

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

When a person enters the final stage of the dying process, 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. Usually this is an orderly and un-dramatic 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, and mental planes 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 from the body has its own priorities, which include the resolution of whatever is unfinished of a practical nature, reconciliation of close relationships, 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 response to the emotional, spiritual and 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 un-reconciled 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, and 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 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 lifestyle of the dying person so 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 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 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.

## **NORMAL PHYSICAL SIGNS & SYMPTOMS WITH APPROPRIATE RESPONSES.**

1. **FLUID & FOOD DECREASES:** 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. Glycerin swabs may help keep the mouth and lips moist and comfortable. A cool moist washcloth on the forehead may also increase physical comfort.
2. **URINE DECREASES:** The person's urine output normally decreases due to the decreased fluid intake as well as decrease in circulation through the kidneys. Consult your hospice nurse to determine whether there may be a need to insert or irrigate a catheter.
3. **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.
4. **SLEEPING:** The person may spend an increasing amount of time sleeping and may 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.
5. **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 soothing music.
6. **DISORIENTATION:** The person may seem to be confused about the time, place, and identity of people surrounding him / her. This is also due, in part, to the metabolism changes. Identify yourself by name before you speak rather than asking the person to guess who you are. Speak softly, clearly, and truthfully when you need to communicate something important for the patient's comfort. An example is, "it is time to take your medication". 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.
7. **SUSPICION:** The person may become suspicious and not want to take his / her medicine, may even spit medication out or attempt to hit or kick at the family. Do not attempt to forcibly restrain him but speak in a calm, quiet voice and contact your nurse for further instructions.

8. FEVER: The person may have an elevated temperature. This is usually not due to infection but to changes in metabolism. Your hospice nurse will instruct you in how to give cooling sponge baths and how to administer medication to reduce fever.
  
9. CONGESTION: The person may have sounds coming from his / 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.
  
10. COOLNESS: The person's hands and then arms and feet and then legs may become increasingly cool to the touch. At the same time, the color of the skin may change. This is a normal indication that the circulation of the blood is decreasing to the body's extremities and is being reserved for the most vital organs. Keep the person warm with a blanket, but do not use an electric one.
  
11. BREATHING PATTERN CHANGE: The person's regular characteristic breathing pattern may change with the onset of interrupted breathing. This is called the "cheyne-stokes" symptom, which is very common and indicates a decrease in the circulation in the internal organs. Elevating the head may help bring comfort. Hold his / her hand and 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 beginning of "letting go". Since hearing remains all the way to the end, speak to our 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".
2. **VISION-LIKE EXPERIENCE**: 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 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 why, 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 / 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 / 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, reading something comforting, play music, and give assurance that it is okay to let go.
4. **FLUID & FOOD DECREASE**: When the person wants 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 in your life that you received from him / her.
5. **DECREASED SOCIALIZATION**: The person may only want to be with very 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 you are not loved or unimportant. It means you have already fulfilled your task with him / her, and it is the "goodbye". 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" statement, gesture, or request. This indicates that he / she is ready to

say “goodbye” 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, 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 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 can give your loved one.
  
8. SAYING GOODBYE: When the person is ready to die and you are able to let go, it is time to say “goodbye”. Saying goodbye 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 take his / her hand and say everything you need to say so that afterward you never have to ask 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 any tension or difficulties in our relationship”. It may also include saying, “thank you for \_\_\_\_\_”. Tears are a normal and natural part of saying goodbye. Tears do not need to be hidden from your loved one or apologized for. Tears express your love and help you let go.

**YOUR HOSPICE SOCIAL WORKER IS ABLE TO PROVIDE GUIDANCE AND SUPPORT FOR THE PATIENT / FAMILY / CAREGIVER AS THEY EXPERIENCE THIS PHASE OF THE DYING PROCESS.**

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

The death of a hospice patient is not an emergency; the police do not need to be called. 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 telephone the hospice number and say, "I want to report a death" and give the patient's name, your name, and the telephone number where you are. A member of the hospice team will contact you to discuss further arrangements, including the nurse coming to the home for the death pronouncement.

The body does not have to be moved until you are ready. If you desire, the hospice team will call the funeral home when you are ready to have the body of your loved one moved. Hospice will notify your physician.

## **THANK YOU!**

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

**This has been created to support Hospice Atlanta families and the community  
Hospice Atlanta serves.**

**Adapted from THE AMERICAN JOURNAL OF HOSPICE AND PALLIATIVE  
CARE July / August 1992.**

**Revised 12/01/98**