The final stages of human life are somewhat of a mystery to most of us. We have been shielded from the realities of death by our very denial of it. We do not know what to expect if we are confronted with the dying process, either our own or that of someone close to us. The unknown is always much more frightening than is actual fact. The physical and emotional changes that a dying person exhibits as death approaches are natural ways by which the body prepares to shut down and the person’s consciousness prepares to let go. You, as caregiver, can make a tremendous difference in the quality of this experience with your understanding and support in carrying out the wishes of the dying person. For most hospice caregivers, the ultimate goal is to achieve a peaceful death that is appropriate to the values, beliefs and lifestyle of the dying person.

It may be helpful for caregivers to review the signs and symptoms of impending death that are described in this section. In general, body systems begin to slow down and eventually cease altogether. Not all of the changes described will occur; they may occur in any sequence; and they may be exhibited months, weeks or hours before death. The changes may occur so gradually that they are difficult to observe. While we are presenting a timetable of sorts by which we begin to look for these signals, the actual experience of dying varies widely and is as individual as the person.

Hospice’s role is to assist and support – but never replace – you. If you have any questions or concerns that are not answered here, please consult with your Hospice team.

WITHDRAWAL FROM SURROUNDINGS

As the body weakens, most dying people come to the realization that their time is limited. While many have known this intellectually for some time, emotional acceptance often occurs only a relatively short time before death. Some people never achieve this level of acceptance,
believing up until the moment of death that a miracle will occur and they will be spared. For these people, gentle compassion and support are particularly important. We must be respectful of a person’s denial since it can be such an important aid to coping.

Regardless of their level of acceptance, most people do begin to develop their own rituals of withdrawal. They begin to lose interest in the outside world, paying less attention to newspapers or television. They may begin to limit visits from friends and neighbors as they withdraw into their own family circle. As time passes, the person eventually withdraws from everything outside his own body and retreats inside. While the person may appear to be sleeping, it is possible that much internal “work” is taking place. The person may be processing his life, weighing its meaning and value. At this point, with words requiring so much precious energy, communication may cease altogether.

What you as caregiver can do:

- Allow the person to sleep and take full advantage of periods of wakefulness.
- Do not feel compelled to follow the same medication or care schedule that you have in the past.
- Seek the advice of your Hospice nurse to assure that the person’s physical symptoms are being adequately treated without overly disturbing the dying process.
- Although the person may be unable to speak to you, do not hesitate to tell her how much you love and will miss her.
- If it is possible and seems appropriate, spend time reminiscing with the dying person and family members. The person may need to hear that she has made a difference and will be remembered.
- Do not hesitate to continue to touch (gently) and speak (softly) to the dying person; it is believed that the senses of hearing and touch are the last to be lost.
- Remember that sometimes just BEING WITH the person is more important than DOING SOMETHING FOR the person. The very best help may be the comforting assurance that you are present and that you care.
REDUCED DESIRE FOR FOOD OR DRINK

This physiological change is particularly difficult for caregivers to accept. Assuring that an ill person is adequately fed and hydrated is an integral part of providing care. When a dying person begins to refuse food or drink, caregivers often panic because they think it is their responsibility to assure nutrition intake. While it is correct that food is what sustains us, it is perfectly natural for a person to stop eating as his body prepares to die. It takes a tremendous amount of energy to process food. As body systems begin to fail, energy that might otherwise have been spent processing food is now reserved to keep vital organs functioning.

Sometimes caregivers may try anything to get the person to eat – resorting to bribes or even guilt. Because the dying person’s body cannot process food, nausea and/or vomiting may occur with the intake of food. This certainly contributes to physical discomfort for the patient as well as to feelings of frustration for the caregiver and patient alike.

What you as caregiver can do:

- Frequently offer, but do not force, food, drink and medications.
- Your Hospice nurse can advise which medications are absolutely necessary for comfort. Many of these medicines can be given in ways other than by mouth: sublingually (concentrated liquid form of the medicine dropped under the tongue); by rectal suppository; or transdermally (absorbed through the skin).
- The process of dehydration is often of particular concern to families, who may request that IV fluids be given to make the person more comfortable. However, research strongly suggests that dehydration is itself often a comfort measure.
- Artificial hydration can cause increased urination, resulting in more frequent bathroom trips or an increased need for personal care. Artificial hydration can also lead to pooling of fluid in the lungs or extremities. Increased gastric secretions causing nausea can also occur as a result of artificial hydration.
• Dry mouth is the only unpleasant side effect consistently reported by terminally ill patients who are no longer able to drink and this is easily treated with frequent cleaning of the mouth, use of ice chips, and moistening of the lips with petroleum jelly.

**INCREASING FATIGUE AND DISORIENTATION**

The dying person will become weaker and sleep more as body systems fail. Disorientation becomes common as the importance of marking time diminishes and the person sleeps much of the day and night. The person seems to be focusing less on this world and may talk of seeing people who are not there, often those who have died before her. She may report visions of a journey to be taken, of someone coming for her soon, of going home – all possible references to her impending transition from life to death.

**What you as caregiver can do:**

• Offer reassurance by your continued presence.
• Do not argue, contradict or attempt to explain away the perceptions of the dying person.
• Calmly accept her statements and gently explore how she feels about what is happening to her, if that seems appropriate.
• If you are not comfortable discussing this topic, call Hospice and ask for a team member to help you.
• Be reassured that these types of dreams or visions are very common during the dying process; do not confuse them with medication-induced hallucinations.
• It may be helpful to know that many patients appear to be comforted by these dreams or visions.

**CHANGES IN BLADDER AND BOWEL FUNCTION**

A decrease in urinary function will probably occur, due to less fluid being taken in and decreased circulation through the kidneys. As the dying person becomes less responsive, bladder and bowel control may be lost. This is very common, and most people appear to be
unaware when it occurs. Because we are always striving to maintain comfort, good hygiene becomes extremely important, coupled with the utmost respect for the person’s dignity.

What you as caregiver can do:

- Use absorbent, plastic-backed pads to protect bedding.
- Dress the person in clothing that allows easy accessibility, to avoid prolonging the time needed for bathing and changing.
- Protective briefs may be helpful. Adult sizes are readily available for purchase, and a limited supply may be provided by Hospice.
- Ask the Hospice nurse or aide to show you how to bathe the person and change bed linens while the patient remains in the bed.
- Provide for privacy while this personal care is done; have no more people present than absolutely necessary and keep the person as covered as possible.
- If the person has not urinated in 10-12 hours, report this to the Hospice nurse.
- The Hospice nurse will assess as to the need for a catheter. A catheter can relieve a full bladder caused by blockage and/or make personal care easier for both patient and caregiver.
- If the person already has a catheter and no urine appears in the bag for 6-8 hours, the Hospice nurse should be notified. The catheter may need to be irrigated to remove an obstruction.

CHANGES IN BREATHING PATTERNS

Breathing becomes irregular and shallower, with breaths spaced further apart. There may be periods of apnea, which are pauses in the person’s breathing lasting 10-30 seconds. The person may seem to be working very hard to breathe and make a moaning noise when exhaling. Oral secretions may collect in the back of the throat and rattle or gurgle as the person breathes. Dry secretions may become encrusted in the mouth and on the lips.
What you as caregiver can do:

- Turn the person on his side. This may help secretions drain instead of pooling in the back of the throat.
- Provide frequent, thorough mouth care using oral sponges, as a Hospice nurse will demonstrate for you. This can relieve dry mouth and remove dried secretions.
- Apply petroleum jelly or a similar product to the lips to prevent dryness.
- Call the Hospice nurse if the person appears to be in distress from excess mucous or shortness of breath. The nurse will assess the need for oxygen, special medications or other treatments.

CHANGES IN SKIN

As the person weakens and takes in less nutrition, the skin becomes paler. If liver disease is involved, a yellow or even orange skin tone may be observed. Elderly patients and those who have been ill for an extended time have very fragile skin that is especially prone to developing ulcers called “bedsores.” As death approaches, with body systems rapidly failing, mottling (purplish blotches on the skin) may become apparent, especially on the arms and legs, and the extremities may feel cooler or cold. This is caused by lack of proper blood circulation as the heart fails.

What you as caregiver can do:

- Maintain good hygiene to prevent bedsores.
- Hospice may arrange for special equipment to alleviate pressure and keep bedsores from forming, such as a special thick pad or alternating pressure mattress for the bed.
- Frequently change the person’s position in bed if she can no longer do this herself. The Hospice nurse can show you how to position the person with pillows to provide the most comfort and prevent pressure areas.
CONTROL OF PAIN

Many patients have said that they do not fear death: it is dying that frightens them. They have envisioned a long, painful process filled with physical agony and indignities to a body already ravaged by disease. With proper care, this should not be the case. Pain control is among the highest of Hospice’s priorities. The goal is to manage pain to the point of comfort. To the extent that the patient can assess the pain himself, he is the judge of his own comfort level. If he cannot convey information about his pain verbally, nonverbal indicators of pain should be assessed.

What you as caregiver can do:

- Believe the person when he says he is experiencing pain.
- Promptly report any changes in condition to the Hospice nurse.
- The Hospice nurse is your best guide to managing pain.
- Medication is the first line of defense when combating pain. It works quickly, is relatively inexpensive, and is generally easy to administer.
- When managing pain with medication, it is best to “stay ahead of the pain” and prevent sudden escalations.
- Other methods of pain control may be of significant help, as well. Most of these require no special equipment or supplies needed.
  1. Touch – Never underestimate the power of human touch.
     - Massage can be a wonderful help – ranging from deep massage of large muscles to gentle kneading of the hands and feet.
     - Lotions and oils, especially those designed for massage therapy, can help hands slide easily over the skin.
     - For those patients who do not feel comfortable with such intimate contact, simple hand-holding, hugs or stroking of the arms and face can be very soothing.
2. Heat and Cold – May relieve pain related to bone involvement.
   - Sources of heat may include heating pads (set on low) or warm towels.
   - Sources of cold could be ice packs or cold compresses. (Be very careful to use a layer of cloth between the source of cold and the person’s skin.)
   - Proceed carefully. Damage can occur very quickly, especially to fragile skin.
   - Try alternating heat and cold, leaving each on for 10-15 minutes.
   - Try alternating the placement of the source, putting it just above or below the pain, rather than directly over the site of pain.
   - If you are unsure about using heat or cold, ask your Hospice nurse to demonstrate several techniques.

3. Positioning – Changing the person’s position frequently can sometimes make a tremendous difference.
   - Use pillows or rolled towels to provide support and prevent pressure.
   - Use a “turn sheet” under the person to help you turn her in the bed without straining your back.
   - Hospice may arrange for a hospital bed to ease positioning and other caregiving activities easier.
   - Ask your Hospice nurse or Hospice aide to demonstrate how to use a turn sheet, position the person with pillows, and use good body mechanics to avoid hurting yourself.

   - Effective distraction activities could include watching television, listening to music, playing card games, etc.
   - The success of this technique **should not** be considered or used as a “test” to prove whether the person was really experiencing
pain. ("She couldn’t be hurting that much if she is able to laugh and joke with us.")

RESTLESSNESS

Restlessness may be described as the inability to rest or be still and quiet. The person may make repetitive movements. At times, restlessness may be due to physical factors such as pain or anxiety. If you suspect this may be the case, or in any instance where you feel restlessness is a problem, call your Hospice nurse.

It may also be the case that restlessness is due to the emotional, spiritual or mental effort to let go. If a dying person’s body is ready to stop functioning but the person is still struggling with a particular unfinished issue or unresolved relationship, there may be restlessness related to these psychological or existential processes. An excess of stimulation surrounding the dying person can also be a cause of restlessness.

What you as caregiver can do:

- Call Hospice if you think that pain or anxiety is causing restlessness. There are medications for easing both symptoms.
- Request a visit from your Hospice social worker or chaplain if you think that emotional distress over a particular issue or relationship is causing restlessness in the patient.
- Provide a calm, relaxed atmosphere; speak softly, eliminate bright lights and loud noises.
- Instruct visitors to behave according to the cues of the dying person.
- Listening to favorite poems or religious readings may be comforting to the person.
- Play soothing music; use gentle touch; respect the person’s emotional withdrawal that often is part of the dying process.
SAYING GOOD-BYE

One of the most difficult aspects of caring for someone who is dying is saying good-bye to the person. Sometimes a dying person may appear to be holding on in order to see a loved one who is en route or to find reassurance that those left behind will be all right. The time to say good-bye may be at the time of death but could occur at any time that feels appropriate to you. Good-byes enrich and often ease the dying process for both patient and loved ones. The moment may include touching, recounting fond memories, or saying simple words to assure the dying person that she is appreciated and will be remembered. Tears are a normal and natural part of good-byes. They provide testimony to the depth of feeling you have for this person.

Sometimes the dying person holds onto his hope and denial so fiercely that caregivers and other loved ones find no opportunity to verbalize words of good-bye. The feelings can still be conveyed through touch, gentle care, and simple presence.

AS DEATH OCCURS...

The impending death of a Hospice patient does not require emergency treatment. If you sense the person is very near death and you need assistance or support, call Hospice. If the person appears free of distress, you may prefer not to call Hospice until the death has occurred. You may feel that the actual event of your loved one’s death is an intimate and private time in which the presence of Hospice staff would feel like an intrusion. Nothing needs to be done immediately.

Once notified, the Hospice nurse will take her cues from you and provide as much or as little support as you need.

The signs that death has occurred include the following:

- Absence of breathing
- Absence of heartbeat
- Absence of response of any kind
Other common occurrences at time of death:

- Eyes slightly open, no blinking, and a fixed stare
- Jaw relaxed and slightly open
- Possible release of bladder or bowel contents

Call Hospice to report the death as soon as you feel ready. A Hospice nurse will come promptly to verify the absence of vital signs and to inform the physician and funeral home. You will hear from your Hospice primary nurse and your Hospice social worker in the days following the death of your loved one. You will also receive information about bereavement support that is available to you from JSSA Hospice for the year to come. Please know that we at Hospice will continue to care deeply about you as you grieve. We hope you are able to find solace in the gift of care you so lovingly provided. Hospice will continue to care deeply about you as you grieve. We hope you are able to find solace in the gift of care you so lovingly provided.