A guide for caregivers

Introduction to caregiving – hospice care and support

The hospice caregiver has an important role. In a hospice situation, a caregiver is a helper, guide, friend and witness to the ending of a life’s journey. Caring for a family member or friend is not always easy. Nor is it something you may be completely prepared to do. Yet the rewards and experience can be rich and fulfilling.

Care, support and understanding

Having adequate information about what to expect as a hospice caregiver will make your experience more comfortable for both you and your loved one. You are providing a gift of love, understanding and comfort at a time when your loved one is going through many physical, mental and emotional changes. He or she may be confused and experiencing pain or simply tired and in need of rest. The focus of hospice is to provide comfort and peace in the final stages of your loved one’s life.

You are not alone in your role as caregiver. You always have help to answer your questions and concerns or to handle challenging situations. We are here to care for your loved one and to support you during this time.

Physical and emotional symptoms – what you can do

During the natural dying process, your loved one or friend will experience a series of changes in mental, emotional and physical conditions. These symptoms occur differently with every individual in no particular order and at times may overlap. Physically, the body undergoes a process of shutting down, while the emotional process may include a desire to take care of unfinished business as a person begins to let go and withdraw from the world.

The following pages list the common physical and emotional symptoms and the appropriate steps you can follow to provide comfort and assistance. By recognizing these changes, you will be more prepared and better able to help your loved one find peace with the dying process.

What is hospice?

Hospice is a form of compassionate and quality care for people facing a life-limiting illness or injury. It affirms life and looks at dying as a normal process. Hospice is based on the belief that each of us has the right to die pain free and with dignity and that our loved ones will receive the support they need to allow us this right.

Becoming a better caregiver

As a caregiver, you have an important and challenging job. The person you are caring for must deal with the physical effects of disease and medications, as well as the psychological challenges of accepting death. If possible, it’s helpful to involve your loved one and family members in making decisions and supporting the hospice process.

Work with and communicate effectively with your loved one or friend.

• Help to resolve any unfinished business.
• Work closely with your hospice team of professionals.
• Work with family and friends to help them accept the processes occurring.
• Support your loved one’s spiritual concerns.
• Take care of your own needs and feelings.
Loss of appetite:
When a body is preparing for death, hunger and thirst are experienced differently than in someone who is healthy. It is natural for a person to have a decreased appetite or to desire only certain foods or beverages. Your loved one or friend may say that food no longer tastes good, or he or she may lose interest in eating altogether. Meats and heavy proteins are often the first food group to lose appeal, followed by fruits and vegetables. During this phase, a person’s diet may be reduced to soft foods and liquids. This may be difficult to accept since eating is regularly associated with vitality, but it is OK for your loved one to not eat. Sometimes eating may only increase your loved one’s discomfort.

What you can do
• Don’t force your loved one to eat or drink.
• Offer small, frequent snacks of the types of foods he or she prefers.
• Use bendable straws with cool water or a favorite beverage to keep the mouth and lips moist and comfortable. Sponge swabs soaked in water or a favorite beverage may also be used.

Desire to be alone:
It’s normal for your loved one or friend to want to see fewer people or to be alone. He or she may be growing weak or tired, and this is how some people emotionally prepare for the separation of death. Simply honor this need if and when it occurs.

What you can do
• Limit visits to those your loved one wishes to see.
• Recommend short visits for everyone.
• It is not always important to talk when you are with your loved one. Being present or holding his or her hand may be all that’s needed to feel comfort and peace.
• Keep lights turned low; some people feel uncomfortable under bright lights.

Sleeping:
You may find your loved one spends an increasing amount of time sleeping and may appear withdrawn, uncommunicative or unresponsive. This is also normal as the body slows and a person withdraws further in preparation for death.

What you can do
• Plan to spend time with your loved one when he or she is most awake.
• Just because a loved one seems unresponsive, he or she may still be aware of what is going on or being said.
• Speak normally though there may be no response. Your loved one may only be listening.
• Hold hands with your loved one; touch is comforting.

Restlessness:
It’s normal for hospice patients to seem restless or make repetitive motions. Do not try to interfere or restrain your loved one from moving.

What you can do
• Create a calm and comforting atmosphere and temperature in the room; eliminate bright lights.
• Speak in a quiet, normal tone.
• You can even try other things that may help calm someone such as holding a hand, stroking arms or forehead, reading aloud, or playing soft, soothing music.
• Reassure your loved one that you are there if he or she needs anything at all.
Changes in breathing and congestion:
It is common for the regular breathing pattern of a person to change. Breathing may become slow and shallow and at times hardly noticeable. If your loved one develops gurgling or rattling in the chest and throat, it may be due to an inability to clear or cough up secretions. Congestion is normal and not necessarily an indicator of discomfort.

What you can do
• Elevate your loved one’s head with a pillow or blanket.
• Turn your loved one on his or her side, or turn the head to one side if he are she is uncomfortable; this may help clear the fluid.
• Be reassuring that all is OK; hold your loved one’s hands and speak gently.
• Mouth care may be given as instructed by your nurse.

Pain:
Your friend or loved one may experience pain in differing ways. Your loved one may feel pain increase, it may lessen, or your loved one may experience no change at all. It is common for someone’s perception of pain to change. Watch for complaints or signs of pain, but do not change medication without the direction of your hospice nurse.

What you can do
• Call your hospice nurse for help with complaints about pain. Our hospice team can provide medication to alleviate symptoms of discomfort such as pain, nausea, agitation or labored breathing. Our goal is to make your loved one as comfortable as possible.

Incontinence:
Changes in the body’s output of urine and the control of these functions is normal and expected. Though it can be troubling, it is not uncommon for hospice patients to lose control of either bladder or bowel movements as muscles relax.

What you can do
• Reassure your loved one that this experience is normal and that you are there to help.
• Discuss with your hospice nurse the best ways to keep your loved one clean and comfortable.

Confusion and disorientation:
It’s not uncommon for hospice patients to lose track of where they are, what time it is or the identity of those around them.

What you can do
• Say your name before you speak to your loved one. Answer questions simply and honestly. Assure your loved one you are there, and there is no reason to worry or fear.
• Don’t try to force or trick your loved one into doing something like taking medications, even if you believe it’s the best thing. It’s more important to maintain trust between the patient and caregiver.
• Speak softly, clearly and honestly. For example, “It’s important to take your medications now so you won’t be in pain.”

Body temperature, fever and skin color changes:
Some hospice patients experience coolness in their face, hands and feet, and may feel cool to your touch, while others may run a fever. Their skin may seem pale, blotchy or even discolored. These are all normal signs of changes in circulation to the body’s extremities.

What you can do
• Keep your loved one lightly covered; if your loved one says he or she is cold, offer a heavier cover.
• Avoid using an electric blanket since the temperature may fluctuate frequently.
• Socks may help keep cold feet warm.
• For fever, use a cool, damp washcloth on the forehead, wrists or under each arm.
• Call your hospice nurse to discuss other comfort measures that might help your loved one.
Visions:
It could happen that your loved one may begin to speak to persons that have already died or claim to see places and things that are not visible to you. This is normal.

What you can do
• If these experiences frighten your loved one, explain they are normal and there is nothing to fear.
• Validate your loved one’s experience, and if you can, gently re-orient him or her to the present. Don’t try to tell your loved one that what is being experienced is unreal or try to explain away what is seen and heard.

Sudden rally or surge in energy:
At times, it happens that a person can become energized and alert when he or she was previously confused or listless. Your loved one may experience a sudden increase in appetite when previously appetite was all but gone, or he or she may decide they want to see visitors when before they wished to be left alone. These are all normal experiences.

What you can do
• Give your loved one all the attention you can and be fully present at this time.
• This sudden burst of energy may not last long and may not happen again. Help your loved one create a quality experience of this time of awareness and presence however long it may last.

Unexpected communication:
Some hospice patients may suddenly make statements or gestures that seem out of character or even indicate they are ready to say good-bye. They may be testing your reaction or alert you they are ready to pass on.

What you can do
• There is no need to panic. Accept this moment as an opportunity to share the experience of dying with your loved one. Give your loved one a hug or kiss, hold hands and be willing to share this moment.

Nearing the end

Giving permission to go:
One of the most difficult things for some family and friends is allowing a person to let go and accept the transition into death. If the dying person believes that those around him or her are hanging on, he or she will sometimes do the same to show concern for loved ones being left behind.

What you can do
• One of the greatest gifts you can give to a dying loved one is to let go and give him or her the freedom to do the same. Death is a natural part of life.
• Reassure your loved one and let him or her know it is all right to let go.

A last goodbye:
The moment of death in the hospice process is a beautiful milestone event, because it allows closure and prepares everyone involved for this last goodbye.

What you can do
• Say goodbye; give or receive forgiveness or whatever feels appropriate for this special intimate moment. You may want to recount favorite memories, hold hands or share your love and appreciation for your loved one and for all that life has offered.
• Your loved one may wish to know if his or her life has made a difference in your life or the lives of others. Assure your loved one he or she will be remembered.

The role and purpose of hospice
In a hospice setting, the approach of death is not an emergency. It is the purpose of hospice to create a situation in which your loved one or friend may welcome death in comfortable surroundings without painful or extreme treatments.

The signs of death may include:
• Breathing slows and stops
• Heartbeat and pulse stops
• Eyes may fix on a certain point without blinking
• Mouth is slightly open, with jaw relaxed
• Release of bladder or bowels