

Wings of Transformation  
*Whole Person Care  
at End of Life*



[allinahealth.org](http://allinahealth.org)

© 2022 ALLINA HEALTH SYSTEM. TM – A TRADEMARK OF ALLINA HEALTH SYSTEM.  
OTHER TRADEMARKS USED ARE OWNED BY THEIR RESPECTIVE OWNERS  
THIS BOOKLET DOES NOT REPLACE MEDICAL OR PROFESSIONAL ADVICE. IT IS ONLY A GUIDE.  
gen-ah-28845 (8/19)

  
Allina Health  
**HOSPICE &  
PALLIATIVE CARE**

## After Death

After the death, it is important to take the time you need to grieve. When you feel ready, call hospice at one of the phone numbers below.

**Twin Cities Metro Area:**  
651-635-9173 or 1-800-261-0879

**Hutchinson/Glencoe:** 320-234-5031

**New Ulm:** 507-217-5555

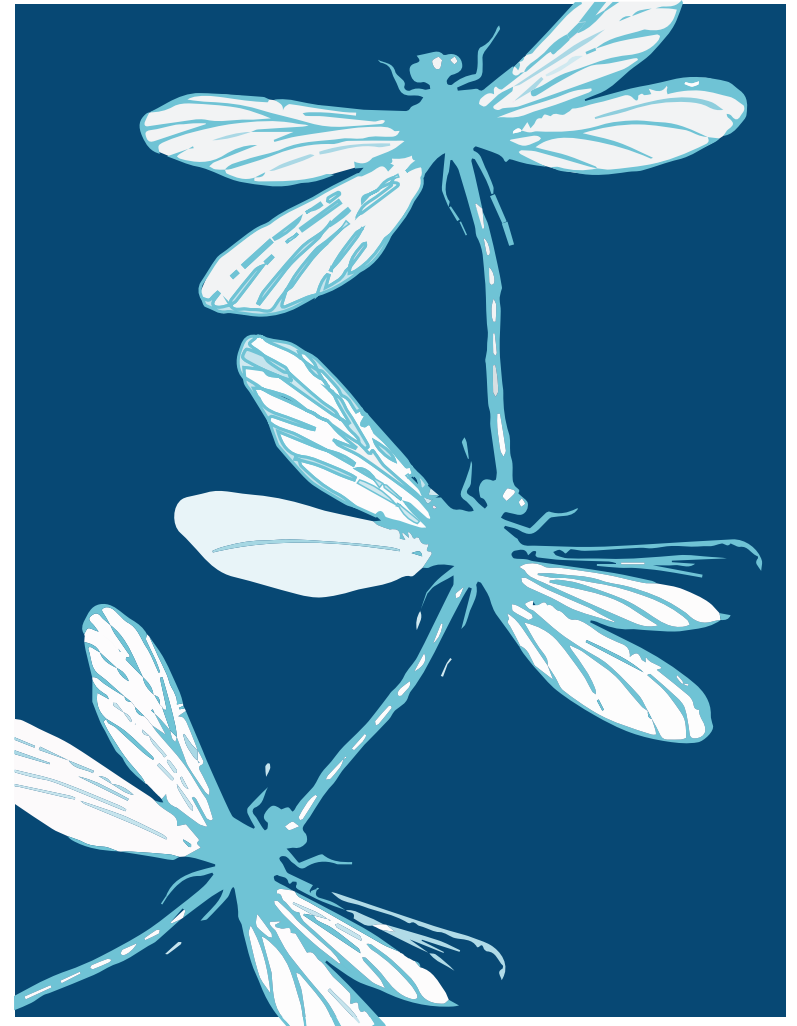
**Owatonna:** 507-446-0936



- Breathing is fast, shallow and uneven. Later, breathing slows and becomes uneven, even with long pauses between breaths.
- Mucus may stay in the back of the throat and might cause a gurgling sound. This does not cause physical discomfort. It may be helpful to raise your loved one's head or have him or her lie on one side.
- The muscles in your loved one's jaw and face relax. The mouth stays open.
- Hearing is the sense that usually stays with each person the longest. Favorite music can be refreshing. Even while sleeping without stirring, the tender voice of a loved one can be heard.

### **When Death Has Occurred**

There is no breathing or pulse for several minutes.



## Whole Person Care

Whole Person Care is a holistic approach to care that considers the connections of body, mind, spirit and community. When you practice Whole Person Care in your own life you are able to better care for your family, friends and others close to you.

### How to Reach Allina Health Hospice

A hospice nurse is awake and available by phone anytime (24 hours a day, 7 days a week) at 651-635-9173 if you have a question or need help right away.

## As Death Nears

Remember that each person is unique and experiences may vary. The following are some signs you may see in the last days and hours:

- Your loved one may withdraw and “move inward,” see visions or talk with people who have died.
- Blood circulation slows. This causes the skin to change color to gray or blue in hands, feet and around the mouth.
- His or her skin may feel clammy (cold and damp), even if the temperature shows a slight fever.
- Alertness varies. Some people remain aware of others, some become drowsy, others go into a coma.
- Blood pressure is lower.
- The pulse is faster than normal, then later slows and is weak with an uneven beat.
- There is little or no urine production.

## Reconciliation

The desire to make amends and heal old wounds can be an important part of this journey. Moving toward peace happens in many ways. A few helpful hints for finding the difficult words:

- **“Forgive me.”** Relationships often involve hurt.
- **“I forgive you.”** Seize the moment. It is unhealthy to hold on to old wounds or past mistakes.
- **“Thank you.”** It is a wonderful gift to offer thanks for people and things that hold meaning in your life. It is a legacy to have loved and been loved.
- **“I love you.”** Expressing love with words and touch is a powerful affirmation of life.
- **“Goodbye. We will be alright.”** This may be the hardest but most important gift you can give to your loved one and yourself.

## What’s Most Important to You

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

## Introduction

Dying is a natural process. It can be sudden and unexpected, or drawn out over weeks and months. Each individual experiences dying in his or her own way.

This booklet will help guide you through what to expect during the dying process.

Read this booklet at your own pace.

It may help you to talk about the information with your loved one, family and friends.

Remember, you are not alone. Your hospice care team is here to help and support you.

## Emotions

When facing the death of someone you love, there are no rules about how to feel or how to act. This is an emotional time. Often people feel many things, sometimes in a random, chaotic order.

**You are not alone!** The hospice care team is here to listen and provide support without judgement.

## Grieving as you go

Both you and your loved one may feel the emotions of grief (disbelief, anger, despair, blame, sadness, peace).

The work of moving toward peace can include:

- facing and accepting mortality
- grieving the loss of one's own independence, relationships, and goals and dreams not fulfilled
- changing identities within the family as members shift roles and learn new patterns out of need.

## Caregiving

Caregiving at home can be exhausting, even for the kindest of people.

- Do the best you can.
- Reassess how care is done on a regular basis and decide if more or less help might be needed.
- Don't be afraid to ask for help. Living, loving and letting go is hard work for everyone involved.

If more support is needed, it may be helpful to speak with anyone on the hospice care team.

- Take care of yourself to avoid emotional and physical exhaustion.
- Rearrange your family time to take care of your physical or emotional rest.
- Accept offers of help from volunteers or friends, or ask a social worker about respite care. This is a service that offers caregivers a needed break.

## What to Expect

The next two pages list common signs of the dying process. Not all signs happen at the same time and some never happen at all. Every death is as unique as the person who is experiencing it.

## 1 to 3 months before death

- wanting to be left alone (withdrawing)
- sleeping more
- eating less
- talking less.

## 1 to 2 weeks before death

- feeling anxious, agitated, restless (uneasy)
- feeling confused
- picking at clothing or blankets
- talking with loved ones who have died
- decrease in blood pressure
- increase or decrease in pulse
- sweating
- changes in breathing
- feeling congested
- changes in skin coloring
- sleeping more hours during the day
- little or no eating and drinking
- 6 ■ changes in body temperature.

## **Rally**

Your loved one may have a time when his or her signs may decrease. He or she may appear to be stronger and become more alert or even talkative. This is known as a “rally.”

Rally typically lasts only a short time (hours or minutes). This is a good time to share memories or wisdom, say prayers or say goodbye.

### **Important**

Volunteers may be available to spend time with your loved one. This can give you and your family a break from sitting at the bedside. Talk with your hospice care team about this kind of support.



## **Restlessness or agitation**

Restlessness comes and goes. Some days are peaceful, others less calm. It is all part of the normal process as the body makes the transition between the work of living and the process of dying.

Agitation is a symptom with many causes. It is common during the last few hours of life.

### **What you can do:**

Keep voices calm and the room quiet. Dimming the lighting may also be helpful. If restlessness seems extreme, talk about it with the health care provider. While there may be physical causes that are easily corrected, anxiety or fear can cause restlessness. It may be helpful to talk with a chaplain, social worker or friend to share thoughts and address anxieties. There are also medicines for your loved one that can help him or her rest.

## **Days or hours before death**

- more intense 1-to-2-week signs
- having a surge of energy (a rally)
- further decrease in blood pressure
- irregular breathing (start and stop, labored)
- changes in skin coloring on hands, knees and feet
- weak, hard-to-find pulse
- half-open glassy or tearing eyes
- decrease in urine
- unable to control urine (incontinence).

## **Minutes before death**

- changes in breathing patterns
- changes in skin coloring
- unable to be woken up.

## Changes in the Body

Dying is a natural process during which the body is shutting down and preparing to let go. As a result, your loved one will experience changes in his or her body, mind and spirit.

### Pain and discomfort

Emotional, psychological and spiritual pain can make physical pain worse. Physical pain can also worsen suffering that is caused by other sources. Your hospice care team can help your loved one feel more comfortable through music therapy, massage therapy, aromatherapy, supportive presence and medicine.

#### Morphine

The word “morphine” can sound scary but it is a commonly used pain medicine that can also help your loved one breathe easier.

### What you can do:

Supportive touch such as hand-holding if your loved one is OK with it. Sometimes simply sitting in silence will provide comfort.

## Alertness and sleep

It is common to feel an increasing desire to rest or sleep. Sometimes being alert for visiting with family and friends is a drain on energy.

Your loved one may take several naps during the day and be awake several times during the night. This is natural.

- Sleeping is a way of coping with the physical fatigue and the emotional and spiritual work of preparing for death.
- Sleeping more than half the day is common.

### What you can do:

It is important to try to create a calm and pleasing space. Bring in your loved one’s favorite blanket, piece of furniture, photos of family and friends or play some calming music in the background. You can also offer gentle, supportive touch such as hand-holding.

## Hearing

Your loved one is likely able to hear even if he or she cannot respond.

## Breathing

You may begin to notice a change in breathing. A long pause between breaths (apnea) is normal.

A gurgling noise from the throat is common and caused by saliva collecting at the back of the throat. Being weak makes it hard to swallow.

### What you can do:

Changing your loved one's position might help but do not be alarmed if it does not help. Try turning your loved one on his or her side to keep the saliva from building up in the throat. It may also be helpful to clean your loved one's mouth with a swab. The nurse can start medicine to help reduce the amount of saliva made but it is not always possible to clear this up completely. It is expected and a normal part of the dying process.

### Tip

A gurgling sound is a normal part of the dying process. It is likely more disturbing for you to hear than it is uncomfortable for your loved one.

## Medicines to Help Keep Your Loved One Comfortable

Your loved one may be taking medicines to help keep him or her more comfortable. Common examples include:

### ■ pain and breathing medicines

- morphine (Roxanol<sup>®</sup>, MS Contin<sup>®</sup>)
- oxycodone (OxyContin<sup>®</sup>, Percocet<sup>®</sup>)
- hydromorphone (Dilaudid<sup>®</sup>)
- methadone

### ■ anxiety and agitation medicines

- haloperidol (Haldol<sup>®</sup>)
- lorazepam (Ativan<sup>®</sup>)

### ■ constipation medicines

- senna (Senokot<sup>®</sup>)
- bisacodyl (Dulcolax<sup>®</sup>)
- docusate (Colace<sup>®</sup>).

## Food

As death approaches, the body naturally decreases its need for food to lessen the demands on the body. Appetite decreases and eventually disappears. Your loved one may start to have trouble swallowing.

While the desire for food lessens, your loved one's need for comfort and community remains and increases. Nourishment also comes in the form of touch, conversation, story, music, laughter and caring presence.

### What you can do:

In hospice, nutrition shifts from a special diet to providing comfort. A feeding schedule may no longer be appropriate and can take away from comfort. Although food is often used to provide comfort and love, force feeding can be harmful at this time.

## Liquids

As your loved one moves toward the end of life and the kidneys begin to shut down, excess fluids (including intravenous fluids) can cause discomfort and even place extra demands on the body.

### What you can do:

Swab the mouth or offer water from a straw to wet the tongue. These will provide comfort without giving your loved one too much liquid.

### Tip

Music may be comforting for your loved one at this time. Try playing music with a gentle tone and soft volume in the background. If you feel comfortable singing or humming, your voice may provide an expression of love and support.