Old Colony Hospice created this guide for our hospice family and caregivers by revising and adapting the following journal article: "Hospice Techniques: Preparing for the Death of a Loved One"

The American Journal of Hospice and Palliative Care

We gratefully acknowledge the authors and helpful content in the article and permission granted from Sage Publications to use this material.



Old Colony Hospice realizes that in the final stages of a terminal illness, caregiver anxiety reaches its peak and anticipation of the unknown brings many questions to mind. We hope the following information will help families be comfortable in continuing to provide the same loving support that has sustained a patient during their illness.

We hope this information helps you in your experience as caregiver(s). Please call us at any time with needs, questions and concerns. Thank you for allowing us to care for you and your loved one.

Saying good-bye

When your loved one is ready to die, and the family is able to let go, this is the time to say good-bye in personal ways. This closure allows for the final release. It may be helpful to just lay in bed with the person, hold a hand, and say everything you need to say. Tears are a natural part of making peace and saying good-bye. Families do not need to hide tears or apologize for them, as tears are an expression of love.

At the time of death

Most people have not been present at the death of a loved one. Here are some things that will happen:

- Breathing ceases
- Heartbeat ceases
- The person cannot be aroused
- The eyelids may be partially open with eyes in a fixed stare
- The mouth may fall open as the jaw relaxes
- There is sometimes a release of bowel and bladder contents as the body relaxes

When the death has occurred, please call us. The nurse will come to your home to complete the pronouncement and make the necessary calls to the funeral home and physician. The nurse will also dispose of medications, following hospice guidelines.

wo different but interrelated dynamics occur in the final stage of the dying process. All the physical systems weaken and move toward ceasing to function. These changes are natural and are not considered medical emergencies, but rather the way in which the body prepares itself to stop.

The other dynamic involves emotional, spiritual, and mental changes. The person may become anxious, confused, see and speak about deceased family members and may even linger because of concerns or unresolved issues.

Each person is unique, has a unique way of living, and also a unique way of dying.

The following information describes changes in the final stage. For some, these signs appear a few hours before death, while for others a few days. Some may not happen at all. We have included suggestions on how family might respond when symptoms appear, and can promote patient comfort, acceptance and support.

Fluid and Food Intake

Your loved one may have a decrease of appetite and want little or no food or anything to drink. Why is this happening? The body is conserving energy which is often used on these tasks. Oral hydration (fluid by mouth) is often not possible, and it is actually more peaceful to be in a state of dehydration rather than have too much fluid in the body. Your loved one's body will let them know when it no longer desires or can tolerate food or liquids.

What you can do:

Using oral swabs or a moist face cloth will help to keep the mouth and lips moist, comfortable and hydrated. Small chips of ice, frozen juices or popsicles may be refreshing in the mouth. Do not force fluids if your loved one coughs soon after. The reflexes needed to swallow may be sluggish.

Decrease in Urine Output

Your loved one's urine output will decrease and may become tea-colored and referred to as concentrated urine. This is due to the decreased fluid intake, decreased circulation through the kidneys and fluid loss in breathing and respiration.

What you can do:

Keep your loved one warm if they appear cold, but do not use an electric blanket. If they continually remove the covers, then allow them just a light sheet.

Decreased Socialization

Your loved one may want to be alone or just with one person. This is natural when one is weak and fatigued. Too much stimulus arouses a person and takes away quality rest time.

What you can do:

Reassure the person it is okay to sleep.

Permission to go

A dying person will commonly try to hold on, even though it brings prolonged discomfort, in order to be assured that those left behind will be all right. It may be difficult for family to give permission to a loved one to let go, but it can be an act of love for family to find the ability to reassure and release their loved one.

Congestion

Your loved one may develop gurgling noises coming from the chest. These sounds occur when a person is no longer able to clear their throat. As they breathe, air moves over the collected fluid causing the noise. Sometimes the sounds become very loud and they can be distressing to hear. It is probably harder for you to watch than it is on the person, who is usually unaware that this is happening. We do not recommend suctioning as it can be hard for patients to tolerate.

What you can do:

Raising the head of the bed helps the secretions to pool low and therefore don't stimulate the gag reflex. Elevating the head, and/or turning your loved one onto their side may bring comfort. Hold their hand. Speak gently and reassuringly. If you feel uncomfortable, please call us.

Skin Color and Temperature Changes

Your loved one's arms and legs may become cold, hot or discolored. Also, the underside of the body may become discolored as blood circulation decreases. This is normal. Irregular temperatures can be the result of the brain receiving unclear messages.

Incontinence

Your loved one may lose control of urine and/or bowels as the muscles in that area begin to relax. Your nurse and hospice aide will be happy to discuss care needs and help you to obtain supplies to keep your loved one comfortable.

Sleeping Patterns

Your loved one may spend an increasing amount of time sleeping and appear to be uncommunicative, unresponsive and at times, difficult to arouse. This change is normal and due in part to changes in the body's metabolism.

What you can do:

Sit with your loved one, hold their hand and speak softly and naturally. Plan to spend time with them when they are most alert. The most important thing at this time is just being with your loved one and not worrying that you are not doing enough. Remember to speak directly to your loved one even though there may not be a response. Assume your loved one can still hear as hearing is said to be the last of the senses lost.

Restlessness

Your loved one may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in circulation to the brain and the metabolic changes that are occurring.

What you can do:

Do not be alarmed, interfere, or try to restrain such motions. To have a calming effect, speak in a quiet, natural way, lightly massage the hand/forehead, read aloud, or play soothing music.

Disorientation

Your loved one may seem confused about time, place and identity of the people surrounding them, including close and familiar people.

What you can do:

Identify yourself by name rather than asking the person to guess who you are. Speak softly, clearly, and truthfully when communicating something important for your loved one's comfort, such as, "It's time to take your medication or receive treatment." Be sure to explain the reason for the communication such as, "This will keep you comfortable."

Vision-like Experiences

Your loved one may speak or claim to have spoken to persons who have already died or to see places not presently accessible or visible to you. This is normal and common.

What you can do:

Rather than arguing or explaining away the vision, affirm his or her experiences. If however, you feel this may be due to medication or you need additional support please call us.

Breathing Pattern Changes

Your loved one's regular breathing pattern may change. You may see a new and common pattern consisting of irregular breaths with shallow respirations, or periods of no breaths for 5–30 seconds then followed by a deep breath. There may also be periods of rapid, shallow, panting type breathing. Sometimes there is a moaning-like sound on exhale: this is not distress, but rather the sound of air passing over relaxed vocal cords. These patterns are very common, and indicate a decreased circulation in the internal organs.

What you can do:

Elevating your loved one's head, and/or turning them onto their side may bring comfort. Hold their hand. Speak gently and reassuringly.