

Caring for the Dying in Hospice



Introduction

As a person approaches the dying process, their physical body begins to grow steadily weaker. The way and time a person dies is unique. No one can predict exactly when death will occur. But some signs and symptoms are common to the dying process.

Signs and Symptoms

You may have already noticed such changes as decreased appetite, increased weakness, withdrawal from all but the closest family and friends, and increasing sleepiness. As death approaches, these signs and others continue to increase.

Increased Drowsiness and Sleeping

It is common for your loved one to begin sleeping more. They will usually be very slow in responding to you and others. This is a normal slowing of the body rhythms. Be attentive to times when the person you care for is more alert and use those times to tell that person goodbye, thank you and I love you. If the dying person is not lucid or unable to stay awake, don't assume they can't hear you. Even if the patient is not responding, remember their hearing may be very acute. Do continue to communicate and provide comfort by talking and gently touching them. Sometimes, a person is so weak and fatigued that they aren't able to respond, but they are still able to hear you. Continue to speak as you would if the person were awake, and encourage others to do the same.

Increasing Weakness

As their body grows weaker, the person you are caring for will tire easily and may need assistance in doing simple tasks. You may need to assist them with eating and drinking, providing mouth care, and helping them change position. These tasks will be both physically and emotionally draining. They are your way of being present and compassionate, but please plan to reach out to other friends, family and hospice staff for help.

Loss of Appetite

Losing interest in food and drink is the body's way of slowing down the physical process of living. The systems which digest food are no longer working well and the person does not feel the need to eat as they would normally. In most cultures we equate food with love and comfort. As a caregiver, preparing favorite meals has been a way to provide care and love. It can be difficult to know when to stop encouraging the dying person to eat. Remember that your loved one is dying because of their disease; their body is no longer able to use the food you want to provide. Let the person you care for be your guide. If they have an appetite for



something, offer them a small amount.

Decreased Swallowing Reflex

Often an early sign of decline, the normal reflexive ability to swallow is slowed. Initially, the dying person may have difficulty swallowing medications. They may prefer soft foods and liquids. Offer them a small amount of their favorite foods, and remember that it may take time and energy to eat. If they are too tired to eat much, take the food away and let them rest. As the dying process progresses, they may have difficulty swallowing even sips of fluid. Ask your nurse for ways to safely help a person keep their mouth moist and comfortable.

Withdrawal from Family and Friends

Near the end of a person's life they begin sleeping more, talking less and often lose interest in things they have always enjoyed. They may no longer want to watch their favorite TV show, or care about what's happening with family and friends, or worry about a cherished pet. They may not want to talk to friends or relatives, even those closest to them. This is a natural 'letting go' of the world they have known and the life they have lived.

Increased Fears, Including a Fear of Being Left Alone

Sometimes a person who is not usually fearful of being alone begins to call out to caregivers more often to stay close by. This anxiety may be a subtle sign that a change in your loved one's condition is occurring. Being alone at times of change can make anyone fearful. You can help by being a caring presence. Your touch, a gentle and quick reassurance that you are close by, your kindness and willingness to stay nearby is usually sufficient to see your loved one through their fear. If your loved one remains restless or agitated, call your nurse right away to help relieve any distressing symptoms.

Increased Awareness of Spiritual and/or Religious Issues

Seeking and receiving forgiveness is an important task many people share toward the end of life. No matter how strong a person's faith, most people seek to understand what lies beyond this life and how difficult the passage will be. If you sense that the person you are caring for has questions or concerns of this nature, you may want to address these issues. Your hospice team can help you contact your faith community. The hospice chaplain is trained to address these concerns from a non-denominational point of view and is very experienced in dealing with the spiritual transitions that occur as death approaches.

Increase or Decrease in Pain

Changes in pain levels and pain awareness can change as death approaches. Pain medications may need to be adjusted for the patient to help them be aware



and alert as possible while maintaining an acceptable level of comfort. Your hospice nurse should be notified with any changes or concerns you have.

Changes in Bowel and Bladder Function

It is always difficult when a person becomes weak or sick and becomes dependent on the caregiver(s) to assist with elimination. Constipation is common due to medications, reduced fluid intake and disease. Your physician will want to establish a regular regimen of laxatives and stool softeners to establish a regular pattern. Expect the hospice nurse to coach you in the use of medications and help you learn how to best assist your patient in using a bedside commode, bedpan or diapers if needed. Urine may decrease and turn darker and smell stronger as food and fluid intake decreases. This is normal. Sometimes the dying person will need diapers or have a urinary catheter inserted to keep them clean and dry. If you need help in learning how to provide this care, and in helping your loved one accept your help, be sure to ask your hospice team for assistance. They will help you and your loved one feel more comfortable.

Confusion, Visions

Changes in metabolism, side effects of medications, disease progression and changes in the amount of oxygen available to the brain can prompt episodes of confusion and occasionally visions or voices that only the patient can see or hear. As long as these are not upsetting or disturbing to the patient, there is no need to be concerned. Be gentle and kind; do not try to convince the person that what they say or think is not real. If they are disturbed or frightened by these experiences, let your doctor or nurse know so they can adjust medications. Dying people often describe visits by loved ones who have passed or have experiences which are spiritually and emotionally comforting to them. Allow yourself to find peace and comfort in their experiences.

Changes in Skin Color

As death draws near, sometimes the hands, feet and other dependent (or underside) areas of the body will feel cool to touch and appear mottled and sometimes look bruised. This is a normal consequence of the body adjusting to changing blood circulation. More blood is directed to the vital organs to keep them functioning and less blood circulates to the extremities. You may want to put socks on the person's feet. Let your nurse know when you see these changes as it means death may be near.

Remember your hospice team is just a phone call away. You are not alone. Call anytime for help and reassurance during this important time.

