



Introduction

The end of life is a natural part of the human experience. Many people feel unprepared when a loved one reaches life's final stage. It is common to experience a wide range of emotions and uncertainty.

The reassurance and acceptance of family, friends and caregivers can help your loved one through this transition. Even the simple act of being present provides comfort and support. It's the greatest gift of love you can offer as the end approaches.

Remember, no matter how well-prepared or informed you may be, it's natural to become forgetful or unable to follow simple instructions. Sudden mood changes are to be expected. Be tolerant; take your time.

The final stage of life is a unique experience. There is no set path or sequence to follow. The process should happen in a way that honors your loved one's values, beliefs and lifestyle. We hope this guide will provide some light along your path.

**Reach out to Hope, day or night,
for support and guidance.**

(239) 482-4673

(800) 835-1673



The End-of-Life Journey

When a person enters the final stage of the dying process two dynamics - physical and emotional - are at work.

Physically, the body begins the process of shutting down in an orderly and progressive series of changes. These are not usually medical emergencies that require invasive interventions - but the natural, normal way that the body prepares to stop. At this time, it's appropriate to provide comfort-enhancing measures.

Emotionally, your loved one begins to seek release. They may need resolution of a troubling issue, to complete something unfinished or to receive permission to let go.

When the body is ready to stop but the mind has not reconciled an important issue or relationship, your loved one may linger, despite discomfort, in order to reach a resolution. It is appropriate to support your loved one at this time, encouraging their release and transition.



Physical Signs and Symptoms

Coolness

Your loved one's hands, arms, feet and then legs may be increasingly cool to the touch. The color of the skin may change - the underside of the body may become darker and the skin may become spotty. This is a normal as the circulation of blood decreases to the body's extremities in order to support the most vital organs.

You can help:

- ❖ Keep your loved one warm with a blanket.

Sleeping

Your loved one may spend more time sleeping. He or she may be unresponsive or difficult to arouse. This is a normal consequence of metabolism changes in the body.

You can help:

- ❖ Sit with your loved one and hold his or her hand.
(Do not shake.)
- ❖ Speak softly and naturally, even though there may be no response. Never assume the person cannot hear. Hearing is the last of the senses to be lost.
- ❖ Plan to spend time with your loved one when he or she seems most alert.

Incontinence

Your loved one may lose control of the bladder or bowels as the muscles in that area begin to relax.

You can help:

- ❖ Discuss with your nurse what can be done to keep your loved one clean and comfortable.
- ❖ Maintain dignity and privacy when providing personal care.

Confusion

At times, your loved one may seem confused about the time, place or the identity of people – including close and familiar people. This is due, in part, to metabolism changes.

You can help:

- ❖ Remind your loved one of your presence, who you are and what you are going to be doing. Let him or her know that you will keep them safe.
- ❖ Point out familiar items or landmarks.
- ❖ Speak softly, clearly and truthfully when you need to communicate. For example, you might say, “*it’s time to take your medication*” and explain the reason for the communication, “*so you won’t begin to hurt.*”

Urine Decrease

You may notice a decrease in your loved one’s urine output, and it may become tea colored. This is natural and normal due to the decreased fluid intake and decreased circulation through the kidneys.

Congestion

You may hear gurgling sounds coming from your loved one's chest, as though marbles were rolling around inside. These sounds may become very loud. The sound does not indicate the onset of severe or new pain. This normal change is due to secretions. Suctioning usually only increases the secretions and causes sharp discomfort.

You can help:

- ❖ Gently turn your loved one's head to the side and allow gravity to drain the secretions; gently wipe the mouth with a cloth.

Restlessness

Restless and repetitive motions, such as pulling at the bed linen or clothing, are common. This may be caused by decreased oxygen flow to the brain and by metabolism changes. The physician may order medication to assist in controlling restlessness.

You can help:

- ❖ Do not interfere or try to restrain motions.
- ❖ Speak in a quiet, natural way for a calming effect.
- ❖ Lightly massage the forehead.
- ❖ Read to your loved one or play soothing music.

Food and Fluid Decrease

At the end of life, it is natural for your loved one to want less food or fluids. As the body begins to slow down, it's no longer able to digest food or absorb fluids.

You can help:

- ❖ Let your loved one be the guide. They will let you know if food or fluids are needed.
- ❖ Offer small chips of ice, frozen sports drinks or juice, which may be refreshing. If your loved one is able to swallow, fluids may be given in small amounts by syringe (ask a nurse for guidance).
- ❖ Glycerin swabs may keep the lips comfortable.
- ❖ A cool washcloth on the forehead may also increase physical comfort.

Breathing Pattern Changes

Breathing may slow or may consist of a “rattling” sound. You may notice shallow breathing, rapid pant-like breathing or no breathing for 5 to 30 seconds – even up to a full minute. These patterns are common because of decreased circulation through the internal organs. While this may be distressing to hear, it does not mean that your loved one is suffering.

You can help:

- ❖ Elevate your loved one's head or turn it to the side.
- ❖ Hold your loved one's hand.
- ❖ Speak gently.



Emotional Signs and Symptoms

Withdrawal

Your loved one may seem unresponsive, withdrawn or comatose. This indicates preparation for release and the beginning of letting go.

You can help:

- ❖ Since hearing is the last of the senses to be lost, speak to your loved one in a normal tone of voice.
- ❖ Identify yourself by name, hold his or her hand and say whatever you need to say to help the person let go.

Decreased Socialization

Your loved one may only want to be with very few people - or even just one person. This is a sign that your loved one is preparing for release. It is an affirmation of whose support is needed in order to make the appropriate transition. If you're not part of this inner circle at the end, it doesn't mean you're not loved or important. It means it's time for you to say goodbye.

You can help:

- ❖ If you are part of the final inner circle of support, give your loved one your support and permission to let go.

Disorientation

Your loved one may speak of, or claim to have spoken to, people who have already died. Or, they may claim to see places not visible to you. This is common. Your loved one is beginning to detach from this life and is preparing to make the end-of-life transition less frightening.

You can help:

- ❖ Don't contradict, explain away or argue your loved one's claims. It is real to your loved one. Affirm these experiences and understand they are normal.
- ❖ If this process frightens your loved one, explain that the experiences are not unusual. Provide comfort by sharing memories that include the loved ones who have passed on.
- ❖ Invite a social worker or chaplain to help with the anxiety or fear.

Unusual Behavior or Sudden Alertness

Your loved one may experience a brief, unexplained surge of energy and alertness. Out-of-character statements, gestures or requests can occur. Your loved one may be seeking resolution or preparing to say goodbye.

You can help:

- ❖ Offer to resolve issues or complete final tasks.
- ❖ These moments are precious. Cherish them. Kiss, hug, hold, cry and say what you need to say most.

Agitation/Restlessness

Performing repetitive and restless motions is common. This may indicate that something is still unresolved and is preventing him or her from letting go.

You can help:

- ❖ Ask a member of the Hope team to assist you in identifying what may be happening and help you find ways to relieve your loved one of tension or fear.
- ❖ Recall a favorite place or experience for your loved one.
- ❖ Read something comforting or play music.
- ❖ Give assurance that it's okay to let go.

Giving Permission

It can be difficult to give permission for your loved one to let go without making them feel guilty for leaving, or trying to keep them with you to meet your own needs. Even though it may bring prolonged discomfort, a dying person will normally try to hold on to be sure those who are left behind will be all right.

Keep in mind:

- ❖ When you are ready, one of the greatest gifts you can give is to release your loved one from these concerns and assure them that it's okay to let go.

Saying Goodbye

When your loved one is ready to pass on and you're able to let go, it's time to say goodbye. Saying goodbye is your ultimate gift of love, for it achieves closure and makes the final release possible.

To help you through these moments:

- ❖ It may be helpful to lie in bed or hold hands and then say everything you need to say. It may be as simple as saying *"I love you."*
- ❖ Recount favorite memories, places and activities you shared. It may include saying, *"I'm sorry for whatever I contributed to any tensions or difficulties in our relationship."* It may also include saying, *"Thank you for..."*
- ❖ Tears are a normal and a natural part of saying goodbye. You don't need to hide or apologize for your tears. Tears express your love and help you let go.



What to Expect Following Death

Although you may feel prepared for these end-of-life stages, you may not feel prepared for the actual time that death occurs.

It is helpful for your family to discuss this moment. Consider what you will do at the time of death, whose help you will rely on and what your family will need to decide in the hours that follow.

When your loved one has passed, there will be no breathing or heartbeat. There will be no response to your voice or touch. The eyelids may be slightly open with pupils enlarged. The jaw will relax and the mouth will slightly open. There may be a release of the bowel and bladder. All of this is natural, normal and to be expected.

If you think your loved one is close to death or has died, **there is no need to call 911**. It is time to call Hope. A staff member can support you in these final moments and will assist after their passing.

**Hope is here for you at all times – day or night.
Please call us with any questions or concerns.**

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Caregiver Care

The final weeks of a loved one's life can be physically and emotionally overwhelming. While you support a loved one in their last moments, your well-being can suffer. Remember, you must find the time to take good care of yourself as well.

Challenge yourself to:

- ❖ Stop and take a deep breath.
- ❖ Step outside for fresh air or sit in quiet place to collect your thoughts.
- ❖ Go for a walk to boost your energy.
- ❖ Drink water and follow a balanced diet.
- ❖ Limit any stressful calls or visits in order to spend more private time with your loved one.
- ❖ Ask for help, in all aspects of your life.
- ❖ Confide in friends, a spiritual counselor or Hope.

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