

## PREPARING FOR THE DYING PROCESS

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 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 and enhancing measures.

The other dynamic of the dying process is a 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 releases from the body, its immediate environment and all attachments. This release from the body, its own priorities, which include the resolution of whatever is unfinished of a practical nature, reconciliation of close relationship 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 materialistically oriented realm of 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 or she will tend to linger even though very 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 for the values, beliefs and life-style of the dying person so that the death can occur as a peaceful release.

Therefore, as you seek to prepare yourself as this event approaches, the members of your hospice care team will 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 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 these signs and symptoms will occur with every person, nor will they occur in this particular sequence. Each person is unique, and what has been most characteristic of the way your loved one has lived consistently will affect the final shut down and release. This is not the time to try to change your loved one, but the time to give full acceptance, support and comfort.

1. **Coolness.** The person's hands and then arms and feet and then legs, may become increasingly cool to the touch and at the same time the color of the skin may change. 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.
2. **Sleeping.** The person may spend an increasing amount of time sleeping, and appear to be uncommunicative and unresponsive. This normal change is due in part to changes in the metabolism of the body. Sit down with your loved one, hold his/her hand, do not shake or speak loudly, but speak softly and naturally.
3. **Disorientation.** The person may seem to be confused about the time, place and identity of the people surrounding him/her. This is also due in part to the metabolism changes. Identify yourself by name before you speak rather than ask the person to guess who 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 will not begin to hurt”. Do not use this method to try to manipulate the patient to meet your needs.

4. **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.
5. **Congestion.** The person may have sounds coming from his or her chest as though marbles were rolling around inside. 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.
6. **Restlessness.** The person may make restless and repetitive motions. 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 have a calming effect, speak in a quiet natural way, lightly massage the forehead; read to the person or play some soothing music.
7. **Fluid and Food Decrease.** The person may begin to want little or no food or fluid. This means the body is conserving for other functions the energy which would be expended in processing these items. 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, frozen Gatorade or juice may be refreshing in the mouth. Glycerine swabs may help to keep the mouth and lips moist and comfortable. A cool moist washcloth on the forehead may also increase physical comfort.
8. **Urine Decrease.** The person’s urine output normally decreases due to the decreased fluid intake as well as the decrease in circulation through the kidneys. Consult your hospice nurse to determine whether there may be a need to insert or irrigate a catheter.
9. **Breathing Pattern Change.** The person’s regular characteristic breathing pattern may change with the onset of a different breathing pace which alternates with periods of no breathing. This is called the “Cheyne-Stokes” symptom. It is very common and indicates decrease in circulation in the internal organs. Elevating the head may help bring comfort. Hold his or her hand, speak gently.

#### **NORMAL EMOTIONAL/SPIRITUAL/MENTAL SIGNS WITH APPROPRIATE RESPONSES**

1. **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 to “let go”.
2. **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 indicate an 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, does not mean it is not real to your loved one. Affirm his/her experience. They are normal and common. If they frighten your loved one, explain to him or her that they are normal.
3. **Restlessness.** The person may perform repetitive and restless tasks. They may in part indicate that something is still unresolved or unfinished that is disturbing him or her, and preventing him/her from letting go. Your hospice team members will assist you in identifying what may be happening, and will 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.

4. **Fluid and Food Decrease.** When the person may want little or no food, this may indicate that the person is ready for the final shutdown. You may help your loved one by giving him/her 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.
5. **Decreased Socialization.** The person may only want to be with a few or even just one person. This is a sign of preparation for release and an affirming from whom support is most needed in order to make the approaching transition. If you are not part of this "inner circle" at the end, it does not mean that you are not loved or are unimportant. It means that 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.
6. **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.
7. **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 those who are going to be left behind will be alright. Therefore, your ability to release the dying person from this concern and give him/her assurance that it is alright to let go whenever he/she is ready is one of the greatest gifts you can give your loved one.
8. **Saying Good-bye.** When the person is ready to die and you are able to let go it is 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 his/her hand and say everything you need to say so that afterward you never have to say to yourself "Why didn't I say this or that to him/her".

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 the tensions of our relationship". It may also include saying "Thank you for...". Tears are normal and 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 let go.

#### **HOW WILL YOU KNOW WHEN DEATH HAS OCCURRED?**

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, eyes fixed on a certain spot, no blinking, jaw relaxed and mouth slightly open. Please call the VNA number and state: "I want to report a death" and give the patient's name, your name, and the phone number where you are. A VNA nurse will come to assist you if needed or desired. If not, phone support is available. 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, that may be done. VNA will notify the physician.

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