



Caring for Jefferson County Since 1985

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PREPARING FOR THE FINAL STAGE OF LIFE

*“You don’t have to do or say
something to make things better.
Just be there as fully as you can.”*

-Sogyal Rinpoche

Dear Caregiver,

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 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 approaching death.

Our philosophy of care is that the “fear of the unknown” is always greater than the “fear of the known.” Therefore we offer you this booklet of information to help you prepare and anticipate symptoms which signal 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 some 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 indicate (or) are indicators of how the body prepares itself for the final stage of life.

Thank you,

Your Hospice Team

The Final Stage of Life's Journey

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.

What You Can Do

When you are caring for someone who is seriously ill, you may experience many different emotions. At times, you may be very thankful for the time you are spending together. At other times, you may feel overwhelmed, unsure or afraid. All these emotions are normal and expected. You have a tool in your hand right now that will help.

Use the Team

This handbook will help guide you through much of what to expect when caring for someone who is seriously ill. It will give you concrete steps to take to be confident that you are providing the best care possible. Beyond this handbook, however, your Hospice Team is ready to answer your questions, help you make sense of what you are experiencing and navigate you through this time. Always know that you are part of an expert Hospice Team and you can do this!

Relax

The first step to take usually is allowing yourself to relax when feeling anxious. Taking a moment to take a few slow breaths and focus on what needs to be done can make a world of difference. Your level of anxiety often transfers to those around you, so if you can stay relaxed, that will ease your loved one's anxiety as well.

Be Present

Perhaps the most powerful tool you have is your presence and your companionship. You hold a unique place in your loved one's life, a place that no one else on the care team can fill. Just being present is often the strongest of medicines and the greatest of comforts.



What You May Encounter Throughout the Illness

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 of Approaching Death

Pain

For many families, pain is the most feared symptom when facing a life-threatening illness. Most pain can be controlled with the medications provided by the physician. Your Hospice Nurse will frequently ask questions to determine the location, severity and duration of pain. It is important to answer these questions honestly so the Nurse can notify the physician and get the most effective medications ordered. Many times a combination of medications will be necessary to control the pain and often increases in the medications will be needed as the disease progresses.

Weakness

As an illness progresses, many people will experience increasing weakness. This is a common symptom but may present several challenges in providing care. You may notice that your loved one tires after little activity. Tasks which once were simple may become extremely tiring. In most cases, the weakness will progress. At this time questions will naturally arise regarding further testing or options. Treatments (e.g. blood transfusions, certain medications, and other therapies) that have worked in the past may no longer provide enough comfort or relief. It may be helpful to have an open, honest discussion with your Hospice Team and your physician regarding the risks and benefits of treatments.

- Try to prioritize activities which are important. If visitors are coming you may want to plan for a quiet time earlier in day to conserve energy.
- Plan frequent rest periods into the daily routine. Even the process of taking a bath or shower can be physically draining.

The primary concern for weakened patients is safety. If you notice your loved one is beginning to have poor balance or stumble, it may be time to try an assistive device such as a walker or wheelchair. Your team can assist you in determining the right time, the right equipment, and how to obtain that equipment.

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.

Nausea/Vomiting

Nausea can be considered the sensation of sickness in the stomach. Nausea can happen alone or with vomiting. Identifying the cause or causes and treating the symptoms quickly is important. The treatments may include fresh air, applying a cool compress to the person's forehead, avoiding heavy odors, and/or offering small meals. There are medications that may need to be ordered to treat the symptoms. If these suggestions do not work, talk with your Hospice Nurse.



Difficulty Breathing/Shortness of Breath

With some diseases, a person may become short of breath with exertion and even at rest. 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. There is a natural tendency to think oxygen therapy is needed, but it is rarely helpful.

- Hold the person's hand and speak gently
- Elevating the head, and/or turning the person on his/her side may bring comfort.
- A fan blowing toward the person can also be very helpful.
- Your Hospice Nurse will order oxygen, if needed, and will talk with the physician about ordering medications that will make your loved one's breathing easier.

Restlessness/Agitation

As disease progresses, a person may appear restless or unable to keep still. 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.
- If the restlessness increases to the point of agitation the Hospice nursing staff should be notified.
- Your Nurse will call in a Social Worker or Spiritual Care Counselor if needed for emotional or spiritual support. There are also medications that can be used to treat these symptoms.



Changes in Appetite

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. 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. Weight loss is expected and does not mean that the person is hungry or that the body is being starved by the absence of food.

- 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.
- Artificial nutrition and hydration are not necessarily a comfort measure.
- Small chips of ice or juice may be refreshing in the mouth.
- A cool, moist washcloth on the forehead may also increase physical comfort.
- Moistened sponge swabs or washcloths help keep the mouth moist and more comfortable.

Changes in Elimination

Incontinence is the loss of control of the bladder and/or bowels that can sometime happen as the muscles in the lower body begin to relax. As a person declines, there is less urine output and the color becomes darker and may have a strong odor. Adult disposable briefs and under pads on the bed may be needed. Your Hospice Nurse may suggest a catheter (a tube that goes into the patient's bladder) for comfort and to keep the person dry. Good skin care is important and your Hospice Nurse may give you ointments to use to prevent skin breakdown.

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 your nurse.

Changes in Body Temperature

As the body becomes weaker, it may not be able to control temperature for different reasons. A person may be very warm with a fever or cool to the touch. The patient's hands, arms, feet, and legs may be increasingly cool, 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.

- If there is a fever
 - a cool washcloth to the forehead and removing some of the blankets may help
 - Tylenol may be needed and your Hospice Nurse will advise you if it should be given
 - A fan or an open window can also help
- If the person is cool
 - You may use a warm blanket or extra blankets
 - Do not use an electric blanket for risk of burns

Disorientation

The patient may seem to be confused about time, place, and the identity of people surrounding him/her – even close and familiar people. A person may also see people or things that are not there. 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").
- Your Hospice Nurse will evaluate the person to see if it is medication related or a normal part of the disease progression.
- Provide reassurance and support to the person.
- Remind the person who you are and what you are going to do.
- Try not to contradict the person because the experience is real to him or her.



Emotional-Spiritual-Mental Signs and Symptoms of Approaching Death

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.

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.

Unusual Communication

The person may make a seemingly out of character 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.

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.

Vision-like Experiences

The patient may tell of speaking to persons who have already died; or of seeing 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 tells you they 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.

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.

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 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:

- No breathing
- No response to verbal or physical stimuli
- No heartbeat
- Jaw relaxed and slightly open
- 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 goodbye.

If we are not with you at the time, please call our hospice number 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.