



# Guide for Caring



Hospice  
of Cincinnati

Experience. Compassionate. Caring.<sup>SM</sup>

### Our Mission

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

### Our Vision

*Through the leadership of Hospice of Cincinnati, our region embraces the value of end-of-life care and planning, and relies on HOC for the highest quality end-of-life and bereavement services. We are recognized for providing compassionate physical, emotional and spiritual care in an atmosphere of sensitivity and respect.*

### Values

<i>Compassion</i>	<i>Stewardship</i>
<i>Respect</i>	<i>Inclusion</i>
<i>Excellence</i>	<i>Integrity</i>
<i>Teamwork</i>	<i>Patient/Family Centered</i>

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.

## GUIDE FOR CARING

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**W**hen a person enters the final stage of the dying process, two different dynamics that are closely related are at work. Physically, the body begins the final process of shutting down. Death occurs when all physical systems cease to function. Usually, this is an orderly and undramatic series of physical changes that may be stressful to observe, but are not considered medical emergencies. These physical changes are a normal, natural way in which the body prepares itself to shut down and the most appropriate kind of response to this process 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 also may withdraw from family members. These events are normal and natural. The most appropriate kind of 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 still is unresolved to some important issue or with some 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 its natural process of shutting down and the emotional and spiritual processes are reconciled. The hope is that these processes will come together in a way that is appropriate for the values, beliefs and lifestyle of the dying person so that death occurs as a peaceful release.

Therefore, 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 impending death are listed to help you understand the natural occurrences that may happen and how you can respond appropriately. Not all of these signs and symptoms will occur with each person, nor will they occur in a particular sequence. Each person is unique and whatever has been most characteristic 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 or concerns.

## Normal Physical Signs and Symptoms and Appropriate Responses

**Pain** — The patient may have pain. The management of pain will be a priority. Ongoing assessments will occur and your physician will make the appropriate changes to medications. Pain medications may change in frequency, amount or the way the medication is given. Caregivers can contribute significantly because they may see subtle signs and detect changes sooner, which can 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 experience hunger or thirst. This means that the body is conserving energy for other functions. IV fluids and tube feedings are generally not recommended, since the body is shutting down and added fluids can cause more congestion and swelling. Your physician will order the appropriate management. Do not try to force patients to take food or fluids or try to manipulate 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 preferences of your loved one.

Petroleum jelly can be applied to dry lips. Swabs also 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.

**Urine decrease and incontinence** — The patient may lose control of urine as the muscles in that area relax. Discuss this with your Hospice of Cincinnati nurse to determine what can be done to protect the bed and keep the patient clean and comfortable. Urine output often declines because of decreased fluid intake as well as a decrease in circulation through the kidneys.

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

**Restlessness** — The patient may make restless or repetitive motions. This often happens and is due partially to the decrease in oxygen to the brain as well as metabolic changes. 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 backrub, stroking the arms or forehead, reading aloud or playing soothing music may help.

**Disorientation** — Your loved one may seem to be confused about the time, place and identity of people. This also is due, in part, to metabolic change. Identify yourself by name before you speak. Speak softly, clearly and truthfully when you need to communicate. For example: “It is 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 does not indicate discomfort for your loved one. Generally, suctioning is not recommended.

**Sleeping** — Your loved one may spend an increasing amount of time sleeping and appear to be noncommunicative, 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 extremities is decreasing and is being reserved for the most vital organs. Keep the person warm. Avoid using an electric blanket. Socks may help keep the feet warm.

**Breathing pattern change** — The regular breathing pattern of the patient may change. There may be periods of several seconds at a time when there is no breathing. This is a common experience. Elevating the head may help. 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.

**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 the 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.

**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 all right 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 process of death through which everyone must pass. 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 a seemingly out of character statement, gesture or request. This may indicate that they are ready to say good-bye 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 good-bye** — Saying good-bye 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 "I'm sorry for..." "Thank you for..." or some other phrase that has meaning to the two of you. The dying person may wish to know that they have made a difference and that they will be remembered. Tears are a normal and natural part of saying good-bye. Tears need not be hidden and apologies for them are not necessary.

## 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 without pain and/or extraordinary treatments. It is important to reach out to your support systems at this time.

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. The nurse will visit and verify that the death has occurred. The nurse will make the necessary official calls for you, including the call to the funeral home.

*What we once enjoyed and deeply loved  
we can never lose, for all that we love  
deeply becomes part of us.  
— Helen Keller*

**W**e at Hospice of Cincinnati 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.

*Hospice of Cincinnati is sponsored by Bethesda Inc. in a collaborative community partnership with TriHealth and Mercy Health Partners.*

*\*Hospice of Hamilton is an affiliate of Hospice of Cincinnati*

**513-891-7700 and 1-800-691-7255**  
**[HospiceofCincinnati.org](http://HospiceofCincinnati.org)**

