

WHAT TO EXPECT
**When Death
is Approaching**

*A guide to common signs and
symptoms at the end of life*



Agrace | Hospice
Care

Table of Contents

The Hospice Team	1
As Death Nears	
Changes in Appetite	
Food and Fluids	2
Changes in Bladder and Bowel Function	3
Fatigue and Sleep	
Changes in Breathing	4
Congestion/Loud Breathing	
Temperature and Color Changes	5
Pain	
Confusion	
Anxiety	
Consciousness	6
Restlessness	
Symbolic Language	
Withdrawal	7
A Note to Family and Friends	
Things to Say and Do When Time is Short	
When Death Occurs at Home	8
When Death Occurs at Agrace	
When Death Occurs at a Long-term Care Facility	9
Grief Support for Family and Friends	

This brochure explains many signs and symptoms people may experience as they near the end of life. It is important to remember that each person's death will be as unique as their life has been. Please contact your Agrace team with any questions or concerns.



The Hospice Team

Agrace's staff and volunteers work as a team to assess and meet the unique needs of hospice patients and their loved ones as the end of life draws near. Your team includes doctors, nurses and a social worker, and may also include certified nursing assistants, specially trained volunteers, a spiritual & grief counselor and others.

We accept and respect everyone we encounter: patients, clients, family members, friends, guest, private caregivers, facility partners, volunteers and staff. People have many different cultural, religious and family traditions and rituals related to the end of life. Please tell us what is important to you, so we may respond to your needs and preferences.

As Death Nears

You may observe some of the following signs as death nears. They are part of the body's natural process of dying.

Changes in Appetite

Appetite changes are common in people with advanced illnesses. Many lose interest in eating. Sometimes, taste changes and favorite foods no longer taste good. People may say that their foods taste "off" or have a "metallic" taste.

People with serious illnesses may feel full or have no taste for food for many reasons:

- As body functions slow down, the brain is signaled that food and fluids are no longer needed.
- A person may feel nauseated by movement, medications or blockages due to tumors.
- Cancer cells can release chemicals that affect the appetite center of the brain.

Food and Fluids

It is natural and common for people to lose their desire to eat and drink as their condition declines. They may take only sips of liquids or small bites of food that can be swallowed easily. At some point, they may lose the ability to swallow well and may not take in anything at all.

This change can be upsetting for loved ones, because we know food and drink are necessary—for healthy people. Running out of water on a hot day makes *healthy* people feel uncomfortable as the body sends triggers to cause thirst.

How is it possible that a dying person who is not eating or drinking can be comfortable? As the body begins to shut down, it needs less energy. The person may no longer need food and be unable to process it. If they eat or drink when not hungry or thirsty, they may choke, vomit, feel nauseated, have trouble breathing or have swelling of the hands or feet. Dehydration that comes from *gradually* eating and drinking less seems to have a natural anesthetic (numbing) effect, which can lead to a peaceful, comfortable death.*

A person who is not hungry or thirsty may feel discomfort from having a dry mouth. Using mouth swabs and moisturizers for the lips can help bring relief.

What can family or caregivers do to help?

- **Let the person who is dying decide when and how often they want to eat and drink.** Let them know it is OK to say “no” to food and fluids—and accept their decision.
- Offer a selection of food and drink, but do not pressure or push. Trust that the person is following cues from their body.
- Keep their lips and mouth moist.
- Find other ways to show love and concern, such as giving a massage, playing cards or reading aloud.
- Remember that your presence, comfort and loving care are the most important things you can offer.

* Printz, L.A. (1988). “Is Withholding Hydration a Valid Comfort Measure in the Terminally Ill?” *Geriatrics Advisor*, 43(11): 84-88.

- Understand that delivering fluids or nutrition through an IV or feeding tube is not effective for people who are close to death and may make them *more* uncomfortable. Dehydration at the end of life is the body's natural response to the dying process and can make the person less aware of pain or discomfort.

Other helpful suggestions:

- Talk with a member of your Agrace team about your concerns.
- Allow the person to eat in a pleasant place, preferably at the table or in a sitting position.
- Ask them what tastes best, and respect their wishes.
- To prevent choking, offer food and fluids only when they are awake and alert enough to eat and swallow.

Changes in Bladder and Bowel Function

The amount of urine a dying person produces typically decreases. Urine may become darker as both fluid intake and blood-flow through the kidneys decrease.

As the person declines, they may lose control of their bladder and bowels. This is completely normal. A urinary catheter or protective underwear may be needed to prevent skin breakdown and keep the person comfortable.

Fatigue and Sleep

Weakness and fatigue increase as death nears. The person may need help with simple tasks, such as taking a sip of water or turning in bed, and may sleep most of the day.

Your team will help make a plan to ensure everyday needs, such as bathing and grooming, are met. We will offer suggestions for conserving energy, so time can be spent focusing on whatever the person enjoys. We work to help them be as awake as they would like and as comfortable as possible.

Changes in Breathing

A person who is dying may have unusual breathing patterns. Although these patterns might be distressing to those who hear them, they rarely cause discomfort to the person who is ill.

Breathing may be slow and even at times and irregular and shallow at other times. Breaths may be separated by long pauses. These pauses are called “periods of apnea” and may last from seconds to more than a minute. As death nears, periods of apnea may become longer. A person may have periods of apnea for several days before death.

Breathing may also be very fast at times. Again, while this can be distressing to hear, it rarely causes discomfort. If you question a patient’s comfort at any time, please call your Agrace team immediately. Most people experience an irregular pattern of breathing minutes before death. It is often followed by a short period of very shallow breaths, and then breathing stops.

Congestion/Loud Breathing

Some people have loud, rattling breathing as they become less able to swallow saliva or to process fluids. Their breathing may become louder and moist sounding. Often this is because they have a small amount of saliva in their throat that they are unable to cough up or clear. Despite the sound, the person generally does not show any signs of distress or have trouble breathing.

What can family or caregivers do to help?

- Changing the person’s position may help ease the sound. Turning or elevating their head allows gravity to drain the saliva and can also help change breathing patterns.
- Medications may also be used to reduce the production of saliva.

Suctioning has limited benefits, and it may make the congestion worse.

Temperature and Color Changes

Changes in blood flow may cause some noticeable changes in the person's body. Hands and feet may become darker or paler and colder to the touch. The skin on the arms and legs may appear blotchy and purplish. This discoloration, called "mottling," is the result of reduced blood flow. An increase in mottling can be a sign that death may be near. People who are dying are not usually aware of these changes and rarely feel discomfort from them.

Some people develop a fever as they near death. The nurse may give medication for the fever, but it does not always work to reduce the temperature. Most people do not appear uncomfortable as a result of fever.

Pain

Managing pain is an essential part of end-of-life care. Pain can almost always be controlled, and the person can be kept comfortable through the dying process. Medications can be used to keep them comfortable without too many side effects and without excessive drowsiness.

Confusion

Changes in body chemistry may cause a person to be confused about what time it is or where they are. They may not recognize close and familiar people. Loved ones can help by providing calm reassurance in response to their questions.

Anxiety

As death approaches, it is common to feel fear and anxiety about the dying process and death itself. The person who is dying may show their anxiety through anger, withdrawal, restlessness, demanding behavior, irritability or crying. Most people feel some level of anxiety at times. Comforting them with touch, active listening, calmness and medication can ease the anxiety. It may also help to keep lights low, keep the room quiet or play soothing music, and try relaxation techniques such as deep, controlled breathing.

Consciousness

Some people become minimally responsive for hours or even days before death. They show little awareness of their surroundings. Others remain clear and alert up to the last few moments. Generally, people are gradually less and less alert as death approaches.

As a person becomes less responsive, there may be less opportunity to have meaningful communication. Even if they cannot respond, they may continue to hear and have a level of awareness. You should always assume the person hears everything you are saying. Talk to them as clearly and directly as if they were awake and alert.

Restlessness

Some people have a period of restlessness as death approaches. Restlessness may be caused by physical, emotional or spiritual factors. You may see them picking at their clothes or bedding, reaching into the air or moving about in bed. It can help if you provide a calm and reassuring environment. If their restlessness appears to be bothersome, contact your Agrace team for suggestions.

Symbolic Language

Sometimes a person who is nearing death will use words and phrases that lead others to believe they are confused. This language can be very meaningful to the patient and their family, and it can be symbolic of the life they led.

People who are dying may talk about events in their past. They may use words that describe the need to move, travel or go to another place, or they may talk about a specific time that they will die. They may speak to someone who is no longer alive or express a need for reconciliation or forgiveness. This is common at the end of life.

Offer your supportive presence, and pay attention to what is said. It is often very meaningful. Many dying people do not appear to be distressed because of symbolic language or visions. If the person seems distressed or you have concerns, contact your Agrace team.

Withdrawal

People often become less interactive and more withdrawn as death nears. This may be partly due to physical factors but may also reflect the person's need to process the situation emotionally and/or spiritually. Withdrawal can be a difficult experience for loved ones. A loving, supportive presence may be all the person needs or wants at this time.

A Note to Family and other Loved Ones

There are few things about death and dying that are predictable. We don't know when it will happen or how it will happen, and we don't know who will be with us or how we will feel. Agrace is always available to assist you during this time.

Your Agrace team will do their best to identify when a person is approaching death. We do our best to inform and contact families when changes occur, to allow them to be present if they choose. Please understand that there are times when hospice patients die without showing the typical signs.

Things to Say and Do When Time is Short

- Spend time with those who are important to you. Gather loved ones around you.
- Reminisce and celebrate life.
- Create a legacy: write a journal, write letters, take pictures, record a video.
- Give and accept compliments and gratitude.
- Say "I love you," "I'm sorry," "I forgive you," "Forgive me."
- Celebrate an important event or take a trip (if time allows).
- Make time for emotional and/or spiritual needs as well as physical needs.
- Say "Goodbye," "I'll miss you," "I'll be OK."

- Drawn in part from the work of Ira Byock, MD

When Death Occurs at Home

Call Agrace if you think the patient is in the dying process or has died. **Do not call 911.**

You should call us no matter what time of the day or night; however, you do not have to call us immediately. You are welcome to take some time alone or wait for loved ones to gather before calling Agrace. There is no hurry. Help is always as close as your telephone.

Immediately after the death, you may feel “numb” and may have trouble concentrating. Survivors often ask, “What do I do now?” Your Agrace team is available to assist and support you.

Once you call Agrace, we will send a nurse. If you want to have a social worker, spiritual & grief counselor, clergy member or a spiritual-care person present, the nurse will help you contact them. Please tell our staff if there are traditions or rituals you would like observed. We will respect your final moments with your loved one.

When Death Occurs at Agrace

If you think your loved one has died, tell a staff member. A nurse will check for signs of a pulse or breathing, and confirm that the person has died. Some counties require that we call the coroner for every death; in other cases, we call because there was a recent injury, like a fall, or because they had a life-altering injury before starting hospice (such as being in a car accident).

If you wish, our staff will help you contact family members, friends and anyone else you want to be present. When you are ready, we will call the funeral home of your choice. Please tell us if there are any special traditions or rituals you would like observed.

We offer a special quilt to place over the body. You can choose to leave the face uncovered.

If you are present when the body is moved, you may go along with the procession out of the building. Agrace staff are honored to join this procession. If you decide not to participate, our staff will escort the body, which will be covered with the quilt.

When Death Occurs at a Long-term Care Facility

If you think your loved one has died, tell a nurse or other facility staff member. They will call Agrace, and an Agrace nurse will come to confirm that the person has died. Some counties require that we call the coroner for every death; in other cases, we call because there was a recent injury, like a fall, or because they had a life-altering injury before starting hospice (such as being in a car accident).

If you want, you may call family members, friends and other important people. If you want to have anyone else present for emotional or spiritual support, we will help you contact them. Please tell the Agrace staff if there are special traditions or rituals you would like observed.

You will have time with your loved one, either alone or with our staff present, as you prefer. We will respect your wishes. When you are ready, we will call the funeral home of your choice to have them come and transport the body.

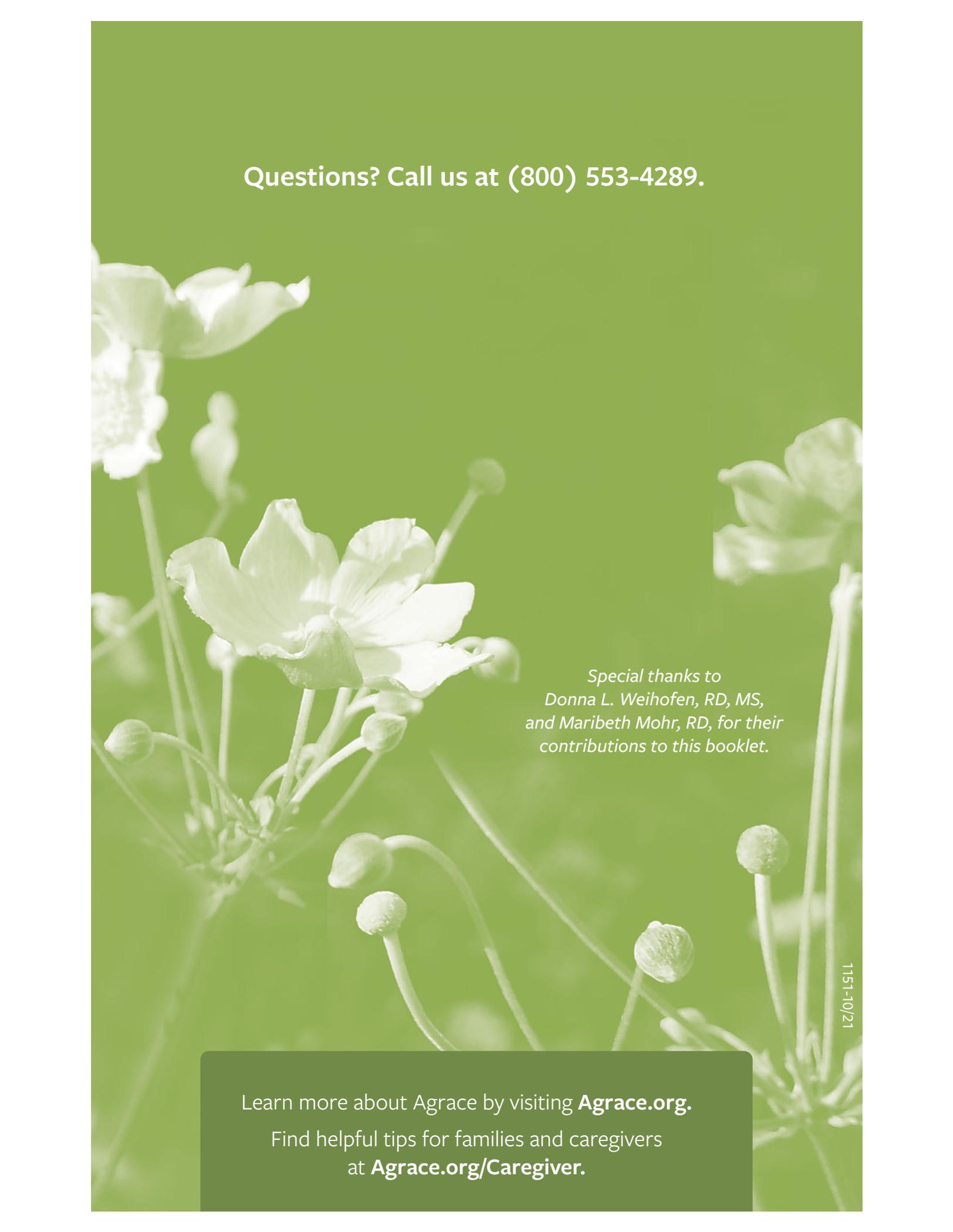
Grief Support for Family and Friends

Agrace's support does not end with the death of the patient. Grief support services are offered to family members and other loved ones for a year afterward, without cost. You can expect to be contacted in the next week by your Agrace social worker. Your Agrace spiritual & grief counselor will also call in a month or so. Please call and talk with a member of our Spiritual & Grief Services staff if you need support sooner.

Our support includes these services:

- Informational mailings
- Supportive counseling
- Grief support groups
- Specialized services for families with school-aged children
- Memorial events and remembrance programs
- Referrals to one-on-one counseling resources or other community resources

For details on any of these support services, please call Agrace and ask to speak to a spiritual & grief counselor.



Questions? Call us at (800) 553-4289.

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Learn more about Agrace by visiting **Agrace.org**.
Find helpful tips for families and caregivers
at **Agrace.org/Caregiver**.