care Lake Norman**  
705 Griffith Street, Suite 203 • Davidson, NC 28036

**Hospice & Palliative Care Lincoln County**  
900 Dontia Drive • Lincolnton, NC 28092

**Hospice Cleveland County**  
951 Wendover Heights Drive • Shelby, NC 28150

**Philip L. Van Every Learning Resource Center**  
6624 Walsh Boulevard • Charlotte, NC 28226

**Center for Palliative Care Advancement**  
7600 Little Avenue • Charlotte, NC 28226

### South Carolina

**Hospice & Palliative Care Palmetto Region**  
1057 Red Ventures Drive, Suite 150 • Fort Mill, SC 29707

**Hospice & Palliative Care Palmetto Region - Laurens County**  
1304 Springdale Drive • Clinton, SC 29325

### Inpatient Care Facilities

**Hospice & Palliative Care Palmetto Region - Laurens County Hospice House**  
1304 Springdale Drive • Clinton, SC 29325

**Levine & Dickson Hospice House - Huntersville**  
11900 Vanstory Drive • Huntersville, NC 28078

**Levine & Dickson Hospice House at Aldersgate**  
1825 Eastway Drive • Charlotte, NC 28205

**Levine & Dickson Hospice House at Southminster**  
8919 Park Road • Charlotte, NC 28210

**Testa Family Hospice House**  
321 Kings Mountain Boulevard • Kings Mountain, NC 28086

**Wendover Hospice House**  
953 Wendover Heights Drive • Shelby, NC 28150

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**PO Box 470408, Charlotte, NC 28247**  
**704.375.0100**

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**[hpccr.org](http://hpccr.org) • [hpcpr.org](http://hpcpr.org) • [hospicecares.cc](http://hospicecares.cc)**

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