

## **PREPARING FOR THE DEATH** **OF A LOVED ONE**

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**Editor's Note:** *We at The American Journal of Hospice and Palliative Care realize that in the final stage of terminal illness, care giver anxiety reaches its peak and anticipation of the unknown brings many questions to mind. In an attempt to answer some of these questions, we present the following information to hospice teams and families of the terminally ill. It consists of the signs which precede death in most people as their body systems slow down and finally cease functioning. For some people, these signs appear a few hours before death, for others, a few days. There is no particular order in which these events occur, and some people will not experience all of them. We hope that by knowing what to expect, hospice teams and families will be comfortable in continuing to provide the same loving support which has sustained a patient during illness. We have included some suggestions for promoting the comfort of patients as these signs occur. We feel that during this final stage of life, there are no "rights" or "wrongs".*

*This information was provided to us by the Neighborhood Visiting Nurse Association of West Chester, Pennsylvania. We are grateful to them for providing such timely and sorely needed information for our readers.*

When a person enters the final stage of the dying process, two different dynamics 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 an orderly and undramatic 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 dynamic of the dying process is at work on the *emotional -spiritual - mental* plain. 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 a resolution of whatever is unfinished of a practical nature and reception of permission to "let go" from those gathered. 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 and wanting to stop, but the person is still unresolved or unreconciled over some important issue or with some significant relationship, she/he 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 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 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 terminally ill person.

Therefore, as families seek to prepare themselves as this event approaches, the members of the hospice care team will want them to know what to expect and how to respond in ways that will help the loved one accomplish this transition with support, understanding, and ease. This is the great gift of love to be offered a loved one as this moment approaches.

The physical and emotional - spiritual - mental signs and symptoms of impending death which follow are offered to help with understanding the natural kinds of things which may happen and how to respond appropriately. Not all 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 impose change, but the time to give full acceptance, support and comfort.

The following signs and symptoms describe how the body prepares itself for the final stage of life:

***Food and fluid decrease***

The person may have a decrease in appetite and thirst, wanting little or no food or fluids. The body will naturally begin to conserve energy which 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. Since normal hydration is often not feasible, it is more peaceful to decline in a state of dehydration than fluid overload. Small chips of ice, frozen juices/popsicles may be refreshing in the mouth. Be careful of decreases in swallowing ability, and do not force fluids if the person coughs soon after. Reflexes needed to swallow may be sluggish. The person's body lets him/her know when it no longer desires or can tolerate food or liquids. The *loss* of this *desire* is a signal that the person is making ready to leave. Dehydration no longer makes them uncomfortable. Glycerine swabs to apply K-Y jelly (a water soluble lubricant) may keep the mouth and lips moist, comfortable and hydrated.

### ***Decreased socialization***

The person may want to be alone, with just one person, or with very few. It is natural to not feel like socializing when one is weak and fatigued. As well, the path seems a solitary one of progressive detachment. It appears that our works can sometimes arouse a person to be present with us, so be careful to allow quality rest time as is possible. Reassure the person it is okay to sleep.

### ***Sleeping***

The person may spend an increasing amount of time sleeping, and appear to be uncommunicative, unresponsive, and, at times, difficult to arouse. This normal change is due in part to changes in the metabolism of the body. Sit with the patient, hold his/her hand, do not shake loudly, but rather speak softly and naturally. Plan to spend time when he/she is most alert.

At this point, *being with* is more important than *doing for*. Speak directly and normally, even though there may be no response. Never assume that the person cannot hear; hearing is said to be the last of the senses to be lost.

### ***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 circulation to the brain and metabolic changes. Do not be alarmed, interfere, or try to restrain such motions. To have a calming effect, speak in a quiet, natural way, lightly massage the hand/forehead, read to the person, or play soothing music.

### ***Disorientation***

The person may seem confused about time, place, and identity of the people surrounding him/her, including close and familiar people. Identify yourself by name before you speak rather than asking the person to guess who you are. Speak softly, clearly, and truthfully when communicating something important for the patient's comfort, such as, "it's time to take your medication," and explain the reason for the communication, such as, "so you won't begin to hurt."

### ***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 decreased circulation through the kidneys, and fluid loss in breathing and respiration. A hospice nurse can determine if there is a need to insert or irrigate a catheter.

### ***Incontinence***

The person may lose control of urine and/or bowels as the muscles in that area begin to relax. Protective measures should be taken to keep the patient clean and comfortable.

### ***Breathing pattern changes***

The person's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly with shallow respirations, or periods of no breaths for 5 - 30 seconds, followed by a deep breath. The person may also have periods of rapid shallow panting type breathing. Sometimes there is a moaning - like sound on exhale: this is not distress, but rather the sound of air passing over relaxed vocal cords. These patterns are very common, and indicate a decreased circulation in the internal organs. Elevating the head, and/or turning onto the side may bring comfort. Hold his/her hand. Speak gently and reassuringly.

### ***Congestion***

The person may develop gurgling sounds coming from the chest like a percolator. Sometimes these sounds become very loud and they can be very distressing to hear. Watch your loved one closely and note that they are usually unaware of their bodily processes. It is probably harder for you to watch than it is on the patient. Suctioning is usually ineffective, and can be hard on the patient. Raise the head of the bed so the secretions pool low and therefore they don't stimulate the gag reflex. Elevating the head, and/or turning onto the side may bring comfort. Hold his/her hand. Speak gently and reassuringly.

### ***Color changes***

The person's arms and legs may become cold, hot or discolored. The underside of the body may become discolored as circulation decreases. This is a normal indication that the circulation is conserving to the core to support the most vital organs. Irregular temperatures can be the result of the brain sending unclear messages. Keep the patient warm if he/she appears cold, but do not use an electric blanket. If the person continually removes the covers, then allow him/her just a light sheet.

### ***Permission to go***

Families need to give permission to a loved one to let go without making him/her feel guilty for leaving or trying to keep him/her with that family to meet its own needs. A dying person will commonly try to hold on, even though it brings prolonged discomfort, in order to be assured that those left behind will be all right. A family's ability to reassure and release the dying person from this concern is the greatest gift of love they can give at this time.

### ***Saying good-bye***

When the person is ready to die, and the family is able to let go, this is the time to say good-bye in personal ways. This closure allows for the final release. It may be helpful to just lay in bed with the person, hold a hand, and/or say everything you need to say. Tears are a natural part of making peace and saying good-bye. They do not need to be hidden or apologized for; they are expressions of love.

Although the death of a patient or loved one is a stressful time, we at *The American Journal of Hospice and Palliative Care* hope that this information will help to prepare those involved with hospice care for that moment. If you can free yourself from anxiety and fear, then you can help the terminally ill to experience the final stage of life in an atmosphere of calmness and peacefulness.

## **AT THE TIME OF DEATH**

- \* BREATHING CEASES**
- \* HEARTBEAT CEASES**
- \* THE PERSON CANNOT BE AROUSED**
- \* THE EYELIDS MAY BE PARTIALLY OPEN WITH EYES IN A FIXED STARE**
- \* THE MOUTH MAY FALL OPEN AS THE JAW RELAXES**
- \* THERE IS SOMETIMES A RELEASE OF BOWEL AND BLADDER CONTENTS AS THE BODY RELAXES**

When the death has occurred, take the time needed to call a supportive person, or to adjust to the situation. There is no rush. Taking care of yourself is what is most important now.