WHAT YOU NEED TO KNOW ABOUT HOSPICE PATIENTS

The Home Aide provides basic bedside care for the patient. The Home Aide will often be the Team member who actually spends the most time with the hospice patient and family, because they are providing the basic care in the home (or facility) and helping the patient with the routine activities of daily living (ADLs).

The home aide reports directly to the RN case manager and must follow the plan of care and nursing orders made by the RN case manager. The home aide will make regular visits to the patient and family, provide help as needed for bathing, dressing, and eating, for example. She checks the patient's vital signs (heart rate, breathing rate, temperature, and blood pressure) and also reports immediately to the RN case manager if there are any significant changes in the patient's condition.

The home aide will help to transfer the patient from bed to chair or sofa, into the bathroom, or other areas. The home aide, along with other staff will share techniques for safely transferring the patient. However, it is the RN case manager's responsibility for teaching the patient and family. A physical therapist may also explain safe transfer techniques to the family and patient.

Homemakers help to keep the patient's care area clean, neat, and safe. The homemaker may provide cleaning services, grocery shopping or other errands. The homemaker may also run errands for the patient and/or family.

Helping the Hospice Patient In and Out of Bed

Transfers from Bed to Chair: In many cases there will most likely be times when the patient will wish to get up out of bed. It may not be advisable for him to get up in some cases. If there is a realistic danger that your care recipient will fall, he should not get up alone, and must be assisted by enough people to assure his or her safety.

There are times when some hospice patients will repeatedly request to get up out of bed, and then once in a chair, will soon thereafter request to get back in bed...repeatedly requesting to get in and out of bed over and over. In this case, the patient may be suffering from what is called "terminal agitation" or "terminal restlessness." This problem can become exhausting to you and the hospice RN case manager and physician must be notified. There are several medications commonly used to relieve this terminal agitation or restlessness.

When a patient is suffering from various symptoms or pain, moving them can make things worse. If your physician has ordered pain medications to be given on an as-needed basis, it is good to administer pain medications at least one-half to one hour before attempting to move him. Listen closely to your hospice RN case manager for tips on managing pain before transfers.

You may find that your care recipient will suffer from dizziness after laying down for prolonged periods. If you have two persons helping out, one person can lower the patient's legs over the edge of the bed while the other simultaneously helps him to sit up on the edge of the bed, supporting him at the shoulders. This technique for sitting up is simple to accomplish (if you are strong enough to support the patient) once you've watched professional nurses demonstrate. After waiting for him to recover from any dizziness, the transfer to a chair can be attempted (if your RN case manager agrees)

Depending on the patient's strength, the distance to the chair should be adjusted. If the patient is able to support his weight and stand, a little walk to the chair is good exercise, as long as someone is assisting him, supporting him by the arm to steady him if necessary. If however, he is weaker, the chair should be placed next to the bed without any space in between; you may wish to use a transfer or gait belt which is applied around the patient's waist, secured and which can be held to support the patient's weight during the transfer. Watching this done is helpful to learn safe technique.

When your care recipient is feeling quite weak, it is important to prevent falls to the floor and any injury that might result. Watch how the hospice nurses assist the patient. You will notice that the nurse assisting him will place her feet and knees directly in front of the patient's feet and knees, blocking them in place, preventing his legs from sliding out from under him. Proper lifting technique will help you avoid injuring yourself as well. Using the legs to lift, positioning your care recipient as close as possible to the chair,using a gait/transfer belt to help him up, all of these techniques are helpful.

Assisting the Hospice Patient Back to Bed: If your care recipient has already fallen to the floor, do NOT move him or her until you have determined if there has been an injury. If you think there is a real chance that an injury has occurred, you must get help from an RN or the EMS. If there has been no injury, it is still important for you not to strain while helping him back to the chair or bed. Get help when lifting him back up. If you have any doubt about your own ability to assist him back up, getting assistance from other family members, neighbors or friends is appropriate.

If there is nobody around who can assist you, you may call the hospice for assistance. In some cases, the hospice will advise you to call the EMS/ambulance for assistance. Straining yourself in the process will only make things more difficult for all involved.

If the patient has fallen to the floor, it is important to notice if there has been any injury. If there has been an injury, it is important to have an RN assess the patient before moving him or her...or call your EMS ambulance to assess the patient. If the patient does not appear to be injured, a useful method of lifting is for two helpers to join in lifting simultaneously, grasping each others wrists under the patient's hips with one arm and grasping each others wrists behind the patient's back & under his arms (sometimes called a fireman's carrying technique). Another method is to take a strong blanket and spread that out on the floor next to the patient, and positions him on the blanket...then using two to four helpers, lift the patient by lifting the blanket up like a stretcher.

It is important to have enough people assisting depending on the weight of your care recipient. Ask your RN case manager for guidelines on moving the patient and to demonstrate methods for assisting the patient in and out of bed or up from the floor.

Assisting to Bathroom: If you need to assist him to the bathroom, the transfer or gait belt can be used as well as using a walker or cane, if the patient is strong enough to use them. Your patient's ability to walk may become unreliable, and you will need to carefully evaluate his ability as you begin. If there is any indication he's unable to safely transfer, then the attempt to get up should be stopped immediately. Your hospice RN case manager will be able to give you guidance.

If the patient is unable to walk so far, then a portable commode may be placed next to the bed for his use, or a wheel chair can be used. On the bedside commode while visitors are present. It is appropriate to ask others to step into another room during use of the bedside commode or bathing. If the patient's bed is not in a private bedroom, a sheet may be hung across the room for visual privacy as well.

Maintaining a Peaceful Atmosphere

Sound music: The type of environment that will be conducive to peaceful rest for your care recipient will depend on his or her preferences. Many patients enjoy listening to restful, beautiful music which helps them relax, while some are used to the TV or radio blaring at all hours of the day or night. Others will prefer silence. What is important is to be sensitive to the patient's wishes and keep things the way he or she prefers.

Lighting: While a few patients will appreciate opening all the curtains and letting the scenery in from outside, many others will be bothered by the bright lights from outside. Some will want windows open, others may be disturbed by drafts and ask for windows to be closed. All of these factors are important.

Signs and Symptoms of Approaching Death

When confronted with approaching death, many of us wonder when exactly death will occur. Many of us ask the question, "How much time is left?" This can often be a difficult question to answer. The dying do not always cooperate with the predictions of the doctors, nurses or others who tell family members or patients how much time is left.

Hospice staff has frequently observed that even the predictions by physicians about the length of time from the original diagnosis till death is often inaccurate. Many families report that "the doctor told us he [the patient] only had so much time left, and he's lived much longer than that." ... or a similar story. Statistical averages do not tell us exactly how long a particular patient has to live; they can only serve as a general guideline or point of reference.

Although statistical averages do not help much in an individual case, there are specific signs of approaching death which may be observed, and which does indicate that death is approaching nearer. Each individual patient is different. Not all individuals will show all of these signs, nor are all of the signs of approaching death always present in every case.

Depending on the type of terminal illness and the metabolic condition of the patient, different signs and symptoms arise. An experienced physician or hospice nurse can often explain these signs and symptoms to you. If you have questions about changes in your care recipient's condition, ask your hospice nurse for an explanation that is one of the reasons she is serving you.

There are two phases which arise prior to the actual time of death: the "pre-active phase of dying," and the "active phase of dying." On average, the pre-active phase of dying may last approximately two weeks, while on average, the active phase of dying lasts about three days.

We say "on average" because there are often exceptions to the rule. Some patients have exhibited signs of the pre-

active phase of dying for a month or longer, while some patients exhibit signs of the active phase of dying for two weeks. Many hospice staff have been fooled into thinking that death was about to occur, when the patient had unusually low blood pressure or longer periods of pausing in the breathing rhythm. However, some patients with these symptoms can suddenly recover and live a week, a month or even longer. Low blood pressure alone or long periods of pausing in the breathing (apnea) are not reliable indicators of imminent death in all cases. God alone knows for sure when death will occur.

Signs of the Pre-Active Phase of Dying:

- increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently (exhausting family and caregivers)
- withdrawal from active participation in social activities
- increased periods of sleep, lethargy
- decreased intake of food and liquids
- beginning to show periods of pausing in the breathing (apnea) whether awake or sleeping
- patient reports seeing persons who had already died
- patient states that he or she is dying
- patient requests family visit to settle "unfinished business" and tie up "loose ends"
- inability to heal or recover from wounds or infections
- increased swelling (edema) of either the extremities or the entire body

Signs of the Active Phase of Dying:

- inability to arouse patient at all (coma) or, ability to only arouse patient with great effort but patient quickly returns to severely unresponsive state (semi-coma)
- severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality
- much longer periods of pausing in the breathing (apnea)
- dramatic changes in the breathing pattern including apnea, but also including very rapid breathing or cyclic changes in the patterns of breathing (such as slow progressing to very fast and then slow again, or shallow progressing to very deep breathing while also changing rate of breathing to very fast and then slow)
- other very abnormal breathing patterns
- severely increased respiratory congestion or fluid buildup in lungs
- inability to swallow any fluids at all (not taking any food by mouth voluntarily as well)
- patient states that he or she is going to die
- patient breathing through wide open mouth continuously and no longer can speak even if awake
- urinary or bowel incontinence in a patient who was not incontinent before
- marked decrease in urine output and darkening color of urine or very abnormal colors (such as red or brown)
- blood pressure dropping dramatically from patient's normal blood pressure range (more than a 20 or 30 point drop)
- systolic blood pressure below 70, diastolic blood pressure below 50
- patient's extremities (such as hands, arms, feet and legs) feel very cold to touch
- patient complains that his or her legs/feet are numb and cannot be felt at all
- cyanosis, or a bluish or purple coloring to the patients arms and legs (especially the feet and hands)
- patient's body is held in rigid unchanging position

Although all patients do not show all of these signs, many of these signs will be seen in some patients. The reason for the tradition of "keeping a vigil" when someone is dying is that we really don't know exactly when death will occur until it is obviously happening. If you wish to "be there" with your patient when death occurs, keeping a vigil at the

bedside is part of the process.

Always remember that your patient can often hear you even up till the very end, even though he or she cannot respond by speaking. Your caring presence at the bedside can be a great expression to your patient and help him to feel calmer and more at peace at the time of death.

If you have questions about any of the changing signs or symptoms appearing in your loved one, ask your hospice nurse to explain them to you.

GONE FROM MY SIGHT: THE DYING EXPERIENCE

Each person approaches death in their own way, bringing to this last experience their own uniqueness. What is listed here is simply a guideline, a road map. Like any map, there are many roads arriving at the same destination, many ways to enter the same city.

Use this guideline while remembering there is nothing concrete here; all is very, very flexible. Any one of the signs in this booklet may be present; all may be present; none may be present. For some, it will take months to separate from their physical body, for others, only minutes.

Death comes in its own time, in its own way.

Death is as unique as the individual who is experiencing it.

If the following signs were t be put on a timetable, a very flexible timetable, we could say these changes begin one to three months before death occurs. The actual dying process often begins within the two weeks prior to death. There is a shift that occurs within a person that takes them from a mental processing of death to a true comprehension and belief in their own mortality. Unfortunately, this understanding is not always shared with others.

One to Three Months Prior to Death: Withdrawal

As the knowledge that "yes, I am dying becomes real, a person begins to withdrawal from the world around them. This is the beginning of separation, first from the world—no more interest in newspapers or television then from people—no more neighbors visiting: "Tell Aunt Jessie I don't feel like company today." And finally from the children, grandchildren, and perhaps even those persons most loved.

This is becoming a time of withdrawing from everything outside of one's self and going inside. Inside where there is sorting out, evaluating one's self and one's life. But inside there is only room for one.

This processing of one's life is usually done with the eyes closed, so sleep increases. A morning nap is added to the usual afternoon nap. Staying in bed all day and spending more time asleep than awake becomes the norm. This appears t be just sleep but know that important work is going on inside on a level of which "outsiders" aren't aware.

With this withdrawal comes less of a need to communicate with others. Words are seen as being connected with the physical life that is being left behind. Words lose their importance; touch and wordlessness take on more meaning.

Food

Food is the way we energize our body. It is the means by which we keep our body going moving, alive. We eat to live. When a body is preparing to die, it is perfectly natural that eating should stop. This is one of the hardest concepts for a family to accept.

There is a gradual decrease in eating habits. Nothing tastes good. Cravings come and go. Liquids are preferred to solids. " I just don't feel like eating." Meats are the first to go, followed by vegetables and other hard to digest foods, until even soft foods are no longer eaten.

It is okay not to eat. A different kind of energy is needed now. A spiritual energy, not a physical one, will sustain from here on.

One to Two Weeks Prior to Death: Disorientation

Sleeping is most of the time now. A person can't seem to keep their eyes open. They can however, be awakened from that sleep. There is literally one foot in each world. A person often becomes confused, talking to people, and about places and events that are unknown to others. They may see and converse with loved ones who have died before then. There may be picking at the bedclothes and agitated arm movements. There is a seeming aimlessness to al physical activity. Focus is changing from this world to the next; they are losing their grounding to earth.

Physical Changes

There are beginning changes that show the physical body is losing its ability to maintain itself.

The blood pressure often lowers.

There are changes in the pulse beat either increasing from a normal of eighty to upward of one hundred fifty, or decreasing anywhere down to zero.

The body temperature fluctuates between fever and cold.

There is increased perspiration often with clamminess.

The skin color changes: flushed with the fever, bluish with the cold. A pale yellowish pallor (not to be confused with jaundice) often accompanies approaching death. The nail beds, hands, and feet are often pale and bluish because the heart can't circulate the blood through the body at a normal flow.

Breathing changes also occur. Respiration may increase from a normal sixteen to twenty, to upward of forty or fifty breaths every minute, or decrease to nine or even six breaths a minute. There can be a puffing, a blowing of the lips on exhaling, or actual stopping of the rhythmic breathing only to resume. This generally occurs during sleep. Congestion can also occur, a rattly sound in the lungs and upper throat. There might be coughing with this but generally nothing can be brought up. All of these breathing changes and congestion have a tendency to come and go. One minute, any of all of these symptoms may be present, the next minute; breathing may clear and be even.

One to Two Days, to Hours Prior to Death

Sometimes there is a surge of energy. A person may talk clearly and alertly when before, there had been disorientation. A favorite meal might be asked for and eaten when nothing had been eaten for days. A person might sit in the living room with relatives and visit when they hadn't wanted to be with anyone for quite a while. The spiritual energy for transition from this world to the next has arrived and it is used for a time of physical expression before moving on. The surge of energy is not always as noticeable as the above examples, but in hindsight, it can usually be recognizes.

The one to two weeks' signs that were present earlier become more intense as death approaches.

Restlessness can further increase due to lack of oxygen in the blood.

The breathing patterns become slower and more irregular. Breathing often stops for ten to fifteen and even thirty to forty five seconds before resuming.

Congestion can be very loud. It can be affected by positioning on one side or the other. It still comes and goes.

The eyes may be open or semi- open but not seeing. There is a glassy look to them, often tearing.

The hands and feet now become purplish. The knees, ankles, and elbows are blotchy. The underside of the arms, legs, back and buttocks also can be blotchy.

Generally, a person becomes non-responsive (unable to respond to their environment) sometimes prior to death.

How we approach death is going to depend upon our fear of life, and how much we participated in that life, and how willing we are to let go of this known expression to venture into a new one. Fear and unfinished business are two big factors in determining how much resistance we put into meeting death.

The separation becomes complete when breathing stops. What appears to be the last breath is often followed by one or two long spaced breaths and then the physical body is empty. The owner is no longer in need of a heavy, non-functioning vehicle.

They have entered a new city, a new life.

SUMMARY OF GUIDELINES

One to Three Months

- Withdrawal from the world and people
- Decrease food intake
- Increase in sleep
- Going inside self

- Less communication

<u>One to Two Weeks</u>

- Disorientation
  - Agitation
  - Talking with the unseen
  - Confusion
  - Picking at clothes

- Physical
  - Decreased blood pressure
  - Pulse increase or decrease
  - Skin color changes: pale, blush
  - Increased perspiration
  - Respiration irregularities
  - Congestion
  - Sleeping but responding
  - Complaints of body tired and heavy
  - Not eating, taking little fluids
  - Body temperature: hot, cold

<u>Days or Hours</u>

- Intensification of one to two week's signs
- Surge of energy
- Decrease in blood pressure
- Eyes glassy, tearing, half open
- Irregular breathing: stop, start
- Restlessness or no activity
- Purplish, blotchy knees, feet, hands
- Pulse weak and hard to find
- Decrease urine output
- May wet or stool the bed

<u>Minutes</u>

- "Fish out of water" breathing
- Cannot be awakened

I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the

blue ocean. She is an object of beauty and strength. I stand and watch her until at length she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

Then someone at my side says: "There, she is gone!"

"Gone where?"

Gone from my sight. That is all. She is just as large in mast and hull and spar as she was when she left my side and she is just as able to bear the load of living freight to her destined port.

Her diminished size is in me, not in her. And just at the moment when someone at my side says: "There she is gone!" There are other eyes watching her coming, and other voices ready to take up the glad shout: "Here she comes!"

And that is dying.

--Henry Van Dyke