

THE FINAL JOURNEY

“Signs & Symptoms of Approaching Death”



St. Joseph Health System
Home Care Services 
ST. JOSEPH
HEALTH SYSTEM

Preparing for the Final Journey

St. Joseph Hospice and Home Health Agency realize that this is one of the most difficult times that you and your family will have to live through. Our approach during this time is to be as honest and straightforward as possible. Our philosophy of care embraces the concept that the "fear of the unknown" is always greater than the "fear of the known." We have prepared the following information to relieve anxiety about the "unknown", and to help you prepare and anticipate the attitudes, changes, and symptoms, which are indicative of approaching death.

Please feel free to ask questions. The Hospice and Home Health Teams are your best resource to clarify any concerns about this information.

Death is an individual thing. No two people experience death exactly the same as they find their own way in this last important phase of life. In the following discussion, keep in mind that **not all changes or symptoms will appear** at the same time. Some may never appear. But because the body, spirit, emotions, and mind are in preparation for the final journey of life, many of these common changes will be seen and can be sign posts to help guide you in caring for your loved one.

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When a person enters the final stage of the dying process, there are two different dynamics are at work which are closely interrelated and interdependent. On the **physical** plane, the body begins the final process of shutting down, which will end when all the physical systems cease to function. These physical changes are a normal, natural way in which the body prepares itself to stop and close down. This is usually an orderly, non-dramatic, progressive series of events that can best be responded to by comfort-enhancing measures.

The second dynamic of the dying process is the **emotional-spiritual-mental** plane. 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 whatever is unfinished of a practical nature and reception of permission to "let go" from family members. These "events" are the normal, natural way in which the spirit prepares 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 which support and encourage this release and transition.

When a person's body is ready to cease functioning, but the person is still unresolved or unreconciled over some important issue or with some significant relationship, he/she may tend to linger even though uncomfortable or debilitated, in order to finish whatever needs finishing. On the other hand, when a person 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.

PHYSICAL SIGNS AND SYMPTOMS OF APPROACHING DEATH

NOT ALL THESE SYMPTOMS WILL APPEAR AT THE SAME TIME, AND SOME MAY NEVER APPEAR.

EARLY CHANGES: ABOUT 1 – 3 MONTHS

1. Your loved one will have decreased need for food and drink because the body will naturally begin to conserve the energy that is expended on this task. Also, since the metabolism is slowing, the body cannot utilize food taken in. *This is the hardest concept for a loving family to accept.*
 - ◆ Do not force your loved one to eat or drink--they feel like they just ate Thanksgiving dinner and cannot eat more.
 - ◆ Give permission to your loved one to eat and drink when and what they want.
 - ◆ Forcing more food than the body wants can cause pain, obstruction and suffering.

2. Constipation may be a problem due to decreased activity, decreased food intake, increased use of pain medications, decreased fluid intake, slowing of metabolism, and weakness. Urine production will also slow down as the body closes down.
 - ◆ Please notify the nurse for instructions, as interventions may differ as the process unfolds.

3. Your loved one will gradually spend more and more time sleeping during the day and at times will be difficult to arouse. This is a result of a change in the body's metabolism.
 - ◆ Plan your time with them for those occasions when they are most alert.
 - ◆ Sit with your loved one, hold their hand.
 - ◆ Do not shake or call out.
 - ◆ Speak to them as you normally would, even if there is no response.

4. He/she may become confused about time, place and even identity of close and familiar people. This is a result of chemical changes in the body. Decreasing visual clarity may add to the problem.
 - ◆ Gently tell them frequently what day and time it is and who is in the room.
 - ◆ Always assume they can understand what you say when you are near.
 - ◆ Do not ask them to guess who you are.
 - ◆ Speak softly and clearly and truthfully.

5. You may notice changes in breathing patterns. There may be periods of 10-30 seconds of non-breathing--especially noticeable at night. This is called Apnea. This is

common and may continue for weeks or months. It is indicative of a decrease in circulation and a build-up of body waste products. Apnea may be distressing to the family, but the person's body is compensating for the changes.

6. Need for increased dosages of pain medication due to increasing pain.

- ◆ Please consult your nurse right away for increased pain.
- ◆ Do not stop giving the pain medication just because you don't see any pain.
- ◆ Pain medication often works to help the person relax and make breathing easier.

LATE CHANGES: WEEKS TO DAYS

7. You may notice your loved one becoming restless, pulling at bed linen and having visions of people or things not evident to us.

- ◆ Talk calmly and assuredly with the confused person so as not to startle or frighten them further.

8. Arms and legs may become cool to touch, blue and blotchy. The underside of the body may become spongy (with fluid) and darker in color. These are symptoms of decreased circulation as the blood is being reserved for the most vital organs.

- ◆ Blankets will help. Do not use an electric blanket.
- ◆ They may wish to remain uncovered--this is because their skin may feel cool to you, but not to them.

9. Your loved one may seem unresponsive, withdrawn, or in a comatose state. This usually means time is short--hours not days.

- ◆ Hearing remains all the way to the end.
- ◆ Speak in normal tones. Identify yourself by name.
- ◆ Use this time to say whatever most needs to be said.
- ◆ Give your permission for them to move on.

10. Oral secretions may become more profuse and collect in the back of the throat. You may have heard this called the "death rattle". This is a result of increased weakness causing an inability to clear the throat. This process is usually harder on the family than the loved one. The person may not be experiencing any discomfort at all.

- ◆ A humidifier to increase humidity may help clear secretions.
- ◆ Roll or prop the person's head higher.

- ◆ Swab the mouth with diluted mouthwash or water or ice chips, or wipe the mouth with a moist cloth.
- ◆ Petroleum jelly will ease dry lips.
- ◆ Turn the head to the side in order to allow the secretions to clear naturally. Let your nurse know, so she can obtain an order for a medication to help dry up the secretions.

11. Heavy breathing or periods of no breathing (called Cheyne-Stokes breathing) and sleeping with eyes open frequently occur.

- ◆ The mouth and eyes both need to be kept moistened. (See above.)
- ◆ For the eyes, use normal saline drops or liquid tears, Murine, or other non-medicated eye drops.

EMOTIONAL, SPIRITUAL, MENTAL SIGNS AND SYMPTOMS

Stages

There are normal and predictable stages that your loved one and even you and other family members may experience in dealing with the dying process. Some of these have been called Denial, Anger, Bargaining, Depression, and Acceptance. Any number of these may occur, and at various times. Being alert to these normal processes can help in dealing with the various emotions and feelings that often surface in times like these. Be especially patient with yourself and the one you love. These stages are unique for everyone and take time to move through. Again, no two people move through them in exactly the same way or timeframe.

Withdrawal

As the knowledge that "Yes, I am dying" becomes real, a person begins to withdraw from the world around them. First, daily newspapers, television, and other interests in the world at hand begin to wane. Then, interest in casual relationships with people (neighbors, acquaintances) diminishes. Finally, withdrawal occurs perhaps even from those closest to the person, as the individual goes inward to sort out and evaluate one's own life.

It may appear that the person is "just sleeping", but often on the inside, work may be in process or ready to occur with just the right encouragement, on a level unseen by "outsiders".

Later, the person may seem unresponsive, withdrawn, or in a comatose-like state. Since hearing remains all the way to the end, feel free to speak to your loved one in your normal tone of voice and identify yourself by name when you speak.

Dream-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 presently accessible or visible to you. This does not indicate a hallucination or a drug reaction. The individual 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. Just because you cannot see or hear it does not mean it is not real to the person. Affirm the experience. It is normal and common. If it frightens the patient, explain that it is a normal occurrence for others.

Restlessness

Your loved one may perform repetitive and restless tasks. This may in part indicate that something still unresolved or unfinished is disturbing him/her and preventing him/her from letting go. It may be helpful to explore those areas with other family members, clergy, and meaningful support to help your loved one through the distress.

Decreased Socialization

The person may only want to be with a very few or even just one person. This is a sign of preparation for release and an affirmation of who the support is most needed from in order to make the appropriate transition. Family members can help by understanding that if they are not part of this inner circle at the end, it does not mean they are not loved or are unimportant, but that they have already fulfilled their tasks and it is time to say good-bye.

Unusual Communication

The person may make a seemingly out of character or illogical statement, gesture, or request. This may indicate that he/she is ready to say good-bye and is testing to see if the family is ready to let him/her go, or may show that something may still need to be resolved.

Giving Permission

Giving permission to your loved one to let go, without making them feel guilty for leaving, can be difficult. A dying person will normally try to hold on, even though it brings prolonged discomfort, in order to be sure those who are going to be left behind will be all right. Therefore, your ability to release the dying person from this concern and give them assurance that it is all right to let go whenever they are ready, is one of the greatest gifts you have to give your loved one.

Saying Good-Bye

When the person is ready to die and you are able to let go, then is the time to say goodbye. Saying goodbye is your final gift of love to your loved one, for it achieves closure and makes the final release possible. It may be helpful to lie in bed and hold the person, or to take their hand and say everything you need to say.

It may be as simple as saying, "I love you". It may include recounting favorite memories, places, and activities you shared. It may include saying, "I'm sorry for whatever I contributed to any tension or difficulties in our relationship." It may also include saying, "Thank you for..."

Tears are a normal and a natural part of saying good-bye. Tears do not need to be hidden from your loved one or apologized for. Tears express your love and to help you to let go.

HOW TO KNOW THAT DEATH HAS OCCURRED:

First and foremost, consult your St. Joseph nurse if you believe that death has occurred. Call 714-712-9559 for Hospice and 714-712-9500 for Home Health Agency. A nurse is available 24 hours day, seven days a week. If it is after our normal business hours, inform the answering service. They will page the nurse on call immediately.

Signs of death include:

- no breathing
- no heartbeat
- loss of control of bowel and bladder
- eyelids slightly open
- eyes fixed on a certain spot
- jaw relaxed and mouth open slightly.

Your hospice nurse or a member of the hospice team will help you to confirm that death has occurred and can handle calls to the mortuary and your physician.

Remember that the body does not need to be moved until you are ready. Therefore, if you have any family or loved ones on their way, it is all right to wait several hours for their arrival. The hospice nurse will help you with this process.

WHAT TO DO AT TIME OF DEATH

Your nurse, or other team member, will be available to help you, however you can help with the following steps:

1. Make sure and note the time. This is important for the nurse, the physician, and all records.
2. Call your primary support persons.
3. Notify the nurse on call. She will assist you in any way she can and come out if you need a visit.

****Other calls that can be made by the nurse, if appropriate, include:**

4. Notify the coroner's/sheriff's office, per county lived in. They need to know the patient has died, that the patient was under the care of a physician and was receiving home health/hospice services.
5. Notify the mortuary of choice. The mortuary will come to take your loved one's body at your convenience. They, with the attending physician will complete the death certificate. They will also assist you with funeral arrangements at your convenience.
6. Notify the attending physician.
7. Notify your clergy (if desired).
8. Notify the Medical Equipment Company and arrange a time for pick up of equipment.

Finally, we at St. Joseph Hospice and Home Health Agency wish to 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 them with understanding care, to provide them with comfort and calm, and to enable them to leave this world with a special sense of peace and love.

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

References:

Karnes, Barbara. Gone From My Sight. P.O. Box 335, Stilwell, Kansas 66085. 10th Printing, 1995.

Employee Orientation and Training; Module 14, Death and Dying Patient. © 1999, Pacific Healthcare Consultants, Inc.