



The “Teach” icon in these guidelines marks concepts that most often give patients and families difficulty. Providing education is an important part of your role as an end-of-life practitioner.



Clinical Practice Guidelines

Active Dying: Overview

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This reference is a guide and resource for Agrace staff, as you work with someone who has only **days** to live. Whether you are new to hospice care or simply new to Agrace, this resource provides a baseline understanding to working with patients who are actively dying. As hospice clinicians, we know that each person’s dying process is unique to them. It’s impossible to predict for patients and families what exactly will happen.

At Agrace, our aim is to support natural, comfortable dying, in union with our patients and their families. We use an interdisciplinary approach as we attend to each patient and family’s unique experience. With the patient and family as the drivers, we create Plans of Care that are specific, individualized and goal-oriented. Yet, there are some commonly seen symptoms and some shared experiences among people who are dying. There are factors which, if integrated, make us knowledgeable end-of-life care practitioners.

We get one chance to do this well for each person and their family, and we know that when done well, care at the time of dying can be among the most rewarding of experiences.

Common Signs of Impending Death

PHYSIOLOGIC CHANGES

SIGNS/SYMPTOMS

Cardiac and Circulation Changes	
Decreased blood perfusion	Skin may become mottled and discolored and feel cool to touch
Decreased cerebral perfusion	Decreased level of consciousness; delirium; drowsiness/ disorientation
Decrease in cardiac output and intravascular volume	Tachycardia (heart rate above 100), hypotension (low blood pressure) Cyanosis (discoloration in skin due to lack of oxygenated blood)
Urinary function	
Decreased urinary output	Possible urinary incontinence; Concentrated urine
Food and Fluids	
Decreased interest in food and fluid	Weight loss/dehydration
Swallowing difficulties	Food pocketed in cheeks or mouth/choking with eating/coughing after eating
Skin	
Skin may become mottled or discolored	Patches of purplish or dark pinkish color can be noted on extremities
Respiratory	
Terminal secretions	Noisy respirations caused by accumulation of secretions in upper airway due to decreased consciousness and inability to cough
Dyspnea	Shortness of breath
Notable changes in breathing	Irregular respiratory pattern
General Changes	
Profound weakness and fatigue	Drowsy for extended periods; sleeping more
Decreased alertness	More withdrawn and detached from surroundings; may appear to be in a comatose-like state and may communicate non-verbally (e.g., squeezing hands, purposeful eye movements, wiggle toes)
Near-death awareness	May include symbolic talk, patient speaking and/or seeing persons/loved ones that others cannot see, knowing when death will occur, preparing for travel

Adapted from Stanford School of Medicine – Palliative Care (n.d.) "Signs of Impending Death" retrieved from <https://palliative.stanford.edu/transition-to-death/signs-of-impending-death/>

Physical Indicators of Imminent Death

Families often turn to us with the imploring question: “How much longer?” Sometimes they want answers or levels of specificity we cannot provide. Often, we can offer our informed opinion with a level of confidence they likely could not gain on their own.

Determining time of death is not an exact science. To help prepare patients and their families, end of life practitioners will look at prognosis in the following timeframes: “weeks to months,” “days to weeks,” “hours to days.” This does not guarantee life expectancy. It gives a reference to help guide conversation and education. In the previous chart are generalizations about a person’s last “days to weeks” of life. Everyone is different; some people may experience these symptoms earlier and some people may not show these symptoms. Discuss all signs of decline with your team.

It is important that we teach families why we think life expectancy is what we are suggesting—teach them the indicators as we know them. Teach them about what is “normal,” or what is typically seen or experienced in dying. Nurses and providers will want to include information on trends and trajectories specific to the terminal diagnosis as this may indicate the continued pace of decline and death. Remind them that, for some, the dying process moves more quickly than for others, and the closer a patient gets to dying—despite our inability to ever say for sure—the more accurate we are likely to be with our estimations of time remaining.

Skin Changes

Changes in the skin are often present as the body compensates for decreased cardiac output and a declining circulatory system. Changes are first seen in the extremities as the body preserves oxygenated blood for the vital internal organs.

- Coolness usually begins with the hands and feet; teaching about this in advance can reduce the shock and fear that some families feel when the patient feels cool to the touch. This coolness is not typically associated with increased discomfort.
- Skin color changes indicating approaching death may include paleness, dusky/gray tone, and pale/blueish hue (cyanosis), especially in lips/gums/mouth/nose.
- Mottling may be seen, which appears as purple/blue webbing on the skin in people with light skin tones. In people with dark skin tones, color changes may not be as obvious. Skin may appear darker in areas of mottling. There is no evidence to support that this causes discomfort but could be a sign that death is approaching. This skin change is caused by decreased circulation and can be seen anywhere from months to hours before death, depending on disease trajectory.



Breathing Pattern Changes

Changes in breathing patterns are expected at end of life. Although these patterns can be distressing to the person who hears them, they rarely caused discomfort to the person who is ill.

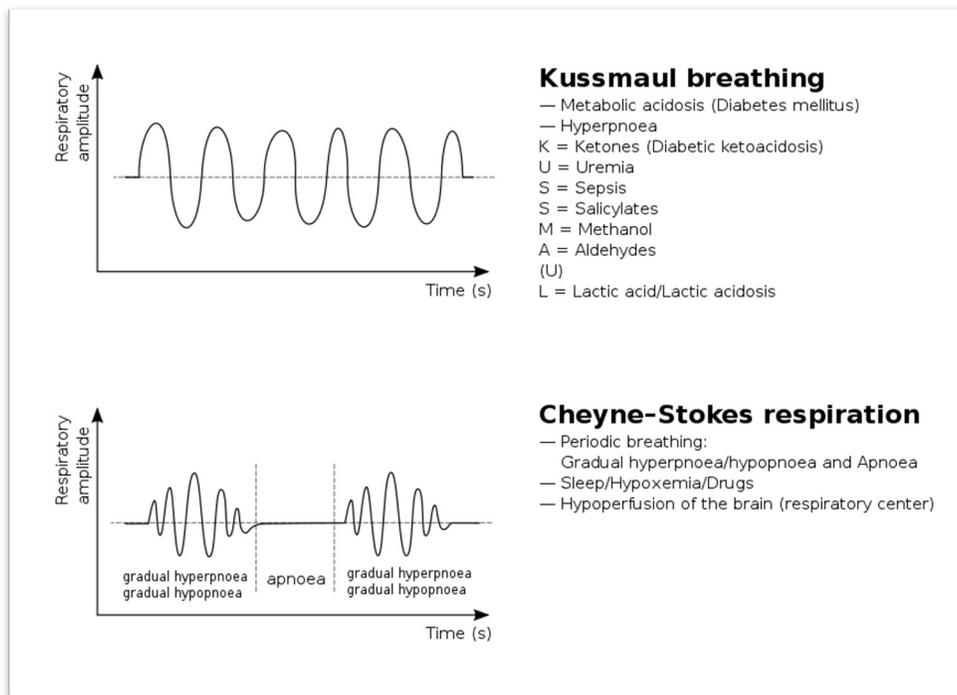
Kussmaul pattern: Constant, deep, rapid breaths. This is the body trying to get rid of carbon dioxide, in a last effort to maintain acid-base balance. Commonly associated with conditions that cause metabolic acidosis.

Cheyne-Stokes pattern:

A cyclical pattern of breathing, including periods of apnea.

Apnea: Suspension of breathing. Apnea is pauses between breaths that can last between 10 and 60 seconds.

Terminal secretions: Often a product of no longer being able to clear saliva through swallowing or coughing. A wet sound is produced when the breath moves around that fluid collection in the back of the throat. This is seen most often as people become less responsive.



Breathing abnormalities. (2012). [Graph].

https://commons.wikimedia.org/wiki/File:Breathing_abnormalities.svg

Strong side to side repositioning is the most effective intervention, as it helps move that fluid and reduce the noise. Medications are not always effective; however, these are common anti-cholinergics used to prevent further saliva production:

- Hyoscyamine
- Atropine drops
- Glycopyrrolate

These medications carry the risk of side effects and should be reserved for use during the active dying process.



Teach

Families remember and fear the sound of terminal secretions. Teach that it is not uncommon, nor uncomfortable. There is no evidence to support that patients feel discomfort. Continue to thoroughly observe the patient for any signs of discomfort that may exist and respond accordingly.

At times, patients may experience **dyspnea** (shortness of breath), so it is important for end-of-life care practitioners to watch for signs of distress associated with breathing changes. If breathing discomfort is suspected, here are some interventions that might provide comfort:

- Collaborate with the hospice team on individualized interventions.
- Elevate the head of the bed.
- Direct a fan toward the patient or open a window, as air movement across the trigeminal nerve in the face can help reduce shortness of breath.
- Use a short-acting opioid for dyspnea relief. Provide ongoing education about the effectiveness of opioids in reducing the sensation of shortness of breath. Reassure families that appropriate, judicious dosing of opioids essentially eliminates the risk of over-sedation.

Vital Sign Changes

- Vital signs change due to dehydration, infection or other organ failure.
- Heart rate often increases as death approaches, blood pressure drops and temperature may be elevated.

Note: Acetaminophen is often not required, though it is an option if the patient appears uncomfortable with fever or is at risk of seizures. Cool compresses on the forehead and/or in the axilla or groin can be used as comfort.

Hydration and Nutrition in the Final Days or Hours

Maintaining weight or caloric intake are not reasonable or achievable goals in the final days of life. Dehydration is also a normal part of the process of a natural death. Goals around nutrition and hydration in the final stages of life should be directed at comfort.

Diminishing appetite is not distressing or uncomfortable for patients. For families, however, it is often a different story. We must remain sensitive to—and validate—the fact that feeding is emotional and symbolic in nearly every culture.



Teach

Worry, misunderstanding and sadness about loved ones no longer eating weighs heavily on many family members. We can help ease this worry by educating about nutrition needs at end of life.

The appetite center in the brain is affected during the dying process. Patients' bodies no longer require the calories they once did because their body is shutting down. In fact, if the patient takes in or is given more than their body can tolerate, this may create more discomfort than benefit.

Trouble with pain, nausea, edema, breathing—a whole host of symptoms—could begin as the risk of pulmonary congestion, cardiac overload and ascites (excessive abdominal fluid) increases.

What We Can Do

- Explain to patients and families the physiologic rationale for the patient's lack of appetite and thirst.
- Offer bites and sips if the patient is able. Follow the patient's physical cues being mindful of patient goals.
- Caution families about the risk of aspiration as swallowing difficulties increase.
- As intake reduces or stops, regular oral care is essential for maintaining comfort.
- Oral swabs lightly dampened (do this by pressing the swab against the glass to wring excess water out of the swab) can be provided to the patient. This is a great skill to teach families.
- Acknowledge the emotional difficulty of watching a loved one refrain from eating.
- Suggest that families read about food and nutrition at the end of life in the Agrace [Patient & Family Care Handbook](#) and *When Death is Approaching*.

Pain and Active Dying

Pain is not necessarily a part of the dying process. However, many patients experience pain as part of their disease progression through end of life. Decreased mobility at end of life may contribute to discomfort for many people. Regardless of why the patient is in pain, managing it is a top priority.

What We Can Do

- Anticipate needs, to minimize patient discomfort; for example, when pain is managed on oral analgesics, a route change may be needed as the patient loses the ability to swallow.
- Rely on caregiver observation of signs of pain in last stages as well the patient's report, appearance and behavior.
- Note that behavior change is the most reliable indicator of pain in a nonverbal patient.
- When the Numeric, Wong-Baker or Faces-Revised scales are no longer usable or reliable tools, use the PAINAD or FLACC scale to assess your patient's pain.
- Understand how to identify and assess the different types of pain, and understand appropriate medication choices.
- If appropriate, teach about opioids (e.g., morphine, hydromorphone) and dispel myths; learn how to talk to patients and families about tolerance, dependence and addiction.

- For patients on a long-acting opioid with a slow decline, it will be necessary to change to a short-acting opioid and titrate to comfort at end of life.
- Remember that pain can cause other symptoms; for example, your patient’s anxiety may be escalating because they have unmanaged pain or spiritual distress.
- Ensure that there is an emergency plan in place to address any new onset of pain.
- Always prioritize non-pharmacologic interventions to aid in pain reduction.
- Ask families to document *when* and *what* medications they give; use the tracking form in the [Patient & Family Care Handbook](#).
- Use your staff resources: Collaborate with an Agrace provider or pharmacist when suggesting changes in the Plan of Care.
- Refer to Agrace’s tools for help in decision-making: [Pain and Symptom Management Policy \(PC.P1\)](#) and [Pain and Symptom Management Protocol \(PCP1.12\)](#).

Changes in Mentation

Most patients are less alert during the dying experience. Changes in mentation can range from mild anxiety to severe delirium.

Common changes:

- Decreased consciousness
- Psychological and physical withdrawal from loved ones
- Confusion
- Restlessness and agitation



Increased sleep: Decreased level of consciousness is a normal part of the dying process. This can be alarming to families; it is important to educate caregivers to anticipate this sign that the body is beginning to shut down.

Understanding Anxiety, Agitation and Delirium

Delirium is characterized by disordered awareness, attention and cognition. **Delirium should be suspected for any patient with an acute onset of agitation, personality change, impaired cognitive functioning, fluctuating level of consciousness or uncharacteristic anxiety or depression.** Delirium can be hyper- or hypo- active: It can look like agitation but can also look like quieting or pulling inward.

Causes: There are many causes of delirium, and sometimes a cause is difficult to determine. Common triggers for delirium can include, but are not limited to, hunger, thirst, toileting needs, positioning and spiritual distress. Delirium caused by the dying process itself is sometimes referred to as “terminal restlessness.” In these circumstances, there is not another underlying cause we can reverse. **It is our responsibility to carefully assess our patients for delirium and investigate any possible trigger.**

Common Observation Tool to Determine Potential Causes of Delirium

CHIMBOP Reversible Causes of Delirium	
C	Constipation
H	Hypovolemia or hypoglycemia
I	Infection
M	Medications / Medication changes
B	Bladder catheter or outlet obstruction
O	Oxygen deficiency
P	Pain

Harrison, Alison DNP, RN, NP-C; Smith, Robert MD, MBA; Champagne, Mary PhD, RN, FAAN; Martin, Beth MSN, ACNP-BC; Pursley, Jennifer BSN, RN; Hendrix, Cristina DNS, GNP-BC
Implementation of a Delirium Assessment Protocol in an Inpatient Hospice Setting, *Journal of Hospice & Palliative Nursing*: June 2016 - Volume 18 - Issue 3 - p 227-232

What We Can Do

- Treatment of delirium needs to be holistic: It should include medication, non-medication strategies and control of the environment. If a medication is needed to help with relief of delirium symptoms, haloperidol is often the drug of choice.
- Attempt to reverse the delirium if there is a reversible cause and the intervention is in line with goals of care.
- Extra considerations and skill may be needed to assess and address delirium in patients with dementia or in anyone with a trauma history (e.g., a veteran with combat history).



Acknowledge that delirium is uncomfortable for patients and is difficult for families to witness and to manage alone. Assure the family/caregivers of the quality of their caregiving and encourage them to seek and accept help during this trying time.

- **Know your Agrace resources.** Refer to Agrace’s [Pain and Symptom Management Policy](#) and [Pain and Symptom Management Protocol](#) for further information on managing anxiety or delirium.
- Consult with the IDT, providers and pharmacists regularly.

Psychosocial and Spiritual Issues during Active End of Life

At the end of life, patients and their loved ones may struggle with the emotional and spiritual changes that can occur. There are a lot of potential considerations that may weigh on our patients' mind as well as the minds of their loved ones. These include, but are not limited to, unresolved conflicts from their life, grief for the losses experienced and the losses to come, fear and uncertainty over the future, inadequate support or resources, spiritual/existential questioning and coping. While no one's experience is identical, there are some common issues that may arise.

What We Can Do

- Be aware of the emotional triggers related to death (e.g., grief, anger, relief, guilt)
- Respect the cultural, religious, and spiritual beliefs and practices of others.
- Appreciate that others may have different viewpoints and expressions of grief.
- Allow the patient and family control over their environment and care as much as possible.
- Engage with patients and families; provide them opportunities for control where possible.
- **Maintain dignity:**
 - Though a patient may be minimally responsive, their hearing may be intact; have appropriate bedside conversations and speak *to* the patient as though they are fully alert.
 - Ask permission before starting cares, and gauge a response before proceeding. For minimally responsive patients, be sure to say what you are doing prior to the task.
 - Be sensitive with language; for example, consider using terms like “underwear” as opposed to “diapers.”
 - Maintain privacy during personal cares; if others are in the room, consider the patient's privacy preferences.
 - Promote cleanliness of linens, clothing and room environment.
 - Eliminate odors in the room, as appropriate.
- **Be aware of common spiritual and emotional fears that can cause distress:**

Spiritual fears

- Fear of the unknown—before death, time of death, after death
- Fear of being abandoned by a higher power or others
- Suffering in the search for meaning and purpose

Emotional fears

- Unfinished business
- Being a burden to one's family or support system
- Concern for well-being of loved ones after death

- **Understand importance of communication:**
 - Assess the patient’s ability to communicate with words, facial expressions (e.g., eyebrow raising or squeezing hands).
 - Listen to what is said, and be aware of symbolic language.
 - Address active concerns and ask follow-up questions as appropriate.
 - Reflect the language the patient uses regarding their dying process, which may include spirituality.
 - Respect patient wishes regarding information sharing.
 - Refer to advanced directives as needed.
 - Continue to assess spiritual, religious and cultural needs of patient and family; collaborate further, if needed.
- **Honor the dying time:**
 - Help create a patient-centered environment; this may include music, solitude, pets, visitor frequency, aroma, linens, attire, rituals, prayers and presence of family/friends.



Teach

Promote self-care to the caregivers. Self-care may mean different things to different people: Some may need permission to leave, and others need to know it is OK to stay. Families may feel regret if they miss the moment of death, so validate, support and help reframe (when appropriate) their emotional responses, such as sorrow and guilt. Teach them that sometimes it is the patient’s preference to die alone.

- **Teach about symbolic language and Nearing Death Awareness:**
 - The patient may appear confused; listen for clues that may indicate spiritual experiences, movement or travel (e.g., “going to catch the train,” or “I want to go home.”).
 - They may talk to someone who has already died or refer to a previous occupation or interest.
 - They may gesture forward (e.g., reaching or grabbing) or look through the people around them.
 - Highlight these signs to those present, as it is often a comfort.
- Suggested reading from author Maggie Callahan: “Final Gifts” and “Final Journeys”
- **Handle difficult questions carefully:**
 - Answer questions from within your scope of practice.
 - Do not say “I don’t know.” Say instead “I’m not sure, but I will talk with the team and we will follow up.”
 - Collaborate with the interdisciplinary team.

Family Care

Caregivers and families are key players in the Agrace circle of care, prioritize getting to know families' preferences, wishes, questions and needs. Remember that Agrace defines "family" as those people the patient considers to be their family—including a partner, significant other or friend. Below are ways to care for the family as the patient's death approaches and occurs.



Support patients and families in their decision-making: Validate the difficulties of deciding to stop ineffective treatments or non-essential medications. Stand with the patient and family as they navigate these difficult decisions.

What We Can Do

- **Address common fears of family:**
 - Patient experiencing pain or other symptoms
 - Being alone with the patient at time of death
 - Their own grief response
 - Not knowing the patient has died
 - Fear of causing death
- Encourage family who wish to help with cares to do so.
- Remind family to call if they feel any symptoms are unmanaged.
- **Provide ongoing "what to expect" teaching:**
 - Let families know how breathing could change.
 - Teach about medications that will help keep the patient comfortable.
 - Teach caregivers how to perform activities of daily living, as appropriate.
 - Use Agrace's teaching tools: What to Expect When Death Is Approaching, [Patient & Family Care Handbook](#).
- Provide information about bereavement and spiritual support options, when appropriate.
- Teach, reinforce and remind families about the importance of reaching out and asking for help.

Facilitating a Dignified Time of Death

When the moment of death arrives, families may feel startled, shocked, sad, angry, afraid, relieved, calm or uncertain. They may look to you to provide validation and support, and sometimes, confirmation that their loved one has indeed died. **We must navigate this time skillfully and sensitively, knowing that these are moments a family is likely to remember forever.**

Confirmation of death signs/symptoms by hospice RN or provider:

- No response
- No respirations
- No heartbeat, verified by apical auscultation
- Eyes may remain open
- Pupils fixed
- Jaw likely relaxed/mouth open

Agrace Hospice Care RNs can pronounce death. The RN should use clinical judgment and discretion in how pronouncement is done and what is said. This is a defining moment that people will often remember.

Please reference Agrace's time-of-death protocol and our procedures for a patient's death for further guidance on expectations at the death visit.

What We Can Do

- Treat the body with the same respect as you would if the person were alive (e.g., use warm water).
- Encourage any meaningful family rituals.
- Be mindful of family need for privacy as well as support.
- Ensure your technology (e.g., phone, Vocera) is on silent or vibrate. Remember that each moment of this is theirs, not yours.
- **Teach about normal postmortem physiologic changes:**
 - **Rigor mortis:** Temporary stiffening of the muscles that occurs two to four hours after death and is more noticeable in people with high muscle mass.
 - **Algor mortis:** The cooling of the body to room temperature; skin becomes fragile and is easily torn.
- Prepare families for potential escaping of air or the appearance of bodily fluids.
- Offer the family the opportunity to participate in post-mortem care as they wish. Validate decision to opt out as well.
- Mind the room: Remove trash and used medical supplies, make bed, perhaps open a window.
- Explain next steps, such as funeral home arrival and body removal.
- Discuss DME pickup.
- Provide family with Remember stone and accompanying card.
- Remind the family about grief support resources; detailed information is in our [Patient & Family Care Handbook](#), in the "As Death is Approaches" section.

A Word about Us: Professional Fulfillment

Self-care is one of the mainstays of what fuels longevity and passion for work in this field. In fact, it is a requirement; without self-care—which looks different person to person—it is very difficult to provide lasting and positive influences on our patients.

What does self-care mean to you? Find what is meaningful and useful to you; take time to engage in your meaningful activities. You and your patients will be glad you did.

What We Can Do for Ourselves

Everyone reacts differently to hospice work. It is not uncommon for hospice professionals to grieve the loss of their patients.

- Remind yourself that death is not a failure. It is our privilege to share in this time.
- Create your own rituals (e.g., reading obituaries, debrief with colleagues, engage in spiritual practices or mindfulness).
- Recognize your own emotional limits and speak of them.
- Acknowledge your feelings; they are OK!
- Encourage your colleagues to acknowledge their feelings.
- Provide positive reinforcement and feedback regarding excellent care and outcomes you see.
- Know that compassion fatigue is a real phenomenon; self-care measures are the best preventive actions.
- Seek assistance when needed by talking with your supervisor and/or calling LifeMatters, Agrace’s Employee Assistance Program.

