



A Caregiver's Guide: Active Dying

HOSPICE CARE | PALLIATIVE CARE | GRIEF SUPPORT | EDUCATIONAL INSTITUTE
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This is a guide and resource for family members, friends and other caregivers who are supporting someone in their final days and hours of life.

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What to Expect from Your Agrace Team

Supporting natural, comfortable dying is always our aim. At Agrace, we use a team approach as we provide care to each unique person and their family/caregivers. You are the “drivers” as we create plans of care that focus on your needs and wishes.

- **We will anticipate and manage your needs through:**
 - Teaching that allows your loved one to have a comfortable, natural death
 - Emotional and spiritual support to prepare you for what’s coming
 - Open and honest communication
 - A visit from a nurse every day (or a call, if you prefer) when the patient is actively dying
 - A visit from a social worker or check-in with the nurse by phone daily
 - Demonstrations of caregiving techniques, plus additional resources as needed
- **We will teach patients, caregivers and families what we know about medications and treatments that are helpful during the dying process.**
- **We will honor wishes and current goals of care, by:**
 - Supporting your goals, offering our help and answering your questions
 - Giving fair and equal care, regardless of the patient’s or your background and experiences
- **We will make adjustments needed to support the dying process that is best for the patient, which includes:**
 - Ensuring the space where care is given is comfortable, private and personal
 - Providing care that doesn’t speed up or slow down the dying process
 - Being flexible with schedules

Physical Signs of Nearing Death

As death approaches, people often ask “How much longer?” It is hard to answer that question, even for someone who has experience with the dying process. The signs that might make us think death is near can be very different from person to person.

Here are some common physical signs:

Weeks before death:

More restlessness
Becoming withdrawn
More sleeping
Less eating and drinking
Cool hands and feet
Settling unfinished business
More swelling
More tiredness
Higher body temperature
Faster heart rate

“Nearing Death Awareness”: moments
of “checking out,” appearing far away
or making seemingly random comments

Days/hours before death (“Active Dying”):

Less able to awaken
More pauses in breathing
Loud/rattling breathing
Swallowing difficulty
Difficulty speaking
Open mouth/jaw drop
Inability to hold in urine or stool
Lower blood pressure
Nearing Death Awareness continues or increases
Pale or bluish splotchy skin (mottling)

Caring for Someone Who is Nearing Death

Breathing and Fever

It is normal for there to be changes in breathing or body temperature at end of life. A fever can develop due to infection, dehydration or the disease itself. Breathing may become less regular, very slow or fast, or have long pauses called “apnea.” In the minutes before death, you may see/hear an irregular pattern of breathing. This is often followed by shallow gasps, and then breathing stops.

What you can do as a caregiver:

- Ease the work of breathing by putting the head of bed up slightly or use pillows so the patient is not lying flat.
- Direct a fan toward patient or open a window; air moving across the face can help decrease the feeling of “air hunger.”
- Use medications, as ordered, for breathing. When you use medications as ordered, there is almost no risk of giving too much.
- A rattling sound while breathing may mean there is fluid in the lungs/airway. Repositioning patient to their side or raising their head a little higher might help. Place a washcloth under their cheek to catch any dripping fluids.

- Medications can be used to decrease the rattling sound, which is normal and rarely uncomfortable.
- Tylenol can be given rectally if patient seems to be uncomfortable because of their fever.
- Use cool, damp washcloths on the forehead, armpits or groin area to help lower fever and make them more comfortable.

Eating, Drinking and Hydration

Many caregivers and families worry when their loved one eats and drinks less as death nears. It is normal to feel this way; after all, we are often taught that providing food shows others that we care! Dehydration at the end of life is not painful; it is the body's natural response to the dying process. The patient is less aware of pain or discomfort when this happens.

When people who are dying want to eat and drink less, it is because their body is protecting itself from taking in more than it needs. When too much food or fluid is taken in at this stage, it can cause pain, vomiting, swelling or problems with breathing. As a caregiver, encourage the patient to listen to their body about hunger and thirst, and tell them it's OK to do so.

What you can do as a caregiver:

- Don't force liquids. Swallowing can become more difficult as death nears, and it is unlikely that a patient will be able to take drinks.
- Moisten a dry mouth with a swab and clean the patient's mouth frequently to keep them comfortable.
- Apply lip balm.
- Apply a lotion without alcohol to the skin to maintain comfort.
- Moisten the person's eyes or use a warm, damp cloth over them a few times each day.

Pain

People who are dying do not always have pain. If they do, it could mean that there is a new problem, that their disease is progressing or that their pain issues are hard to treat completely. Even lying still in bed can make a patient uncomfortable. **No matter what is causing pain, it is important to manage it as best we can.**

What you can do as a caregiver:

- Tell your hospice team or doctor if pain seems to be getting worse.
- Watch for signs of pain: As patients communicate less, it can be harder to figure out where their pain is or how bad it is. Watch to see if they are acting differently or look uncomfortable (for example, is their forehead wrinkling, or are they touching a part of their body that they haven't before?).
- Don't skip doses of pain medicine; it is easier to manage pain if it doesn't get out of control.
- Know that as someone nears death their body produces natural pain relievers.
- Watch for other symptoms that can be caused by pain, such as nausea and anxiety; these can get worse if pain isn't managed.
- Try warm compresses, music, distraction or physical touch when your loved one is in pain.
- If you don't understand something about medications used for pain, ask the hospice team.

Anxiety, Restlessness and other Mental Changes

There are many possible causes of anxiety and restlessness during the dying process. Mental and behavioral changes can range from very mild to severe. Confusion or restlessness caused by the dying process itself are sometimes called "terminal restlessness" and may be difficult to reverse. In other cases, we can work to find, treat and manage the cause of these changes.

Possible causes of restlessness or anxiety:

- Constipation—When did the patient last have a bowel movement?
- Low oxygen levels—Would oxygen help?
- Infection—Are they uncomfortable due to fever?
- Medication—Did they have a medication change recently?
- Full bladder—When did they last urinate?
- Mouth pain—Does their mouth or tongue appear dry or have a whitish coating?
- Pain—Are they getting their pain medication as they should? Do they need a higher dose or different type of medication added?

What you can do as a caregiver:

- Consider the list of possible causes on the previous page. Could any be linked to the patient's behaviors or anxiety, and can you take steps to provide relief?
- Keeping the patient's area calm, and reassure them with a soothing voice or touch.
- Medication can be considered if the cause can't be managed in other ways.
- Don't be afraid to reach out to others for help. It can be both physically and mentally exhausting to care for someone who is experiencing these changes at end of life.

Spiritual and Emotional Changes

Even if a person is very close to death, you should always assume they hear everything you are saying. Talk to them as clearly and directly as if he or she were awake and alert. They might communicate with you nonverbally through movements, sounds, facial expressions or raised eyebrows.

At this time, Agrace can offer both you and the patient spiritual and emotional support. Please feel free to ask for the hospice team's help with what you want or need, including help contacting the patient's faith community or spiritual advisor.

Use these phrases to have meaningful conversations at the bedside:

- Love: "I love you."
- Forgiveness: "I forgive you." "Please forgive me."
- Gratitude: "Thank you."
- Affirmation of life and legacy: "I will miss you." "This is how I will remember you."
- Preparedness: "It is OK for you to die." "We are ready when you are."

Honor the dying time:

- Try to build an environment that your loved one would appreciate. Would they choose to have music, quiet, pets, aromas, linens, clothes, rituals, prayers, presence of family/friends?
- It is very hard to predict when your loved one will take their last breath. Be prepared by knowing that the death might not happen according to plan.
- **It's OK to leave your loved one alone. Families and caregivers can be burdened by feeling like they need to be at the bedside constantly, but sometimes it is a person's preference to die alone.**

The lingering death—struggling to “let go”:

- It's OK to talk to your loved one about what might remain “undone” in their mind. Provide reassurance to them.
- Consider who the patient might need to hear from. You can hold the phone to their ear so they can hear the voice on the other end of the line.
- Let your hospice team know if you have any concerns about physical discomfort during this time.

Symbolic talking and Nearing Death Awareness:

- Your loved one may appear confused. Listen for clues and write down what they say if they talk; if you don't understand it now, you might later.
- They may talk to someone who has already died or talk about an old job or hobby.
- They may gesture forward or look ahead, past the people around them.
- Consider reading these books for more information on Nearing Death Awareness: “Final Gifts” and “Final Journeys” by Maggie Callanan.

What you can do as a caregiver:

- Remember that even if your loved one isn't responding, they may still be able to hear you. Keep this in mind as you have conversations within earshot of them, and bring them into your conversation, when possible, by speaking *to* them.
- Explain what you're doing for them when providing care. Say things like, “I'm going to fix your pillows,” or “We're going to swab your mouth now.”
- Carefully choose your words to help maintain their dignity; for example, use words like “padding” instead of “diapers.”
- Remember to keep the patient covered when providing care to maintain their privacy and dignity.
- Consider whether any prayers, meditations or spiritual rituals would be comforting, and arrange for them, if possible.

What May Happen at the Time of Death

When the hour of death arrives, it is normal to feel startled, shocked, sad, angry, afraid, relieved, calm or uncertain. This is your unique journey, and you shouldn't expect to feel a certain way. Each person grieves differently, and many people have already been through parts of the grieving process as the illness has progressed.

Confirmation of death signs/symptoms:

- There is no breath.
- There is no heartbeat.
- Eyes are likely slightly open.
- Pupils are fixed and dilated.
- Jaw is relaxed, with mouth open.

Normal physical changes after death:

- **Muscle stiffening** occurs two to four hours after death, and is temporary. It is more noticeable in people with high muscle mass.
- **Body cooling:** Body cools to room temperature. Skin becomes fragile.
- **Color changes:** The skin surface may look lighter than before, because the heart is no longer pumping blood to the skin. Gravity can cause blood to settle in lower portions of the body and make the skin darker or discolored. Raising the head of the bed after death can lessen color changes in the upper body.
- **Bowel and bladder:** Due to changes in muscle tone, it is normal to have bowel or bladder release during or after death.

What you can do for yourself:

- Consider any meaningful family rituals during this time. It can be helpful to talk about this ahead of time with a spiritual support person or social worker—or with other family members who will be present.
- Don't be afraid to ask for privacy or support.
- Feel free to participate in post-death care of the patient's body. Feel free to opt out, as well.

For more information on care at end of life, please refer to the [Agrace Patient & Family Care Handbook](#).