

## WHAT TO EXPECT

Additional information and support is available by contacting:



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[www.hospiceofwarrenco.org](http://www.hospiceofwarrenco.org)  
[www.hospiceofbutlerco.org](http://www.hospiceofbutlerco.org)

This booklet is designed to help prepare you for the death of a loved one, so that you can share your love and help your loved one in the transition known as dying.

Death occurs when the body completes its natural process of shutting down, and when the “spirit” completes its process of letting go. These two processes need to happen in a way appropriate and unique to the values, beliefs and lifestyle of the dying person.

When a person enters the final stage of the dying process, there are two dynamics involved. They are the physical dynamic and the emotional-spiritual-mental dynamic.

The body begins the physical process of shutting down in an orderly progressive series of events that are not medical emergencies and do not require invasive interventions. These physical changes are a normal, natural way for the body to prepare itself for death, and the most appropriate responses are comfort enhancing measures.

The emotional-spiritual-mental process also involves a series of normal and natural processes as the “spirit” begins to release from the body, its immediate environment and all attachments. This release also tends to follow patterns that may include the resolution of whatever is unfinished and the granting of permission to “let go” from family members. These “events” are also the normal natural way in which the spirit prepares to move from this existence to the next. The most appropriate responses to the emotional-spiritual-mental changes are those that support and encourage this release and transition.

When the body is ready and willing to die but there are still unresolved issues or significant relationships, a person may tend to linger even though uncomfortable and weak. When a person is emotionally-spiritually-mentally resolved and ready for release but his/her body has not completed the final physical process, the person will continue to live until the physical process of dying is completed.

## PHYSICAL SIGNS AND SYMPTOMS OF APPROACHING DEATH

The physical and emotional-spiritual-mental signs and symptoms that a person is nearing death listed here help you understand what is likely to happen and how you can respond. Not all of these symptoms will occur with every person, nor will they occur in any particular order. Each process is unique to each dying person. This is not the time to try and change your loved one but the time to give full acceptance, support and comfort.

The body prepares itself for the final stage of life in a variety of ways.

### COOLNESS

The hands, arms and feet, and then legs may become increasingly cool to the touch and the color of the skin may change. The underside of the body may become darker and the skin mottled. This is a normal indication that the circulation of the blood is decreasing to the hands, arms, legs and feet and is being reserved for the most vital organs. Keep the person warm with a blanket, but do not use an electric one.

### SLEEPING

The person may spend an increasing amount of time sleeping and be difficult to awaken. They may not talk much or respond when spoken to. This normal change is due in part to changes in body metabolism. Sit with your loved one, hold his/her hand or speak during those times when he or she seems most alert or awake. Do not talk about the person in his or her presence. Speak directly to him or her as you normally would, even if there is no response. Never assume the person cannot hear. Hearing is one of the last of the senses to be lost.

### DISORIENTATION

Confusion about time, place, and identity of those surrounding the person, even those close and familiar, is common. This is due to metabolism changes. Identify yourself by name before you speak rather than asking the person to guess who you are. Speak softly, clearly and truthfully when you need to tell the person something important for his/her comfort, such as “It is time to take your medication,” and explain the reason why, “so you won’t begin to hurt.” Do not use this method to try and manipulate the patient to meet your needs.

### INCONTINENCE

Loss of control of urine and bowel as the muscles relax can be expected. Caregivers can help to protect the bedding and keep your loved one clean and comfortable.

### CONGESTION

As the person takes in less fluid, they may be unable to cough up normal secretions. As a result, there may be gurgling sounds that can be heard from the chest. The gurgling may sound like marbles rolling around inside and sometimes can become very loud. The sound of congestion does not indicate the onset of severe or new pain. Suctioning the secretions usually only increases them and causes more discomfort. Instead, gently turn the person’s head to the side and allow gravity to drain the secretions naturally. You may also gently wipe the mouth with a moist cloth.

### RESTLESSNESS

Changes in oxygen circulation to the brain and changes in metabolism can cause the person to make restless and repetitive motions such as pulling at bed linen or clothing. Do not try to stop or interfere with such motions. To help calm the person, speak in a quiet natural way, lightly massage the forehead, read to the person or play some soothing music.

## FLUID AND FOOD DECREASE

The body naturally begins to conserve energy and the person may want little or no food or fluid. Do not try to force food or drink on your loved one, and do not try to use guilt to make them eat or drink. This only adds to their discomfort. Offer small chips of ice or frozen juice that might be refreshing in the mouth. If the person is unable to swallow, fluids can be given in small amounts by syringe. A cool, moist washcloth on the forehead may also increase physical comfort.

## URINE DECREASE

Urine output will decline as fluid intake declines and as the circulation through the kidneys decreases. Urine may become “tea” colored. Ask the caregiver whether a catheter needs to be inserted or irrigated.

## CHANGES IN BREATHING

The regular breathing pattern may abruptly change. A common pattern called “Cheyne-Stokes” breathing involves shallow breaths with periods of no breathing for 5 to 30 seconds, up to a full minute. There may also be periods of rapid shallow, pant-like breathing. These patterns are common and mean the circulation is decreasing in the internal organs. Elevating the head or turning the person on his/her side may bring comfort. Speak gently and hold his/her hand.

## EMOTIONAL-SPIRITUAL-MENTAL SIGNS OF APPROACHING DEATH

### WITHDRAWAL

Your loved one may become unresponsive, withdrawn or in a comatose like state in preparation for “letting go” of surroundings and relationships. The sense of hearing remains strong to the very end, so speak to your loved one in your normal tone of voice, identify yourself by name when you speak, hold his/her hand. Say whatever you need to say that will help the person “let go.”

### VISION-LIKE EXPERIENCES

The person may speak or claim to have spoken to persons who have already died, or to see or have seen places not visible to you. These are not hallucinations or drug reactions. The person is beginning to let go from this life and is preparing for the transition so it will not be frightening. Do not explain away, belittle or argue about what the person claims to have heard or seen. Just because you cannot see or hear it does not mean it is not real to your loved one. Affirm his or her experience. They are normal and common. If they frighten your loved one, explain that they are normal.

### RESTLESSNESS

Performing repetitive and restless tasks may mean something is still unresolved or unfinished that is preventing the person from letting go. Caregivers can help in identifying ways to help the person find release from the tension or fear. Reading, playing music or recalling a favorite place or experience may calm the person. Offer reassurance that it is okay to let go.

## DECREASED SOCIALIZATION

In preparation for letting go, the person may only want to be with a very few or even just one person. If you are not included in this “inner circle” at the end, it does not mean you are not loved or are unimportant. It means you have already fulfilled your task with your loved one and it is time for you to say “good-bye.” If you are part of the final “inner circle” of support, your loved one needs your affirmation, support and permission to let go.

## UNUSUAL COMMUNICATION

Sometimes a dying person make a statement, gesture or request that is “out of character.” This indicates he/she is ready to say “good-bye” and is “testing to see if you are ready to let him/her go. Accept the moment as a beautiful gift when it is offered. Kiss, hug, hold, cry and say whatever you need most to say.

## HOW TO HELP AS DEATH APPROACHES

### GIVE PERMISSION

A dying person will often try to hold on, even though it brings prolonged discomfort, in order to be sure that those who are going to be left behind will be alright. Giving permission to your loved one to let go without making him/her feel guilty for leaving or trying to keep him/her with you to meet your own needs can be difficult. Your ability to release the dying person from such concerns and offer assurance that its all right to let go whenever he/she is ready is one of the greatest gifts you have to offer at this time.

### SAY GOOD-BYE

Saying good-bye is your final gift of love, offering closure and allowing your loved one to let go. It may be helpful to be physically close to the person and hold him/her or hold his/her hand as you say everything you need to say. It may be as simple as saying “I love you.” It may include describing favorite memories, places and activities you’ve shared. It may include saying “I’m sorry for whatever tensions or difficulties I added to our relationship.” It may also include saying “Thank you for...” Tears are a normal and natural part of saying good-bye. Tears do not need to be hidden from your loved one apologized for. Tears express your love and help you to let go.

You will have helped your loved one find comfort and peace. This is your final and most important gift.

