

SIGNS AND SYMPTOMS OF APPROACHING DEATH

An increasing number of individuals are choosing to die in the secure and familiar surroundings of their homes with their loved ones at their side. This takes considerable strength on the part of both the dying individual and his or her family. We realize that this is when anxiety and anticipation of the unknown prompts many questions. The anxiety of caregivers can be reduced if the natural physical manifestations of death are anticipated. In an attempt to answer some of these questions and to help you in maintaining your physical and emotional strength, we have prepared the following information for you. We hope this straightforward information will help you understand and prepare for symptoms you **may** observe as your loved one nears death.

This is a summary of the signs, which precede death in most people as their body systems slow down and finally cease functioning. For some people these signs appear a few hours before death; for others, a few days. Even when many of these signs are present, it is difficult to predict the amount of time before death will occur. There is no particular order in which these events occur, and some people may not experience all of them. We have included some suggestions for promoting the comfort of your loved one as these signs occur. It is important for you to remember that during this final stage of life, there are no “rights” or “wrongs”. Whatever you feel like doing for your family member is the “right” thing for you to do. This may be no more than sitting or lying with him or her and communicating the comforting assurance that you are there. Although watching his or her declining condition may be difficult for you, your loved one is usually unconcerned about these changes.

Usually in the weeks and days before death, your primary Hospice nurse will begin to visit more often and ideally other members of your Interdisciplinary Team will increase their availability and support. We hope that by knowing what to expect you will be more comfortable in continuing to provide your loved one/friend/ care-receiver with the same loving support, which has sustained him or her during the illness.

Things to Watch for

Sleeping

Your family member will gradually spend more and more time sleeping as he or she begins to detach himself from his environment, and at times may be difficult to arouse. This is the result of changes in the body and metabolism slowing down. What to do:

- Understand that this is normal as the body weakens and an individual begins to let go of the physical world.
- Position your loved one for comfort, if this is his/her wish. Attempts to make him/her more comfortable may be refused.
- Let him/her sleep and rest.

- Plan to spend more time with your loved one during those times when he/she is most alert, even if there is nothing to “do for” him or her. Do not feel compelled to continue the same physical care routine that you have followed in the past. **At this point being with is more important than doing for.**

Eating and Drinking

There will be less interest in eating and drinking because the body has a decreased need for food or fluids. For many individuals refusal of food is an indication that he or she is ready to die. What to do:

- Offer, but do not force, favorite foods and fluids.
- Medications may no longer be needed or may be administered differently.
- Mouth care is especially important at this time. Keep your loved one’s mouth moist with a damp cloth or toothettes (a small sponge on a stick). You may keep the lips moist with a lip balm.
- Often when the body is dying and systems are shutting down, food makes the process more difficult by requiring digestion and increased metabolism

Vision, Speech and Hearing

As the nervous system slows, your loved one’s vision will lessen and his or her speech may be difficult to understand. We believe that hearing is the last sense to be lost. What to do:

- Speak distinctly. Explain what you are doing. Reassure him/her of your presence and your caring.
- Keep the room as light as the patient wishes, or at a comfortable level, even at night. The eyes may become dry or sunken, or they may protrude or glaze over and seem to stare. A warm damp cloth may be used to remove eye secretions. The pupils may dilate.
- Soothing music may be enjoyable as well as conversation from family and friends. Even when your loved one cannot respond, he or she may be able to hear and understand. This is an excellent time to express love and caring. Show your feelings; say the things that have not been said. Encourage other family members/friends to do the same.
- Speak clearly but no more loudly than usual. Carry on all conversations as if they can be heard, even if your loved one is sleeping, since hearing is the last of the senses to cease functioning.
- Children may want to talk or have a chance to say good-bye in their own way. They may be encouraged to participate in the process and express their own feelings and fears.

Bladder and Bowel

As death approaches, the nervous system changes and muscles become weaker. Incontinence (loss of control) of urine and/or bowel movements may occur as the bladder and rectum muscles relax. If your loved one has a catheter in the bladder, you may notice a change in the color of the urine in the bag or a decrease in the amount of urine as kidney function slows.

What to do:

- Protect the mattress. Keep Chux or waterproof padding under the patient, and change as needed to keep him/her clean and comfortable.
- Adult diapers should be available for use when bowel/bladder control is lost.
- Ask for information about skin care.
- If he/she expresses a desire to urinate and cannot, or if there is an increased restlessness or moaning in the comatose patient, call Hospice for advice. The doctor may order a catheter for collecting urine.
- Observe the urine output for amount, color and odor.

Pain Management

Often a person's greatest fear when he or she becomes ill is uncontrolled pain. Pain can be very helpful when it serves to let us know something is wrong. As a signal, it tells us where the injury or illness is located and helps the doctor determine how best to treat it. But when the pain lasts beyond the expected time required for tissue to heal – as with cancer or other terminal illnesses – it is considered chronic. Chronic pain is not helpful; it is debilitating. It robs us of energy. It prevents us from performing daily activities. It interferes with our ability to feel pleasure. When an individual is suffering from chronic pain, the pain should be controlled. Pain medication should be given around the clock, even if this means waking him/her. If at all possible, the physician will order a medication, which is time-released and will make your loved one comfortable through the night. If, however, the medication ordered requires that he/she receive a dose every 4 to 6 hours, it must be given around the clock. It is important to know that even severe pain can be controlled by combinations of pain medication. The right combination of pain medications can keep your loved one comfortable and able to enjoy a quality of life not experienced by someone who is constantly battling pain. In order to prescribe the correct medications for pain control, a doctor must be accurately informed as to the nature of the pain. The following information will be helpful:

- Is the pain localized (in one area or body part) or does your loved one describe it as “all over”?
- Is the pain dull, throbbing or sharp? What words does he/she use to describe it?
- Do any activities increase the pain? Walking, eating, reading, etc.?

What to do:

- Administer the pain medications exactly as ordered.
- **Keep a record** of time given, amount given, and effectiveness; if adjustments are needed, you can give doctor or nurse more accurate information.
- Daily laxatives or other medications for the bowels are usually necessary: narcotics are constipating.
- Do not stop or decrease pain medication suddenly once the pain is under control. Ask for advice from your nurse.

Confusion – Hallucinations – Restlessness

As the oxygen supply to the brain decreases, your loved one may become more confused about the time, place and identity of close and familiar people. Speech may be difficult to understand or incoherent. He/she may be disturbed by “strange” dreams. You may notice your loved one is having visual hallucinations or hearing voices of people or things that do not exist. It is not unusual for people to become restless, pulling at bed linens, trying to remove clothing or even to try to get out of bed at this point. These symptoms are anticipated, as less oxygen is available to supply the brain, due to a decrease in circulation and a change in the body’s metabolism and electrolyte balance. What to do:

- Reorient your loved one frequently in a conversational way by reminding him or her of the time and day, and identify yourself and those in the room.
 - It is okay to agree with hallucinations, but comfort with gentle reminders as to time, place, and person. Or, if simply reliving or reviewing another period in his or her life, it may be most appropriate to just listen.
 - Do not insist however, on your perspective being “correct!”
- Maintain his/her surroundings with familiar and favored things. Pets can be an asset in keeping your loved one oriented.
- Some dying individuals prefer a well-lit room, with sunlight if possible. Others prefer the room dark.
- Quiet a noisy environment.
 - Suggest that visitors leave cell phones, etc outside the room. Extraneous conversation is unnecessary
- Reassure your loved one in a calm voice that you are there and that you will take care of him or her.
- Speak slowly and confidently.
- Physical reassurance can be given with a touch, a hand held, a gentle massage of back, hands or feet.
- Soft music or a back rub may help quiet him or her.
- Provide a safe environment. Bedrails may be needed and a soft blanket may be used to cover the rails to prevent injury. Prevent your loved one from falling if he or she tries to get out of bed.

Body Temperature/skin color/heart rate

As the circulation decreases, the pulse may become faster and weaker. It may be difficult to feel a pulse at the wrist. The heartbeat may be irregular and less audible. Reflexes such as coughing and blinking may gradually disappear. The body’s heat regulation system may fail. The body temperature changes back and forth. He/she may feel hot one minute and cold the next.

The arms and legs may become cool to the touch and you may notice that the underside of the body becoming much darker in color. Nail beds may become blue in appearance. The face may become ashen with the body becoming blue and cold. The skin may feel cold and clammy when touched. Skin on the extremities may become “mottled”—blue or reddish. These symptoms

are a result of blood circulation slowing down. The dying individual is usually not conscious of the cold but may be restless, throwing off covering blankets. What to do:

- Add or remove blankets as needed. Do not use electric blankets since the circulation of blood slows down and there is a danger of burns.
- Reposition the patient on his/her side periodically and move his/her arms and legs gently from time to time.
- Sponge the patient with a cool washcloth if this promotes comfort, and change perspiration-soaked garments and bed linens, if it is not too disruptive to the patient.
- For high, troublesome fever, a medication can be ordered and ice packs can be applied to under arms and groin areas.

Breathing

A first indication of approaching death may be changes in your loved one's breathing. Breathing may become irregular with periods of no breathing, or apnea, (lack of breathing) lasting around 20-30 seconds. This symptom is very common and indicates decreased circulation. It is not distressing to the dying individual. He/she may seem to be working very hard to breathe and may make a moaning sound with each breath. As the time of death nears, breathing may again become regular but shallower and more mechanical in nature. As a result of a decrease in the body's inability to cough up normal saliva production, and because he or she has been drinking less, he/she may not be able to cough up secretions. These secretions may collect in the back of the throat causing noisy breathing, which is sometimes called the "death rattle". Rattling or gurgling noises do not mean that your loved one is in discomfort, but these sounds may be upsetting to the caregivers. As your loved one breathes through his or her mouth, it may become dry and encrusted with secretions.

What to do:

- Raise the head of the bed if your loved one breathes more easily this way. The "moaning" is not necessarily indicative of pain or distress, but often is only the sound of air passing over very relaxed vocal cords. Understand that he/she may not be bothered by or aware of the noise.
- Secretions may drain from the mouth if your loved one is placed on his or her side and supported with pillows.
- Cleansing the mouth with swabs dipped in cool water will help relieve the dryness that occurs with mouth breathing. Give careful oral care, wipe mouth with wet cloth and apply lubricant to lips.
- You should check with your nurse about certain medications, which may help control secretions.

As the Time of Death Nears

As your loved one's condition declines and he or she begins to emotionally withdraw from this world, caregivers can suffer feelings of helplessness. Withdrawal is normal for the dying person as he or she becomes less concerned about surroundings. At this time, many of the tasks

mentioned earlier will no longer be appropriate. Alternative ways to keep your loved one comfortable might include a sponge bath and moistening the lips with cool water. Holding his/her hands can be very meaningful and comforting at this time. It is important to continue to talk to your loved one and offer reassurance. Simply saying, "I'm here with you" can offer great support and comfort.

When you feel that death is near, it is a good time to bring the family members together, since they may have some last thoughts or expressions of love to share with the dying person. Family and friends may take turns sitting with him/her and saying their special good-byes. It may be appropriate at this time to give permission to your loved one to surrender his/her hold on life. He/she can be informed that he or she will be missed and his/her family and friends will be fine. Tell visitors and other family members to speak in front of the dying person as if he or she can hear, even if he/she appears to be sleeping. Nothing should be said that would distress him/her should the conversation be overheard.

You should call your Hospice nurse to let her know that death is approaching. Each person is unique and approaches death in his or her own way. Remember, no matter how "well prepared" or informed you are, it is natural to be quite confused, upset and unable to readily read or follow simple instructions for a while. Some people may feel as though they should "do" something to try to revive the loved one as death nears. This feeling is natural, but since, in this situation, death is expected and normal, the greatest service to the patient is simply to maintain comfort. Medical personnel or caregivers who are not prepared for the expected death may be inclined to call for emergency medical procedures.

At The Time Of Death

Death is the permanent cessation of all vital functions. It may come suddenly or after a slow deterioration of your loved one's condition. It is natural for the survivors to often feel that death would be a blessing and wish that it would come quickly. At the time of death:

- Your loved one cannot be aroused.
- Breathing ceases.
- Heartbeat ceases and there is no pulse.
- The eyelids may be partially open with the eyes in a fixed stare.
- Loss of bladder and bowel control occurs.
- The jaw relaxes and the mouth may fall open slightly.

No matter how well prepared you are, facing a death is difficult. We encourage you to have supportive people with you or available.

What To Do When Death Has Occurred

Death is not an emergency. Try not to panic at the time of death. Everything will be taken care of in a timely manner. **PLEASE REMEMBER THAT THIS INFORMATION WAS WRITTEN FOR FAMILY MEMBERS/friends WITH A LOVED ONE WHO IS DYING.**

IF you are present at the time of a person's death, and there is no one else with you, call the HOSPICE RN immediately. IF the client was not in Hospice, first call a family member or healthcare provider. A hospice nurse will be available to come to the home.

The RN will ascertain that death has occurred and make necessary calls.

The following information is for dealing with a personal hospice situation:

Decide when you would like someone to come to pick up the body. It is not necessary that the body be removed immediately. It is permissible to keep the body in the home for several hours. The nurse will call the physician and mortuary when you are ready. The time immediately following death is very special and should not be rushed. There is no need to hurry with the removal of the body.

Family members and friends may wish private time to communicate with the dead person and this is very important. When you are ready to attend to the remaining details, you can ask someone to help you. Don't let well-meaning friends act without specifically delegating responsibility to them. Otherwise, you may later regret the things that were not arranged, as you really would have wished. It may be important to get some food, rest or spend time with members of your family. Perhaps your loved one has left instructions about what to do when the end is reached. **By all means, follow these last wishes.** It is helpful to make arrangements beforehand with a mortuary and place instructions in a prominent place so that appropriate steps will be followed. Misunderstandings and unnecessary stress can be avoided if these matters are handled ahead of time. It is important that the mortuary is informed that this is an expected death.

The family/loved ones may wish to bathe or dress the body and any special requests should be communicated to the mortuary attendants. A death certificate will be completed by the mortuary and signed by the physician for filing with the Health Department. The family may choose to remain with the body and escort it to the door. The removal of the body may have a strong impact on all concerned, even more than when the last breath comes. You may ask the mortuary staff NOT to cover the head of the deceased until they reach their vehicle. It is often disconcerting to witness a "body bag" being zipped up.

Close friends and family can provide security and comfort at this time and should not be dismayed by expressions of grief.

Be assured that your thoughts and actions, after your loved one's death, are at once as unique and as universal as the end of life itself. Some things you do will be instinctive: to cry, to mourn, to feel a sense of relief that you have been freed from your obligation to care for

the dying. Remember that you have, simply by your long vigil, done what has been required of you. You have discharged a difficult responsibility.

While it carries with it immense sorrow, it also can bring great reward—for you have given someone you love very much the deepest measure of love it is possible to express. It is this bond of compassion that is at the core of the Hospice and Palliative Care movement.

*When we walk to the edge of all the light we have
And take that step into the darkness of the unknown,
We must believe that one of two things will happen:
There will be something solid for us to stand on,
Or we will be taught how to fly.*

-D. Overton