PREPARING FOR APPROACHING DEATH

When a person enters the final stage of the dying process two different dynamics are at work, which are closely interrelated 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 non-dramatic progressive series of physical changes that 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 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 a 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 that 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 not reconciled 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 this event approaches, the members of your hospice care team 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.

APPROACHING DEATH

The physical and emotional-spiritual-mental signs and symptoms of impending 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.

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

COOLNESS: The person's hands, arms, feet and/or legs may become 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 blanket.

SLEEPING: The person may spend an increasing amount of time sleeping and may 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 to be most alert/awake. Do not talk about the person in their presence. Speak to him/her directly, as you normally would, even though there may be no response. Never assume the person cannot hear; 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 whom you are. Speak softly, clearly, and truthfully when you need to communicate something important for the patient'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 patient to meet your needs.

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INCONTINENCE: The person may lose control of urine and/or bowel matter as the muscles in that area begin to relax. Discuss with your hospice nurse what can be done to protect the bed and 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 be very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. 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 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. Do not interfere with, or try to restrain such motions. To provide a calming effect, speak in a quiet, natural way, lightly massage the forehead, read to the person, or play soothing music.

FLUID AND FOOD DECREASE: The person may have a decrease in thirst and appetite, 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. To do this only makes the person much more uncomfortable. Small chips of ice, frozen Gatorade, or juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (ask the hospice nurse for guidance). Glycerin swabs may help keep the mouth and lips moist and comfortable. 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. This is referred to as concentrated urine. This is due to the increased fluid intake as well as decrease in circulation through the kidneys. Consult with your hospice nurse to determine whether there may be a need to insert or irrigate a catheter.

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, i.e., shallow breathes with periods of no breathing of 5 to 30 seconds and up to a full minute. This is called "Cheyne-Stokes" breathing. The person may also experience periods of rapid, shallow pant-like breathing. These patterns are very common and indicate a 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 APPROPRIATE 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 person who has 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 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 or 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. Your hospice team members will 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 it is okay to let go.

FLUIDS 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 the permission to let go whenever he/she is ready. At the same time, affirm the person's ongoing value to you and the good you will carry forward into your life that you received from him/her.

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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 "Goodbye." If you are part of the final "inner circle" of support, this person needs your affirmation, support, and permission.

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 "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 to meet your own needs 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 assurance that it is all right 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, this is the time to say "Good-bye." Saying good-bye is your final gift of love to the loved one 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 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 natural part of saying, "Good-bye." Tears do not need to be hidden from your loved one or apologized for as 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 hospice patient is not an emergency. Nothing must be done immediately. The signs of death 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.

At the time of death, please notify us. A Hospice Nurse will come to assist you if needed or desired. If not, phone support is available.

The nurse will help you notify our physician and funeral director. The funeral director will not come to your home until your physician or his/her designee has been notified. The body does not have to be moved until you are ready. If the family wants to assist in preparing the body by bathing or dressing, you may do so. If you have any questions, do not hesitate to call the Hospice Nurse.

THANK YOU

We of Hospice 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 a most wonderful, beautiful, and sensitive gift we humans are capable of, and in giving that gift, you have given yourself a wonderful gift as well.