WHAT TO EXPECT

When Death is Approaching

A guide to common signs and symptoms at the end of life
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 families 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 and a spiritual & grief counselor.

Diversity
Agrace recognizes the value of every person we encounter: patients, family members, friends, guests, volunteers and staff. We believe that every person should be treated with respect and dignity. Please feel free to tell your Agrace team about your cultural, religious and family traditions 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 signalled 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 common for people to lose their appetite or desire to drink as their condition declines. They may take only sips of liquids or small bites of foods that can be swallowed easily. At some point, they may lose the ability to swallow well and may not take in anything at all.

Losing the desire to eat and drink is a natural part of the dying process. As the body begins to shut down and needs less energy, the person no longer needs food.

As death nears, it is more difficult for the body to handle food and fluids. Forcing food and fluids can put a strain on the internal systems and cause discomfort. Eating when not hungry may cause vomiting, nausea, choking or increased swelling of the hands or feet. Losing the ability to swallow may be the body's way of protecting itself from taking in food and fluid it cannot use.

People do not often report feeling hungry or thirsty, but they may feel discomfort from dryness of the mouth. Oral care with mouth swabs and moisturizers for the lips can help improve their comfort.

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 that decision yourself, as well.
- 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, compassion and concern, such as giving a massage, playing cards or reading aloud.
- Remember that comfort and loving care are the most important things you can offer.
- Understand that delivering nutrition through IV fluids or feeding tubes is not effective for people with advanced disease, and may make the patient more uncomfortable. Dehydration at the end of life is not painful. It 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.
- Offer medication for nausea or pain before the person eats, if appropriate.
- 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 sure 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 patient 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

Some people become congested (stuffy) in their sinuses, throat and chest as they become less able to swallow saliva or to process fluids. They may develop pneumonia.

The person’s breathing may become louder and moist sounding. Often this is because they have a small amount of fluid in their throat that they are unable to cough up or clear. Despite the sound, the person generally does not experience any distress or difficulty breathing. Occasionally a person may have greater congestion and secretions.

What can family or caregivers do to help?

- Changing the person’s position may help ease congestion. Turning or elevating their head allows gravity to drain the secretions and can also help change breathing patterns.

- Medications may also be used to reduce the volume of secretions.

Suctioning has limited benefits, and it may make the congestion worse. Using oxygen may benefit some people, but it is not helpful for others.
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. Family 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 for a period of time. Comforting them with touch, calmness and medication can ease the anxiety. Anxiety can be an important part of the person accepting their death.
Consciousness

Some people become unresponsive for hours or even days before death. Others remain clear and alert up to the last few moments. Generally, people have a gradual decrease in their level of consciousness as death approaches. As this happens, they may have unexpected moments of clarity, where they might become more aware—and even talk. We can’t predict if or when this might occur, but we encourage you to treat these moments as gifts.

As a person becomes less responsive, it is harder for others to communicate meaningfully with them. It is important to understand, however, that they continue to hear and have a level of awareness, even if they cannot respond. You should always assume the person hears everything you are saying. We encourage you to 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 continues, 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 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. These visions are very real to the person and usually are comforting to them. Offer your supportive presence during this time, and pay attention to what is said. It is often very meaningful.
Withdrawal

People often become less interactive and more withdrawn from family and friends as death draws near. This may be partly due to physical factors but may also reflect the person’s need to process the situation emotionally. Withdrawal can be a difficult experience for family and friends. A loving, supportive presence may be all the person needs or wants at this time.

A Note to Family and Friends

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 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 friends and family 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 spiritual 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

When the patient dies at home, call Agrace—no matter what time of the day or night it is. **Do not call 911.** A nurse will come to the home to confirm that the person has died. If you want to have a social worker or anyone else present, we will help you contact them. When you are ready, we will call the funeral home to arrange transport. The coroner will be notified, if necessary.

If you want to take some time for family and friends to gather before you call Agrace, you are welcome to do so. Please tell your Agrace team if there are special traditions you would like observed at this time.

There is no hurry. Take the time you need, and do not panic. Help is always as close as your telephone. We will come as soon as you ask us to, but you can spend time alone first, if you choose. We want to respect your final moments with the patient, either alone or with our staff present.

When Death Occurs at Agrace

If you think the patient has died, tell a staff member. A nurse will check for signs of a pulse or breathing, and confirm that the person has died. The nurse will notify the coroner, if necessary.

If you wish, our staff will assist you with contacting family members, friends and anyone else you want to be present. When you are ready, we will notify the funeral home of your choice. Please tell the staff if there are any special traditions you would like observed at this time.

We offer a special quilt to place over the funeral cart. You can choose to leave the face uncovered. If you are present when the patient’s 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 be there when the patient’s body is moved, our staff will escort the body, which will be covered with the quilt.
When Death Occurs at a Skilled Nursing, Assisted Living or Community-based Residential Facility

If you think the patient 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. The coroner will be notified if necessary. If you want, you may call family members, friends and other important people.

If you want to have a social worker or anyone else present, Agrace will help you contact them. Please tell the Agrace staff if there are special traditions you would like observed at this time.

There is no hurry; you are welcome to take whatever time you need with your loved one. We will respect your final moments with the patient, either alone or with our staff present. 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 for a year afterward, without cost. You can expect to be contacted in the next 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.

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