

When the Time is Near



*I am here with you.
I am here with you
until your last breath
and you will be with me
even after and always.*

An End-of-Life Guide for Caregivers



Introduction

Although dying is a natural part of the lifecycle, most people caring for someone during this time are facing a new and unfamiliar experience. Livingston Memorial Visiting Nurses Association & Hospice has put together these brief guidelines to let you know what you may expect and to help you feel more confident as you prepare to provide comfort and support to a loved one in the final stages of life. Everyone's dying experience is different, and there is no way to know exactly what will happen or when. As a result, as a caregiver you may experience uncertainty at times. Nonetheless, be assured that by your presence alone, you are providing great comfort. Further, by understanding some of the emotions and physical symptoms your loved one may be facing, you can aid in the dignity and quality of the last phase of their life.

This can be a time of completing important emotional tasks – from settling worldly affairs to achieving a sense of completion in relationships within the community, friends and family. It's also often a time of acceptance of one's own life – acknowledging and experiencing self-love and love for others. Finally, it may also be a time of "letting go" and acceptance. Again, your presence and support can provide reassurance and comfort.

Symptoms and Comfort Measures as Death Approaches

While everyone's dying process is different, the following is a general timeline of some of the signs and symptoms you might expect to see in a person who is nearing death and how you can address them.

Final Months (one to three)

During the final weeks of life, people often withdraw from friends, families and activities around them. With less need to communicate, there may be periods of silence. Touch becomes more important, and be mindful that while there may be less speech, hearing remains intact. During this time, you might also notice a decrease in eating and drinking as well as an increase in sleeping. Follow the person's lead and don't force foods or drink. Plan for visitors at the times when the person is most likely to be alert.

Final Weeks (one to two)

In the last weeks, your loved one may become confused, restless or disoriented – even talking to people who are not present. Use of expressions like "I want to go home" are symbolic language and may mean the person is trying to say goodbye. There can also be a wide range of physical symptoms including changes in skin color, breathing difficulties, decreased desire to eat and drink, and fluctuations in body temperature, blood pressure and pulse. Incontinence may also develop.

Your presence can be a source of reassurance and help the person to be oriented. Gently remind them who you are and who else might be in the room, but don't argue with them. What they are experiencing is real to them at the moment.

For restlessness and agitation, soft touch, holding hands, speaking calmly, reading aloud and even playing soft music can help bring calm. Talk with your nurse who can assess if the cause may be additional pain or discomfort. The social worker and chaplain are also there to provide emotional

support. Safety is important when dealing with restlessness. Bed rails can help keep the person safe and in bed, and a baby monitor will allow you to watch the person when you are out of the room.

Again follow the person's lead with regard to food. Ice chips and keeping the mouth and lips moist will aid in comfort. Changing position in bed may help with breathing. Fans and open windows or warm blankets may be helpful with temperature changes as will gentle massage.

Adult briefs and bed pads may be needed. Your nurse will be show you how to use them and may suggest lotions to help with skin irritation. Because incontinence may be embarrassing, take care to change disposable briefs and pads in private. Depending on the person's condition, the nurse may need to insert a catheter to keep the skin from being wet constantly.

Final Days

During the final days or hours, the person may sleep most of the time although their eyes may no longer close fully; however, there can also be an increase in restlessness or a surge of energy. Swallowing and breathing may become more difficult with pauses between breaths or rattling sounds. There may be decreased or no urine as well as additional changes in skin color and drop in blood pressure and pulse.

Continue the comfort measures you have been using. If there is a surge of energy, it offers a time to share memories, be together and say goodbye. You may choose to lie in bed with your loved one, to hold hands and to say whatever is in your heart. This is a very personal time, and there are no right or wrong answers.

Final Minutes

In the final minutes, the person's mouth may be open, breath becomes very shallow with long pauses and they will become unresponsive.

At Death

Once death has occurred, there is no heartbeat or pulse, nor any response to sound or touch. The person's eyes may be open, but pupils will not respond. The mouth will be open, and there may be loss of bowel and bladder control.

People respond to death and honor their loved ones in many ways. No matter how you have prepared, it can come as a shock. It's important to know that there is nothing you have to do right away – except call your hospice. You may also want to call family or a trusted friend to be with you. You don't need to call 911, the police or the funeral home.

It is your choice if you wish to dress or bathe the body, when you want the funeral home to come and whether you want to be present when they remove the body. You may choose to wait a period of time and say goodbye or share rituals or family traditions in your own way.

When your nurse or other members of your hospice team do arrive, they will

- Confirm death
- Remove tubes and medications and arrange for medical equipment to be removed
- Notify the physician, hospice team and funeral home if you wish
- Offer to bathe and prepare body
- Provide other supports as needed

The hospice team will follow your needs and wishes. When you do talk to the funeral home, they will let you know about making arrangements for services.

Self-care for the caregiver

Just as important as it is to care for the loved one who is in the final stages of life, it is important to care for yourself. Here are some tips to help protect your well-being during this physically and emotionally demanding time.

Taking care of your body

- Don't forget to eat – it's important to eat well-balanced meals at regular intervals and get plenty to drink, especially water
- Try to stick to any regular exercise routine
- Give yourself 15 minute breaks with your feet up or lie down
- Take deep breaths several times a day and get fresh air regularly – go outside, talk a walk, sit in the yard

Taking care of your emotions

- Ask for help. Often others want to help, but they don't know what you need – so tell them. Make a list of errands or tasks you need help with and share it freely.
- Talk and share your feelings with a trusted friend, family, spiritual counselor, hospice team member or all of them
- Use your hospice volunteer to give you respite – rest, time alone, help with errands
- Manage calls and visits to honor your own needs and private time



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