
The Journey's End

Each of us will pass from this world in our own way and in our own time. It is our goal that this natural series of events be peaceful. Thank you for letting us share in the care of your loved one during this time.

You may be feeling sad and anxious. Having a loved one die is very upsetting, partly because what is unknown and beyond our control is frightening. It is normal to have questions about what to expect in these last hours or days of your loved one's life. Sometimes understanding what you may see in these final moments can help you feel more at ease.

This booklet is designed to help you know what to expect at the end of life and also to provide suggestions about how you can help your loved one and yourself. Please use this guide to complement the advice provided by staff on the Palliative and Comfort Care Unit. The information described in this booklet applies to people with all types of life-threatening illness. But remember, each person is different and may not have every symptom. Our staff is here to guide and support you through this process—please feel free to ask questions and to share your concerns, fears or expectations.

"Love is immortal, and death is only an horizon, and an horizon is nothing save the limit of our sight."

— Rossiter W. Raymond 1840-1918

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Letting Go and Winding Down

In the final days of life there is a gradual shutting down of body functions. During this time people slowly withdraw from their world, pulling away from loved ones, food and activities. They will have limited amounts of energy, be sleepier and take more naps, and will want to stay in one place.

- ❖ **Things you can do:** Just sitting quietly or reading to your loved one can be comforting. Gentle touch and your physical presence speak of your love and concern.

Finding Comfort

You may be worried that your loved one will be in pain or is suffering. In the last days and hours of life, when your loved one is no longer able to speak, we will carefully look for physical signs of pain, which can include:

Grimacing	Tense or rigid body	Restlessness	Clenched fists
Sweating	Moaning	Rapid heart rate	Fast breathing

We can relieve pain in many ways, including medications in the vein or beneath the skin, concentrated oral medications, suppositories, or patches. Other measures for comfort may include massage, changing positions, music, relaxation tapes, pet therapy, and prayer.

- ❖ **Things you can do:** Gently massage your loved one's hand with lotion; moisten the lips with lip balm or oral sponges; play favorite music or read a favorite book out loud; keep noise to a minimum and avoid having too many people in the room at one time.

Nutrition

Even before these last days you may have watched your loved one gradually lose his or her appetite, even for favorite foods. This happens because in the final stages of any illness the body loses its ability to digest and make appropriate use of food or fluids, and when this occurs the person experiences a decrease in the desire to eat. People who are very close to death do not feel hungry or thirsty. In fact, nature is at work to help them die in a comfortable way; during this time, the body releases a pain-control chemical into the bloodstream, naturally reducing discomfort.

With these decreases in the digestion of food and fluids, artificial nutrition or IV fluids may worsen symptoms of breathlessness, swelling, congestion, and skin breakdown. The IV lines or tubes used to deliver food and fluids may also cause direct discomfort.

- ❖ **Things you can do:** Gentle touch, massage, and keeping the skin and lips moisturized are all ways to show that you care. Reminding yourself that your loved one is not hungry or thirsty will help you feel less worried when you are with him or her.

Breathing

Breathing patterns may change due to disease, immobility, body position, weakness, infection, or build up of fluid in the lungs. Your loved one's breathing may become fast, slow, or irregular. There may be long pauses between breaths, especially in the last hours of life. The breath may sound noisy and congested or labored and rattling. Your loved one may even snore loudly.

As the body weakens, people can no longer clear their throats; when this happens, a thin film of fluid may collect at the back of the throat and create a rattling noise. This does not cause your loved one any discomfort, but it can be upsetting to those who hear it. Medications can be given to dry out this fluid if desired.

When breathing finally stops, what seems to be the last breath may be followed moments later by one or two releasing breaths.

We can provide medications, breathing treatments, re-positioning and oxygen to help to make your loved one's breathing more comfortable.

- ❖ ***Things you can do:*** Talk quietly to your loved one in a comforting tone; use a fan if they would like this; and be a calming presence. People mirror the behavior of others around them, so practice taking long, deep, and full breaths when you are at your loved one's bedside.

Circulation and the Skin

At first your loved one may feel hot, but as circulation naturally decreases and the body's heat regulation system begins to slow down the skin becomes cool and clammy—most noticeably in the hands and feet. The face may become pale. There may be a blue tinge to the nail beds, lips or legs. The heart rate may increase at first, but as the heart weakens it will gradually slow down and blood pressure will fall. Swelling may occur and the skin may be very fragile.

- ❖ ***Things you can do:*** Request a fan if they are hot, or more blankets if they are cold; gently massage the hands or feet; hold their hand.

Restlessness and Weakness

As the brain begins to weaken your loved one may become confused, restless or speak to unseen persons. There may be twitching in the hands, feet, arms or legs.

As the body weakens there is loss of bowel and bladder control. The amount of urine produced lessens and the urine becomes darker.

As vision fails, the eyes may be open or semi-open but not seeing. They may become dry, sunken or glazed over. You can use a warm, damp cloth and eye drops to remove eye secretions.

Hearing is the last sense to be lost at the end of life, so even when people can no longer respond they may be able to hear you. They can understand and be soothed by your words or by music that is special to them.

- ❖ ***Things you can do:*** Talk quietly to your loved one, read a favorite book, or play familiar music; avoid overcrowding the room or holding conversations across the bed; dim the lights and minimize noise from the TV, phones, and difficult discussions; mask unpleasant smells with aromatherapy oils on a pillowcase or blanket brought from home.

Taking Care of Yourself

When a loved one is very ill, caregivers often forget to eat, sleep less and worry a lot more. Some people are reluctant to leave their loved one's bedside. Just as a flashlight shines dimly when the battery is low, people who are exhausted, hungry, and overwhelmed by emotion do not have much energy to give to their ill loved one.

You can recharge your battery by doing the following things:

- Take short breaks, even if it is just to step out in the fresh air or walk to the kitchen for coffee
- Eat as regularly as you can
- Try to nap throughout the day, and, if you feel comfortable doing so, spend the night at home in your own bed
- Talk to family and friends who can provide emotional support

Family and friends will often offer to help when a loved one is dying. Letting them help you allows them to feel useful. They can help you in the following ways:

- Pick a person to receive phone calls for you, and a person to give information and updates to others
- Ask trusted family and friends to stay with your loved one while you take breaks or go home to rest
- Ask people to bring you food, clean clothes, and special objects from home

Toward the end of your loved one's life, you may notice that you feel emotionally torn. On the one hand, you do not want the person to leave. On the other hand, you do not want the person to live like this. Deciding that you are ready for your loved one to die is not the same as wanting your loved one to be gone. It is a normal feeling and it means you wish your loved one comfort and peace.

We encourage you to take care of yourself and to let others take care of you. Counselors are available if you have questions or need to talk. Please let us know of your needs and we will do our best to support you.

After Your Loved One Dies

Please spend as much time as you need with your loved one. Family and friends may wish to come to the bedside. You may ask your minister or priest to come for a word of prayer. The nursing staff will help you complete any final paper work and will call the funeral home you wish to use.