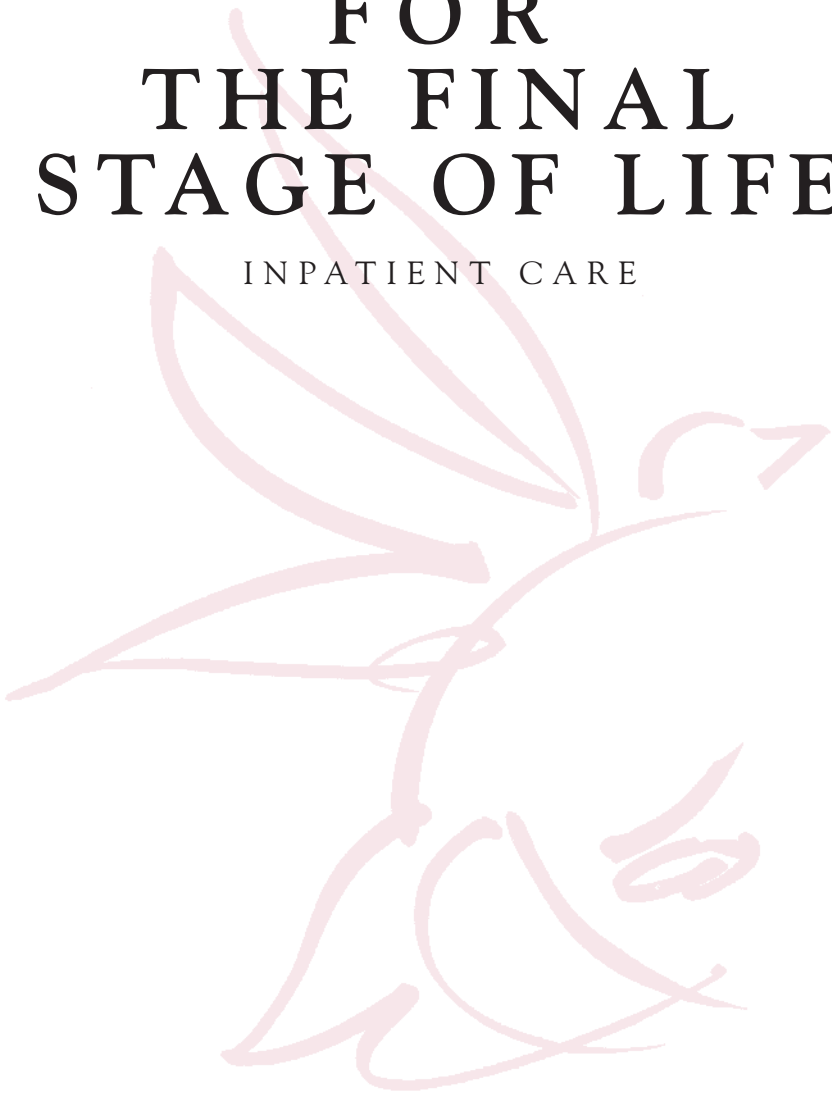


PREPARING FOR THE FINAL STAGE OF LIFE

INPATIENT CARE



THE CENTER FOR
HOSPICE &
PALLIATIVE CARE

The Hospice staff acknowledges that this particular period of time is one of the most difficult times you and your family will have to live through. Our approach in all matters affecting you during this time is to be as honest and straightforward as possible. In this way, the Hospice team members can establish a trusting and open communication relationship with your family member who is very ill and the members of your family who are concerned about the possibility of impending death. Our philosophy of care is that the “fear of the unknown” is always greater than the “fear of the known”. In this vein, we offer you this booklet of information to help you prepare and anticipate symptoms which are indicative of approaching death. Your Hospice nursing staff, social workers, chaplains and physicians are your best resources to help you clarify your concerns about this information. **Not all these symptoms will appear at the same time and may never appear.** We want to relate each possible symptom to you in order to decrease your fear if one should appear suddenly. All the symptoms described are indicative of how the body prepares itself for the final stage of life.

When a person enters the final stage of the dying process, two different dynamics which are closely interrelated and interdependent are at work.

On the physical plane, the body begins the final process of shutting down. This will end when all the physical systems cease to function. Usually, this is an orderly and progressive series of physical changes, and not medical emergencies requiring invasive interventions. These physical changes are the normal, natural way in which the body prepares itself to stop, and the most appropriate kinds of responses are comfort-enhancing measures.

The other dynamic of the dying process is at work on the emotional-spiritual-mental plane, and is a different kind of process. The “spirit” of the dying person begins the final process of release from the body, its immediate environment, and all attachments. This release also tends to follow its own priorities, which may include the resolution of

unfinished practical matters, and receipt of permission to “let go” from family members. These “events” are the normal, natural preparations the spirit makes to move from this existence into the next dimension of life. The most appropriate kinds of responses to the emotional-spiritual-mental changes are those that support and encourage release and transition.

When a person’s body is ready to stop, but the person feels unresolved or unreconciled about an important issue or a significant relationship, the patient may tend to linger, even though uncomfortable or debilitated, in order to finish what needs to be finished. On the other hand, when the patient is emotionally-spiritually-mentally resolved and ready for this release, but his/her body has not completed its final physical process, 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 spirit completes its natural processes of reconciling and finishing. These processes need to happen in a way that is appropriate and unique to the values, beliefs, and lifestyle of the dying person. Therefore, as you seek to prepare yourself for the approach of this event, we want you to know what to expect and how to respond in ways that will help your loved one accomplish the transition with support, understanding, and ease. This is the great, loving gift you have to offer your loved one as death approaches.

This listing of the physical and emotional-spiritual-mental signs and symptoms of impending death is offered to help you understand the natural kinds of things that may happen and how you can respond appropriately. All of these signs and symptoms will not occur with every person, nor will they occur in any particular sequence. Each person is unique, and needs to do things in his/her own way. This is not the time to try to change your loved one; it is the time to give full acceptance, support and comfort.

The physical signs and symptoms that follow describe the body's methods of preparing itself for the final stages of life:

3 Coolness:

The patient's hands, arms, feet and legs may be increasingly cool to the touch and, at the same time, the color of the skin may change. The lower part of the body may become darker and the skin may be mottled. This is a normal indication that the circulation of blood to the body's extremities is decreasing, and that it is being reserved for the most vital organs.

3 Sleeping:

The person may spend an increasing amount of time sleeping, may appear to be uncommunicative or unresponsive, and may, at times, be difficult to arouse. This normal condition is due, in part, to changes in the body's metabolism. Sit with your loved one, and hold his/her hand. Do not shake the person or speak loudly; speak softly and naturally. Plan to spend time with him/her during those times when he/she seems most alert or awake. Even though there may be no response, speak to the patient directly as you normally would. Do not talk about the person in his/her presence. Never assume the person cannot hear; hearing is one of the last senses to be lost.

3 Disorientation:

The patient may seem to be confused about time, place, and the identity of people surrounding him/her - even close and familiar people. This also is due, in part, to metabolism changes. Identify yourself by name as you begin to speak, rather than asking the person to guess who you are. Speak softly, clearly, and truthfully when you need to communicate something important for the patient's comfort ("it is time to take your medication"), and explain the reason for the communication ("so you won't begin to hurt"). Do not use this method to try to manipulate the patient to meet your needs.

3 Incontinence:

The patient may lose control of urine and/or bowel material as the muscles in that area begin to relax. The nursing staff may suggest a catheter to eliminate urinary incontinence, keeping your loved one clean and more comfortable.

Congestion:

You may notice gurgling sounds coming from the patient's throat; you may have heard people refer to a "death rattle". This rattling of oral secretions usually does not cause discomfort to the patient or interfere with breathing, but the sound may be upsetting to hear. This normal change is due to the decrease in fluid intake and the inability to cough up normal secretions which collect in the back of the throat. Suctioning usually only increases the secretions and causes sharp discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You also may wipe the mouth gently with a moist cloth. The sound of the congestion does not indicate the onset of severe or new pain. Medicines may help relieve these symptoms - discuss them with the nurse.

Restlessness:

The patient may make restless and repetitive motions, such as pulling at bed linen or clothing. This often happens and is due, partly, to the decrease in oxygen circulation to the brain, and to metabolism changes. Do not interfere with or try to restrain such motions. To have a calming effect, speak in a quiet, natural way, lightly massage the forehead, read to the person, or play some soothing music.

Fluid and Food Decrease:

The patient may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve the energy normally expended on these tasks. Do not try to force food or drink into the person, or try to use guilt to manipulate them into eating or drinking something. This only makes the person much more uncomfortable. Small chips of ice, or juice may be refreshing in the mouth. A cool, moist washcloth on the forehead may also increase physical comfort. At this time patients tend to consume less than 25% of the amount of food and fluids that were required to maintain bodily functions, yet the near starvation diet seems to maximize their quality of life and they experience no sensation of hunger. Patients often develop nausea or abdominal pain when they eat or drink in an attempt to please their loved ones. Lemon glycerine swabs or moistened sponge swabs help keep the mouth moist and more comfortable.

Urine Decrease:

The person's urine output normally decreases, and may become tea-colored, referred to as concentrated urine. This is due to the decreased fluid intake and a decrease in circulation through the kidneys.

Breathing Pattern Change:

The patient's regular breathing pattern may change to a different pace. A particular pattern of irregular breathing may be noticed: a shallow breath, then periods of no breathing for 5 to 30 seconds - up to a full minute. The person also may experience periods of rapid, shallow, pant-like breathing. These patterns are very common and indicate a decrease in circulation in the internal organs. Hold the person's hand and speak gently. There is a natural tendency to think oxygen therapy is needed, but it is rarely helpful. Elevating the head, and/or turning the person on his/her side may bring comfort.

Emotional-Spiritual-Mental Signs and Symptoms of Approaching Death:

Withdrawal:

The patient may seem unresponsive, withdrawn, or in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships, and the beginning of “letting go”. Since hearing remains until near the end, speak to your loved one in your normal tone of voice, identify yourself by name when you speak, hold his/her hand, and say whatever you need to say to help the person let go. Allow the patient to choose how and with whom to spend time.

Vision-like Experiences:

The patient may speak, or claim to have spoken, to persons who have already died; or may see, or claim to have seen, places not presently accessible or visible to you. The person is beginning to detach from this life and is being prepared for the transition so that it will not be frightening. Do not contradict, explain away, belittle, or argue about what the person claims to have seen or heard. Your own inability to see or hear such things does not mean that they are not real to your loved one. Affirm his or her experiences. They are normal and commonly occur.

Restlessness:

The person may perform repetitive and restless tasks. This may indicate that something is still unresolved or unfinished that is disturbing the patient, and preventing his or her letting go. Your Hospice nurse or social worker can assist you in identifying what may be happening, and can suggest how you might help the patient find release from tension or fear. Other things which may be helpful in calming the person: recalling a favorite place or a favorite experience the person enjoyed, reading something comforting, playing music, and giving assurance that it is okay to let go. More severe agitation can be relieved with medications; discuss this with the nurse.

Decreased Socialization:

The patient may want to be with very few or just one person. This is a sign of preparation for release, and an affirmation of those from whom support is most needed in order to make the appropriate transition. If you are not part of this “inner circle” at the end, it does not mean you are not loved or are not important. It means you have already fulfilled your task with the patient and it is time for you to say goodbye. If you are part of the final “inner circle” of support, the patient needs your affirmation and permission.

3 Unusual Communication:

The person may make a seemingly out of character or non sequitur statement, gesture, or request. This indicates that he/she is ready to say goodbye 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 most need to say.

3 Giving Permission:

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. A dying person normally will 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. Therefore, your ability to release the person from this concern and give him/her assurance that it's okay to let go whenever he/she is ready is one of the greatest gifts you have to give your loved one at this time.

3 Saying Goodbye:

When the person is ready to die, and you are able to let go, it is time to say goodbye. Saying goodbye is your final gift of love to the patient, for it achieves closure and makes the final release possible. It may be helpful to lie in bed with the person and hold him/her, or to take the person's hand and say the things you need to say. This might be as simple as saying "I love you" or "Thank you for...". It might include recounting favorite memories, places, and activities you shared. It may be saying "I'm sorry for..."; "We'll miss you, but it's okay to go"; "We'll always love you and we'll be okay".

Tears are a normal and natural part of saying goodbye. They need not be hidden from your loved one, and you need not apologize for them. Tears express your love and help you let go.

How Will You Know When Death Has Occurred?

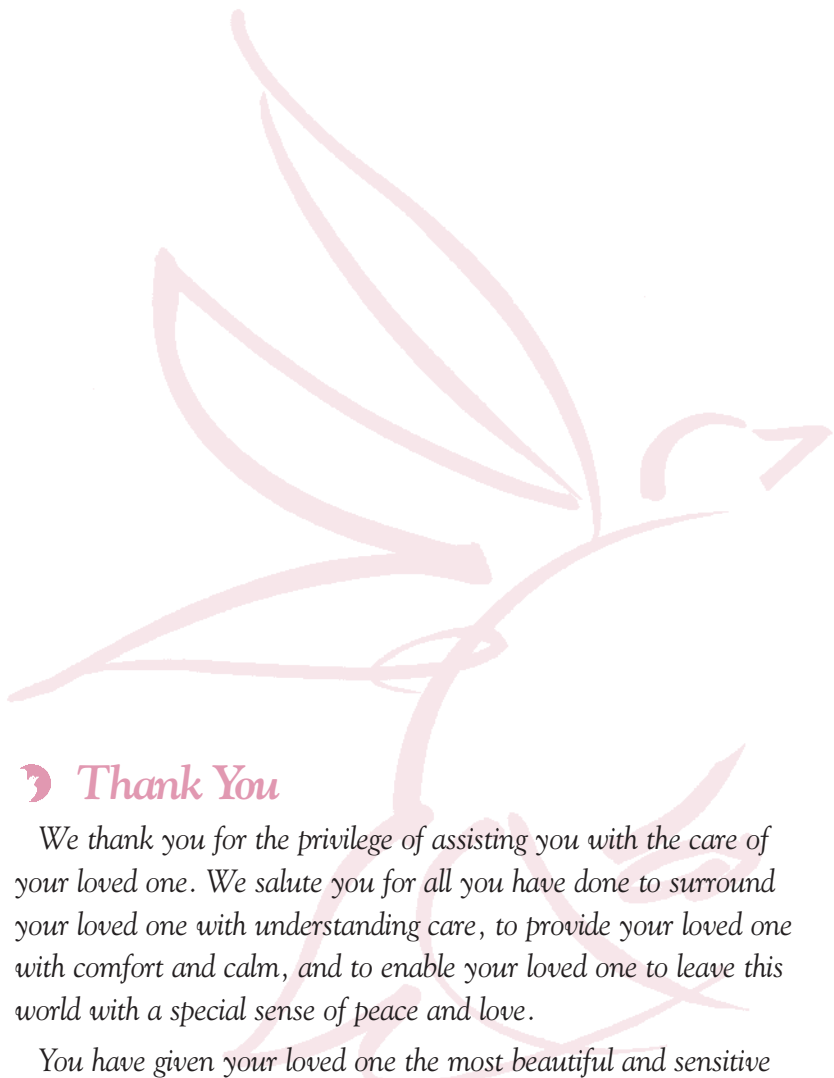
Although you may be prepared for the dying process, you may not be prepared for the actual moment of death. It may be helpful if you and your family think about and discuss what you will do if you are present when death occurs.

The signs of death include:

- 3** No breathing
- 3** No response to verbal or physical stimuli
- 3** No heartbeat
- 3** Jaw relaxed and slightly open
- 3** Eyelids may be slightly open, and fixed on a certain spot, no blinking.

The death of a Hospice patient is not an emergency. There is no need to hurry to do anything. It is important to take the time to say a final good-bye.

If we are not with you at the time, please call a staff member when death occurs. The body does not have to be moved until you are ready. Hospice will call the funeral home when the family wishes. A referral for bereavement care will be made by the Hospice staff.



Thank You

We thank you for the privilege of assisting you with the care of your loved one. We salute you for all you have done to surround your loved one with understanding care, to provide your loved one with comfort and calm, and to enable your loved one to leave this world with a special sense of peace and love.

You have given your loved one the most beautiful and sensitive gifts we humans are capable of, and in giving that gift, have given yourself a wonderful gift as well.

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