

Preparing for Approaching Death

Barbara Mulich, MSN, FNP-BC, ACHPN, Advanced Practice Nurse Palliative Care Medicine, WV University Hospitals
Ed Horvat, MA, BCC, Pastoral & Spiritual Care Department, Monongalia General Hospital

When a person enters the final stage of the dying process, two different processes are at work, which are closely inter-related and inter-dependent. On the physical plane the body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually this is a progressive series of physical changes which are not medical emergencies requiring invasive interventions. These physical changes are a normal natural way in which the body prepares itself to stop, and the most appropriate kinds of responses are comfort-enhancing measures.

The other part 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 whatever is unfinished of a practical nature and reception of permission to "let go" from family members. These events are the normal and 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 and wanting to stop, 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.

The experience we call death occurs when the body completes its natural process of shutting down, and when the "spirit" completes its natural process of reconciling and finishing. These two processes need to happen in a way appropriate and unique to the values, beliefs and life-style of the dying person.

Therefore, as you seek to prepare yourself as death approaches, we want you to know what to expect and how to respond in ways that will help your loved one accomplish this transition with support, understanding and ease. This is the great gift of love you have to offer your loved one as this moment approaches.

The physical and emotional-spiritual-mental signs and symptoms of approaching death which follow are offered to you to help you understand the natural kinds of things which may happen and how you can respond appropriately. Not all of these signs and symptoms will occur with every person, nor will they occur in this 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, but the time to give full acceptance, support, and comfort.

NORMAL PHYSICAL SIGNS AND SYMPTOMS WITH SUGGESTED RESPONSES

Coolness. The person'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 underside of the body may become darker and the skin becomes mottled. This is a normal indication that the circulation of blood is decreasing to the body's extremities and 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 appear to be uncommunicative or unresponsive and at times be difficult to arouse. This normal change is due in part to changes in the metabolism of the body. Sit with your loved one, hold his/her hand, do not shake or speak loudly, but speak softly and naturally. Plan to spend time with him/her during those times when he/she seems most alert/awake. Do not talk about the person in the person's presence. Speak to him/her directly as you normally would even though there may be no response. Never assume the person cannot hear, as hearing is the last of the senses to be lost.

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

Incontinence. The person may lose control of urine and/or bowel matter as the muscles in that area begin to relax. Discuss with the staff what can be done to keep your loved one clean and comfortable.

Congestion. The person may have gurgling sounds coming from his/her chest as though marbles were rolling around inside - these sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning may only increase the secretions and cause discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the congestion does not indicate the onset of severe or new pain.

Restlessness. The person may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. 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 person may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy that is 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. To do this only makes the person much more uncomfortable. Small chips of ice may be refreshing in the mouth. A cool, moist washcloth on the forehead may also increase physical comfort.

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 as well as decrease in circulation through the kidneys.

Breathing Pattern Change. The person's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly, for example, shallow breaths with no breathing of 5 to 30 seconds and up to a full minute. The person may also experience periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head, and/or turning the person on his/her side may bring comfort. Hold his/her hand. Speak gently.

NORMAL EMOTIONAL-SPIRITUAL-MENTAL SIGNS AND SYMPTOMS WITH SUGGESTED RESPONSES

Withdrawal. The person may seem unresponsive, withdrawn, or in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships, and a beginning of "letting go." Since hearing remains all the way to 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 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 presently accessible or visible to you. This does not, necessarily, indicate a hallucination or drug reaction. The person is beginning to detach from this life and is being prepared for the transition so 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 your loved one. Affirm his/her experiences. They are normal and common. If they frighten your loved one, explain to him/her that they are normal.

Restlessness. The person may perform repetitive and restless tasks. This may in part indicate that something is still unresolved or unfinished that is disturbing him/her, and preventing him/her from letting go. Our staff may be able to assist you in identifying what may be happening, and help you find ways to help the person find release from the tension or fear. Other things which may be helpful in calming the person are to recall a favorite place the person enjoyed, a favorite experience, read something comforting, play music, and give assurance that it is OK to let go.

Fluid and Food Decrease. When the person may want little or no fluid or food, this may indicate that the person is ready for the final shut down. Do not try to force food or fluid. You may help your loved one by giving them permission to let go whenever he/she is ready. At the same time affirm the person's on-going value to you and the good you will carry forward into your life that you received from him/her.

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 affirming of who the support is most needed from 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 unimportant. It means you have already fulfilled your task with him/her and it is the time for you to say "Good-bye." If you are part of the final "inner circle" of support, the person needs your affirmation, support and permission.

Unusual Communication. The person may make a seemingly "out of character" statement, gesture or request. This indicates that 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 most need to say.

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 can be difficult. A dying person will normally 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 all right. Therefore, your ability to release the dying person from this concern and give him/her assurances that it is alright 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 Good-bye. When the person is ready to die and you are able to let go, then is the time to say, "Good-bye." Saying "Good-bye" is your final gift of love to the person, for it achieves closure and makes the final release possible. It may be helpful to lay in bed with the person and hold him/her or to take the hand and then 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 normal and 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 help you to let go.

HOW WILL YOU KNOW WHEN DEATH HAS OCCURRED?

Although you may be prepared for the death process you may not be prepared for the actual death moment. It may be helpful for you and your family to think about and discuss what you would do if you were the one present at the death moment. The death of a terminally ill loved one is not an emergency. The signs of death may include such things as: no breathing, no heartbeat, release of bowel and bladder, no response, eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, no blinking, jaw relaxed and mouth slightly open. As you already know, staff are nearby for support. Let us know when we can help.

THANK YOU

We thank you for the privilege of assisting you and your loved one at this time. You have given your loved one the gift of yourself. There is no right or wrong way to deal with separating from a loved one. It is a difficult process. It is our hope that this article has helped prepare you for what to expect, and has provided you with some suggestions to ease the transition to new life.

References:

Ferrell, Betty Rolling and Coyle, Nessa. Textbook of Palliative Nursing. Oxford University Press, 2001.

Callanan, Maggie and Kelley, Patricia. Final Gifts, Understanding the special awareness, needs, and communications of the dying. Bantam Books, NH, 1997.