



# Guide For Caring



HOSPICE OF CINCINNATI



## OUR MISSION

HOC Navigators / Hospice of Cincinnati creates the best possible and most meaningful advanced illness and end-of-life experience for all who need care and support in our community.

This booklet has been written as a guide to help you understand what to expect as the illness progresses. If you have any questions while reading this book, please make a notation and ask or call a Hospice of Cincinnati nurse. We will be happy to discuss any areas that may be of concern to you or your loved ones.



**About HOC Navigators**—Our programs include Hospice of Cincinnati, PalliaCare® Cincinnati, Hospital and Clinic-Based Palliative Medicine, Conversations of a Lifetime®, Social Connections, and The Goldstein Family Grief Center. Fernside, a 501(c)(3) organization, is an affiliate of Hospice of Cincinnati. Hospice of Cincinnati is a non-profit hospice sponsored by Bethesda Inc. in a collaborative community partnership with TriHealth and Bon Secours Mercy Health.

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## Let's begin...

Talking with loved ones openly and honestly gives everyone a shared understanding about what matters most at the end of life. Now is the time to make sure affairs are in order, key information is retrieved, and wishes are discussed, identified and understood.

Knowing the answer to the following questions may be very helpful to begin the conversation of a lifetime and help you meet the end-of-life wishes of your loved one.

- What is your understanding of where you are and of your illness?
- What does a good day look like?
- What are your fears or worries?
- What are your goals and priorities, what are you hoping for?
- What are you willing to give up and what are you not willing to sacrifice?

## If you think you have an emergency, call us first at 513-891-7700 and ask to talk to a nurse.

Our Support Team of Registered Nurses work regularly scheduled weeknight shifts, weekends and holidays, to help you when you need it most. Our Blue Ash Navigation Center is waiting for your call – anytime, day or night – to answer questions and help manage your emergency needs either by phone or by sending a nurse to your home.

## Call us if you:

- See a change in condition of any kind, feel you are in crisis or if you feel the end is near
- Have a question or concern; need help making decisions; or are uncertain about a medication, what to do about pain control, constipation, trouble breathing or any other symptom or discomfort

## Call us first if you:

- A. Feel the need to call your doctor
- B. Are thinking about calling 911
- C. Are considering going to the ER

We honor your wishes to remain at home by providing the care needed to control symptoms, alleviate the crisis and make a plan to manage future medical symptoms.

## Things to Think About and Important Documents to Gather

### Notifications

Attorney/executor of estate  
Employer of family members  
Employer of deceased  
Veteran's Benefit Office  
Insurance agents  
Tax accountant  
Social Security  
Bank

### Insurance

Pre-need insurance  
Life insurance policies

### Tax/Mortgage/Auto

Income tax records  
Mortgages and notes  
Property deeds/auto titles

### Birth/Marriage/Military Records

Patient birth certificate  
Social Security card/ID card  
Children's birth certificates  
DD214 military discharge  
Passwords/Combinations  
Safe combination  
Safe deposit box (SDB)  
Location of keys for SDB

### Financial

Bank accounts  
Credit cards  
401K, IRA, retirement plan  
Investment documents

### Legal Documents

Last will and testament  
Power of attorney

## **When a person enters the final stage of the dying process, two different things happen at once.**

Physically, the body begins the final process of shutting down. Death occurs when all physical systems stop. Usually, this is an orderly and expected series of physical changes that may be stressful to witness, but are not considered medical emergencies. These physical changes are a normal, natural way the body prepares itself to shut down and the most helpful response is to provide physical comfort to the patient.

The second dynamic of the dying process is emotional and spiritual. The dying person may express a need to complete unfinished business. They begin to let go, and may withdraw from family members. These events are normal and natural. The most helpful response to these changes is that of acceptance, understanding and support in carrying out the emotional and spiritual wishes of the dying person.

Sometimes a person's body is ready to stop, but the person may have unresolved matters with a significant relationship. Some people feel that the person may struggle to finish what is left undone. This may occur even though they may be very uncomfortable or debilitated. On the other hand, when a person is resolved emotionally and spiritually and ready for this release, the person will continue to live until the physical shut down is completed.

The experience we call death occurs when the body completes the natural process of shutting down and the emotional and spiritual processes are over. The hope is that these processes will come together in a way that matches the values, beliefs and lifestyle of the dying person so that death occurs as a peaceful release.

To help you prepare for this loss, the members of your Hospice of Cincinnati care team want you to know what to expect. We also want you to know how to respond in ways that will help your loved one accomplish this transition with your support, understanding and presence. These are the great gifts of love you can offer them as death approaches.

The following physical, emotional and spiritual signs of approaching

death are listed to help you understand what naturally may happen and how you can respond. Not all of these signs and symptoms will occur with each person, nor will they occur in a particular order. Each person is unique and whatever has been most typical of your loved one will affect this final stage. This is not a time to try to change the person, but a time to give full acceptance, support and comfort.

Our goal is to make the patient and family as comfortable as possible. We will work as a team. Please do not hesitate to call with any questions, comments or concerns.

## Normal Physical Signs and Helpful Responses

### **Pain**

The patient may have pain. The management of pain will be a priority. Ongoing assessments will occur and your doctor will make the appropriate medication changes. Pain medications may change in regards to how often, how much or the way the medication is given.

Caregivers can be of significant help because they may notice small changes and detect signs sooner, which should be communicated to the hospice nurse. You can reach a registered nurse who will address your concerns 24 hours a day by calling 513-891-7700.

### **Fluid and food decreases**

Your loved one may want little or no food or fluid and usually will not feel hunger or thirst. This means that the body is saving energy for other functions. IV fluids and tube feedings are usually not recommended, since the body is shutting down and not using nutrition as it normally would. Added fluids often causes more congestion and swelling. Your doctor will order the appropriate management. Do not try to force patients to take food or fluids or try to coax them into eating or drinking. This only causes more discomfort. Instead, offer small chips of ice, soft drinks, juice and popsicles. Cater to the likes and wishes of your loved one.

Avoid the use of petroleum jelly when oxygen is in use (it is a fire hazard). Lip balms with petroleum are also dehydrating to the lips. Search for a petroleum-free lip balm if appropriate. EOS Organic Lip Balm Sphere and Burt's Bees are two that are widely available. Swabs can keep the mouth and lips moist and comfortable. The lips and mouth may need to be moistened every hour or two, especially if the patient is breathing through the mouth.

### **Restlessness**

The patient may make restless or repetitive motions. This often happens and is related to the progression of disease. Do not interfere with or try to restrain such motions. Try to establish a calm atmosphere; speak in a quiet, natural way; and eliminate bright lights. Look for calming things to do. Giving a gentle back rub stroking the arms or forehead, reading aloud or playing soothing music may help. If the patient is still restless, contact your Hospice of Cincinnati nurse to discuss the use of medication to relax and comfort your loved one.

### **Urine decrease and incontinence**

Urine output often drops because the person may be drinking less and there is a decrease in circulation through the kidneys which make urine.

The patient may lose control of urine as they become weaker. Discuss this with your Hospice of Cincinnati nurse to learn what can be done to keep the bed dry and the patient clean and comfortable.

### **Bowel management**

There may be a loss of bowel control or constipation. Your nurse will instruct you on care related to these issues.

### **Disorientation**

Your loved one may seem to be confused about the time, place and identity of people. Identify yourself by name before you speak softly, clearly and truthfully when you need to communicate.



For example: “Dad, it’s Debbie. It’s time to take your medication, so you won’t have pain.” Be honest. Don’t try to force or trick them into taking medications, even though you may feel you only are acting in the patient’s best interest. The trust between the patient and caregiver is too important to jeopardize. Talk with your hospice nurse about this.

## **Congestion**

Your loved one may have gurgling, bubbling or rattling sounds coming from the chest or throat. This is normal and is due to poor circulation of normal body fluids, immobility and an inability to cough up secretions. Elevate the patient’s head and gently turn it to the side, allowing gravity to drain the secretions. Your nurse can instruct you. Congestion often is distressing to listen to, but usually is not uncomfortable for your loved one. Generally, suctioning is not recommended.

## **Sleeping**

Your loved one may spend more time sleeping and appear to be unable to speak, withdrawn or unresponsive. This normal change is due in part to changes in the body’s metabolism. Spend time with them; hold hands. Speak to them as you normally would, even though there may be no response. Don’t say anything that you would not want them to hear.

## **Coolness**

The person’s hands, arms, feet and legs may become increasingly cool to the touch and the color of the skin may change. This is a normal sign indicating that circulation of blood to the body’s limbs is reduced. Keep the person warm, dress and cover them as you normally would. Socks may help keep the feet warm. Avoid using an electric blanket. While this coolness is uncomfortable for us as caregivers, it is generally not uncomfortable for the patient.

## **Breathing pattern change**

The regular breathing pattern of the patient will change. Breathing may stop for several seconds at a time. This is normal in the dying process and is not uncomfortable or noticed by the patient. Hold hands, speak gently and be reassuring.

## Normal Emotional / Spiritual Signs and Symptoms, and Appropriate Responses

### **Withdrawal**

Your loved one may seem withdrawn or in a coma-like state. This may indicate preparation for release — a detaching from surroundings and relationships and a beginning of letting go. Since hearing remains to the end, speak to your loved one in a normal tone of voice, identify yourself by name when you speak, hold hands, and say whatever you need to say. Try not to overwhelm the patient with questions that may fatigue them. Limit visitors to what is comfortable to the patient.

### **Vision-like experiences**

Your loved one may speak to or claim to have spoken to people who already have died, or to see or have seen places not visible to you. If you are unable to gently re-orient them, this may mean that they are beginning to detach from this life and are preparing for their transition. Do not contradict, explain away, or argue about what they claim to have seen or heard. Just because you cannot see or hear what they say they do, this does not mean it's not real to your loved one. This is a common experience. If these experiences are frightening to your loved one, explain that they are normal and contact the Hospice of Cincinnati nurse if the patient remains anxious or frightened.

### **Restlessness**

Your loved one may perform repetitive and restless tasks. Your hospice team members will assist you in identifying what may be happening and will assist you in finding ways to help them find release from tension or fear. Other things that may help you to calm your loved one are to recall a favorite place or experience, read something comforting, play music, or give assurance that it is okay for them to let go.

## **Decreased socialization**

Your loved one may only want to be with a few people or just one person. The dying person has limited energy to deal with socialization. This withdrawal and detachment occurs as they become more involved in making the transition, a journey that must be made alone. Do not interpret this as a rejection or lack of love, but a natural part of the dying process which everyone must go through. They need your support and permission. You especially may feel the need for your hospice nurse at this time.

## **Unusual communication**

Your loved one may make an out of character statement, gesture or request. This may indicate that they are ready to say goodbye and are testing to see if you are ready to let them go. Accept the moment as a beautiful gift when it is offered. Kiss, hug, hold, cry and say whatever you need to say.

## **Giving permission**

Giving permission to your loved one to let go is very difficult. A dying person may try to hold on in order to be sure that those who are going to be left behind will be all right. Try to reassure your loved one it's all right to let go whenever they are ready.

## **Saying goodbye**

Saying goodbye is a process that seems to promote closure. You may want to touch or hold them or do whatever is and has been a comfort to you both. The moment may include recounting favorite memories, places and activities you shared. It may include saying "Please forgive me..." "I forgive you..." "Thank you..." and "I love you." The dying person may wish to know that they have made a difference in their life and that they will be remembered. Tears are a normal and natural part of saying goodbye. There is no need to hide or apologize for your tears.

## Finally

Although the impending death is difficult for you, it is not a medical emergency and does not require emergency treatment. You and your Hospice of Cincinnati team have worked together to allow your loved one to die in comfort without extraordinary treatments. Now is the time to reach out to your support systems.

The signs of death include such things as no breathing, no heartbeat, possible release of bowel and bladder contents, no response, eyes fixed on a certain spot, mouth slightly open. When these signs are noted, call the hospice nurse at 513-891-7700, regardless of the hour.

## When the Time Comes, What You Should Know

1. **Call us first.** Hospice of Cincinnati, 513-891-7700, anytime day or night.
  - A. A nurse will come as soon as possible to confirm the time of death and notify the attending physician.
  - B. A nurse will contact a funeral home for transportation of your loved one into their care.
  - C. Special equipment pick-up: Hospice of Cincinnati staff will call the medical equipment company for pick-up. The company should call to verify a pick-up time; however, you may not recognize the phone number so it's important that you answer their call.
  - D. All controlled substances/narcotics must be counted and disposed of in the home by a nurse and a witness.
2. **Connect with the funeral home.** They may have some basic questions that will better prepare them to care for your loved one. They will schedule a time to finalize arrangements with you.

3. **Contact clergy/celebrant.** After arrangements are made with the funeral home, contact clergy/celebrant at the place of worship or the venue for the service, (the funeral home can assist you with this).
4. **Notify loved ones.** Inform family and friends of the death.
5. **Notify others.** Alert attorney/executor of the estate, employer, employer for family members, and insurance agents.
6. **Obtain death certificate.** The death certificate comes from the funeral home after the attending physician has signed it.

**NOTE:** If your loved one preregistered for body donation, Hospice of Cincinnati will call the designated body donation program. The family is responsible for the transportation fee and cost of death certificates.

*We greatly admire you for supporting your loved one. Our hope is that we can be helpful to you during this difficult time. The information in this booklet may decrease some of the anxiety you may feel. Remember, the staff and volunteers of Hospice of Cincinnati are available to help you. Please call us with your questions or concerns.*

## And after...

We believe the death of a loved one can be a meaningful experience with the support and guidance of grief counselors. Through Hospice of Cincinnati's Goldstein Family Grief Center, we provide counseling for 13 months after the loss of a loved one. Families can still contact us for assistance after 13 months. All services through The Goldstein Family Grief Center and Fernside are free of charge.



**GOLDSTEIN FAMILY  
GRIEF CENTER**

Services through **The Goldstein Family Grief Center** include individual, family and group counseling.



**FERNSIDE**  
CENTER FOR GRIEVING CHILDREN

**Fernside—A Center for Grieving Children** offers support for children, teens and families in the Tristate area. Using expressive arts and peer groups, families learn to cope with loss due to the death of a loved one.



You may need us now.

You may need us  
months from now.

Whenever you need us,  
we are here to help.

Please don't hesitate to call us.  
513-891-7700



**HOSPICE OF  
CINCINNATI**

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**HOC NAVIGATORS**<sup>SM</sup>

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