With 35+ years of experience caring for patients and families throughout serious illness, Agrace provides expert education on hospice and palliative care to meet the needs of patients and families, health care professionals and the communities we serve.

HOSPICE CARE | PALLIATIVE CARE
GRIEF SUPPORT | EDUCATIONAL INSTITUTE
This reference is intended as a guide and resource for Agrace staff, as you work with someone who has days to live.

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We know as hospice clinicians that each person’s dying process is unique to them, and it’s impossible to predict for patients and families what exactly will happen. 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. As you see the “Teach” icon throughout this Clinical Practice Guideline, please note that the concepts discussed are those which most often give patients and families difficulty. Embrace your role as teacher.

We get one chance to do this well for each person and his or her family, and we know that when done well, care at the time of dying can be among the most rewarding of experiences.
Differentiating Stages during End of Life

The following are generalizations about an individual's last few weeks of life. As you use this entire tool, please let the chart that follows act as a basic guide.

<table>
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<th>The Month Before Death (Weeks Prognosis)</th>
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<td>Less able to arouse</td>
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<td>Withdrawing</td>
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<td>Increased sleep</td>
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<td>Increased fatigue</td>
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<td>Nearing Death Awareness: moments of “checking out,” appearing far away, or making seemingly random comments</td>
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<td>Increased heart rate</td>
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<td>Elevated temperature</td>
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<td>Cool extremities</td>
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Guiding Principles to Facilitate Natural Dying

Supporting natural, comfortable dying is, in union with our patients and families, our aim.

At Agrace, 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.
Anticipate and manage the needs of the patient and family:

- Our job is to provide the support and education needed to allow for a comfortable, natural death wherever the patient lives. Providing emotional and spiritual support and preparation of family members is central to care, for both the dying experience and the grief experience.
- Open communication is required. Conversations must be facilitated each step of the way.
  > When a patient is actively dying, they will receive a visit (or call if preferred by family) from the RN every day.
  > Social worker will visit or collaborate with RN by phone daily.
- Our role as teacher is essential. Our caregivers and families need education, demonstration where indicated, and reinforcement of teaching. They likely count on us as this source of information and support.

Honor wishes and current goals of care:

- Aim to achieve and uphold patient goals and strive to avoid burdensome care.
- Strive to maintain cultural competence.
  - Support patients and families in their decision-making: Validate the difficulties inherent in deciding to stop ineffective treatments or non-essential medications. It’s important that you stand with the patient and family as they navigate these difficult decisions.

Adjust routines and environment to support the dying process that’s best for the patient:

- Ensure the physical environment is comfortable, private and personal.
- Provide care that neither hastens nor prolongs life.
- Demonstrate flexibility home to home, patient to patient, family to family.

Understand pain and symptom management principles at end of life:

- Definitions
- Etiology
- Psychological and physical effect of symptoms
- Interventions
- Patient and family education and instruction
- Knowledge of Agrace Emergency Comfort Medication Orders (ECMO) protocol
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 prognostic opinions with a level of confidence they likely could not gain on their own. 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. 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.

During this time, Agrace clinicians must carefully assess and individualize plans of care, making decisions about frequency of visits to the home and determining what is most supportive to the patient/family.

Changes in mentation:
- Decreased consciousness
- Psychological and physical withdrawal

  \textit{Increased sleep:} A patient’s decreasing level of consciousness as they die often looks similar to the sleepiness one may experience when they initiate opioid use. Families need help differentiating the two phenomena, and as clinicians we need to be vigilant about assessing the difference. Be sure to help them understand that it is often not the drug alone causing the sedation.

Skin coolness:
- Usually begins with the extremities; anticipatory education about this can reduce the shock and fear some families feel when they feel the cold.

Changes in color:
- Pale or blue skin, which is called mottling. Teach families the effect of decreased blood flow.

Dyspnea:
- Provide breath coaching.
- Direct fan toward patient or open a window, as air movement across the trigeminal nerve in the face can aid in reduction of shortness of breath.
- Use 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 with appropriate, judicious dosing, the risk of oversedation from a narcotic is essentially eliminated.
- Reposition.
Decreased and concentrated urine:

- Due to decreased blood flow through the kidneys; families may need to learn that these phenomena are normal and often occur even in the absence of infection.

New incontinence.

Vital sign changes:

- Heart rate often increases as death approaches, blood pressure drops and temperature may be elevated. Diaphoresis is not uncommon.

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

Breathing pattern changes:

- **Cheyne-Stokes pattern**: Regular respirations turn shallow then cease. Then normal respirations resume and the pattern is repeated.
- **Kussmaul pattern**: Deep, rapid respirations. This is the body trying to get rid of carbon dioxide, in a last effort to maintain acid-base balance.
- **Apnea**: Suspension of breathing. Apnea is perceived by families as pauses, sometimes quite long ones, between breaths.
- **Terminal congestion**: Often a product of no longer being able to swallow one’s saliva. A wet sound is produced when the breath moves around that fluid collection in the back of the throat. Repositioning is the most effective intervention, as it helps move that fluid and subsequently, reduce the noise. Most often, we do not believe this symptom causes the patient distress, but it can be very difficult for families to hear. If anti-cholinergics are used in an effort to prevent further saliva production, be sure aggressive oral care is prioritized so the patient does not experience discomfort from dry mouth.
  > Hyoscyamine
  > Atropine drops
  > Glycopyrrolate
  > Scopolamine: This drug crosses the blood-brain barrier and has a significant side effect profile that is often not well-tolerated, especially in people who are still ambulatory.

Families remember and fear the sound of terminal congestion. Teach that it is not uncommon, nor uncomfortable, for the patient and may be relieved by repositioning. Then continue thoroughly assessing the patient for any signs of shortness of breath or discomfort that may exist and respond accordingly.
Hydration and Nutrition in the Final Days or Hours

Attempts at maintaining weight or caloric intake are not reasonable or achievable goals in the final weeks and 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 typically a distressing or uncomfortable symptom 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. Worry, misunderstanding and sadness about loved ones no longer eating weighs heavily on many family members. We can help ease this weight by educating about nutrition at end of life.

The appetite center in the brain is affected during the dying process. Lack of desire to take in food and fluids may be a protective mechanism for the dying. Patients’ bodies no longer require the calories they once did. In fact, if the patient’s natural desire to eat and drink is challenged, if they take in or are given more than their body wants, 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 increasing ascites increases.

A family may say to you, “He’s dying because he’s not eating!” You can gently help them reframe: “He’s not eating because he’s dying.”

What We Can Do

- Educate patients and families about the physiologic rationale for their loved one’s lack of appetite.
- Encourage families to allow eating what is comfortable. Let eating be social as long as comfortable.
- Encourage frequent sips when appetite diminishes.
- Caution families about aspiration risk as swallowing difficulties increase.
- Prevent fluid overload when possible.
- Attend quickly to any symptom created by limited nutritional intake: Offer food when hungry. Provide oral hygiene when thirsty.
- Always acknowledge the emotional difficulty of watching a loved one not eat.
- Regular oral care as one’s intake reduces or ceases is imperative for maintenance of comfort.
- Suggest that families read about food and nutrition at the end of life in the Agrace Patient & Family Care Handbook; information can be found on pages 9, 10 and 50.
Pain and Active Dying

Pain itself is not a requirement of dying. In fact, new pain as a person is dying usually indicates a new problem, e.g., a pathologic fracture. Decreased mobility at end of life also contributes to discomfort for many people. We also serve a number of patients who do experience disease-related pain or have other complicated pain syndromes. Regardless of why the patient is in pain, managing their pain is a top priority.

What We Can Do

- Rely on caregiver observation of signs of pain in last stages as well the patient’s report, appearance and behavior.
- 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.
- Remember that behavior change is the most reliable indicator of pain in an unresponsive patient.
- Understand how to assess and identify the different types of pain and understand appropriate medication choices. Narcotics are not the best or only choice in many circumstances.
- Providing education about morphine and dispelling myths is an essential and likely ongoing role of Agrace nurses. Understand how to teach patients and families about tolerance, dependence and addiction.
- Anticipate; for example, when pain is managed on oral analgesics, there may be a need for a pill-to-liquid transition or a route change as the patient loses ability to swallow. Anticipating these needs will help minimize the risk of a lapse in patient comfort.
- Continuing the opioid at the same dose as end of life approaches is generally appropriate, unless the patient shows signs of opioid toxicity. Note that as the body dies, substances that act as natural analgesics are also produced.
- For patients on a long-acting opioid with a slow decline, it may be necessary to change to a short-acting opioid and titrate to comfort at end of life.
- Reference Agrace’s Pain Protocols for assistance in decision-making.
- Use your resources. Collaborate with an Agrace physician or pharmacist when suggesting changes in the Plan of Care.
- Remember that other symptoms can be caused by pain. For example, perhaps your patient’s nausea is escalating due to unmanaged pain or unrelieved spiritual distress.
• Secure Emergency Comfort Medication Orders (ECMO) in all appropriate circumstances; understand its purpose and review with caregivers.
• Always prioritize non-pharmacologic interventions to aide in pain reduction.
• Ask families to document when and what medications they give.
• Demonstrate whenever you can. Show how to crush a pill, how to use a syringe, how to reposition a patient. Then ask families for a return demonstration, and confirm their comfort level. They will benefit from your teaching.

Understanding Anxiety, Agitation, and Delirium

Few patients retain complete mental clarity during the dying experience. Changes in mentation can range from mild anxiety to occasional confusion that is caused by severe delirium. Delirium is said to be a disorder of global, cerebral dysfunction characterized by disordered awareness, attention and cognition.

The diagnosis of delirium should be considered in any patient demonstrating 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 potential causes of delirium, and sometimes a cause is difficult to determine. Delirium caused by the dying process itself is sometimes referred to as “terminal restlessness.” In these circumstances, there is likely not another underlying cause we can hope to amend or reverse. For some, it is a natural part of the dying process, the experience of living and dying. It is our responsibility to carefully assess our patients for delirium, however, and investigate any conceivable underlying cause.

How do you know if your patient is delirious?

Are there any alterations or impairments in JOMAC?

J  Judgment
O  Orientation
M  Mentation
A  Attention
C  Concentration
Potential Causes of Delirium:

DELIRIUM
D  Drugs
E  Electrolytes
L  Liver
I  Ischemia
R  Retention
I  Infectious
U  Uremia
M  Metabolic

CHIMBOPP
C  Constipation
H  Hypercalcemia or hypoglycemia or hypoxia
I  Infection or increased ICP
M  Medication, motility issues, motion sickness, metabolic changes
B  Bowel obstruction/bladder (retention)
O  Oral candidiasis or organ failure
P  Peptic ulcer disease
P  Pain

What We Can Do

Often, something as simple as a full bladder can cause delirium; a catheter can easily relieve this! Something as esoteric as unresolved spiritual issues can also cause delirium. We need to stay open. Lorazepam is often not the answer.

- 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 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.
- Validate the extra skill and considerations needed when assessing and addressing delirium in patients with dementia or in veterans who served active duty.

- Acknowledge that delirium is uncomfortable for patients to experience and is difficult for families to witness.
- Delirium is difficult for caregivers to manage alone. Assure the family/caregivers of the quality of their caregiving, and caution them that they may need help during this trying time.

- Know your Agrace resources. Refer to Agrace’s Pain and Symptom Management Protocols for further information on managing anxiety or delirium. Consult with the IDT, physicians and pharmacists regularly.
Psychosocial and Spiritual Issues during Active End of Life

It is our privilege to companion those who are dying, their families, their caregivers and their friends. We offer this through our assessments, our interventions, our presence and the holistic nature of our work. While we reflect the values of Agrace, we also bring ourselves into each situation, focusing on the individuality of each person and each story. Witnessing the dying of another can have a profound effect on us. We must be prepared to maintain both our compassion and our professional objectivity as we assist people in navigating this time.

What We Can Do

Keep self in check:
- Be aware of one’s understanding of death and surrounding emotional triggers.
- Respect the religious and spiritual beliefs and practices of others.
- Appreciate that others may have different viewpoints and expressions of grief.

Allow patient and family control over their environment and care.

Engage and empower patients and families where possible.

Maintain dignity:
- Be mindful that though someone may be unresponsive, hearing may be intact. Have appropriate bedside conversations, incorporating the patient into the conversation as possible. Speak to the patient as opposed to speaking as though he or she is not there.
- Ask permission before initiating cares, and gauge a response before proceeding.
- Know when it feels “right” to talk through cares versus remaining silent.
- Be sensitive with language; for example, consider using terms like “padding” as opposed to “diapers.”
- Maintain privacy during personal cares.
- Promote cleanliness of linens, bed clothes and air.

Be aware of common spiritual and emotional fears that can create distress:
- Spiritual
  > Fear of the unknown—before death, time of death, after death
  > Fear of being abandoned by God or others
  > Suffering in the search for meaning and purpose
Clinical Practice Guideline: Active Dying

- **Emotional:**
  - Unfinished business *(see The Lingering Death on page 12)*
  - Being a burden to one’s family or support system
  - Concern for well-being of loved ones after death

**Understand importance of communication:**
- Assess patient’s ability to communicate, e.g., words, facial expressions, eyebrow raising.
- Listen to what is said, and the nuances. Be sure to address active concerns. Ask follow-up questions.
- Orient patient regularly, if appropriate.
- Acknowledge patient changes as appropriate.
- Use patient’s spiritual language if possible.
- Review Advance Directives as indicated.
- Respect patient wishes regarding information sharing.
- Ongoing assessment of spiritual, religious and cultural beliefs. Collaborate further, if needed.

**Facilitate expressions:**
- 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: “I am ready to die.” “We are ready when you are.”

**Honor the dying time:**
- Be mindful in creating the expressed or desired environment for the patient. Would they like music, solitude, pets, visitor frequency, aroma, linens, attire, rituals, prayers, presence of family/friends?
- Ask family their preferences and expectations. Remind loved ones that we are not always able to predict the last breath. Help prepare family and caregivers, informing them that it doesn’t always unfold according to “plan.”
- **Promote self-care to the caregivers.** Offer permission: “It’s OK to leave the patient alone.” Families can feel burdened forever by missing the moment of death, so validate, support and help reframe (when appropriate) their emotional responses, such as sorrow, guilt or regret about missing the death. Teach them that sometimes it is the patient’s preference to die alone.
The lingering death—struggling to “let go”:

- Facilitate discussions about what could remain “undone.”
- Offer encouragement in helping families anticipate what the patient might need.
- Consider who the patient might need to hear from; assist them with making phone calls, if necessary.
- Assess for unmanaged symptoms.
- Assess for general comfort.
- Keep perspective; we don’t always understand this time and this may be a unique experience for them.
- Remind them that the Agrace team is available 24/7 for support and ongoing management of symptoms.

Provide teaching about symbolic language and Nearing Death Awareness:

- The patient may appear confused. Listen for clues that may indicate internal cognitive or spiritual experiences, inner movement or travel.
- They may talk to someone who has already died or refer to a previous occupation or interest.
- They may gesture forward or look ahead, past the people around them.
- Highlight this to those present, as it is often a comfort.
- Suggested reading: “Final Gifts” and “Final Journeys”

Handling difficult questions:

- Answer questions from within your scope of practice. Don’t be afraid to say “I don’t know.”
- Collaborate with the interdisciplinary team.
- Specifically regarding euthanasia,
  > Remain non-judgmental.
  > Determine the underlying reason for the request.
  > Know Agrace’s policy: Physician-assisted suicide is not an option with Agrace.
  > Develop a plan to address source of suffering.
Family Care

Caregivers and families are key players in the Agrace circle of care. Agrace clinicians prioritize getting to know families and their preferences, wishes, questions, desires and needs. This page highlights some important information regarding care of the family as the patient’s death approaches and as dying occurs.

Remember that Agrace defines “family” as those people the patient considers to be their family—including a partner, significant other or friend.

What We Can Do

Address common fears of family:

- Patient experiencing pain
- Being alone with patient at time of death
- Their own grief response
- Not knowing patient has died
- Fear of causing the 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 what breathing could look like, for example.
- Remind families that some deaths seem “sudden” and others do not.
- Review Emergency Comfort Medication Orders (ECMO)s.
- Teach provision of personal care as indicated.
- Provide mobility/transfer instructions.

Facilitate discussions about post-death concerns or rituals as indicated:

- Funeral homes
- Body donation
- Coroner case
- Religious or spiritual rituals
- Cultural preferences
Encourage communication with patient for the duration of the patient’s life, despite patient’s inability to verbalize back.

Teach about bereavement and spiritual support options. Be aware of “high risk bereavement.”

- History of depression or mental illness
- Extreme grief reaction
- Self-destructive behavior
- Increased alcohol or drug use
- Inadequate or perceived lack of support
- Suicidal ideation

Teach, reinforce, and remind about the importance of reaching out and asking for help.

Always be mindful of your role as teacher. Supplement your teaching with the Patient and Family Care Handbook regularly.

Facilitating a Dignified Time of Death

When the hour of death arrives, families may feel startled, shocked, sad, angry, afraid, relieved, calm, 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:

- No respirations
- No heartbeat, verified by apical auscultation
- Eyes likely slightly open
- Pupils fixed and dilated
- Jaw likely relaxed/mouth open

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

Please reference Agrace’s time-of-death protocol 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.
- Encourage any meaningful family rituals.
- Be mindful of family need for privacy as well as support.
- Assure phone is on silent or vibrate. Remember that each moment of this is theirs, not yours. Avoid extraneous conversations.
- Teach about normal postmortem physiologic changes:
  - **Rigor mortis**: Occurring two to four hours after death, this is the temporary stiffening of the muscles. It is more noticeable in people with high muscle mass.
  - **Algor mortis**: This is the cooling of the body to room temperature. Skin becomes fragile and is easily torn.
  - **Liver mortis**: This is the decomposition or breakdown of red blood cells. Elevating the head of the bed can lessen the color changes in the upper body.
- Prepare families for potential escaping of air or evacuation of bladder or bowels after death.
- Allow/encourage family to participate in post-mortem care as they wish. Validate decision to opt out as well.
- Make efforts at any odor reduction. Recheck body regularly, as stooling could have occurred.
- Mind the room; perhaps open a window, remove the trash, arrange some flowers.
- Prepare family for the body removal.
- Arrange DME pick-up as the family desires.
- Provide family with Remembrance Stone and accompanying card.
- Remind the family about grief support resources. Detailed information is in the Patient & Family Care Handbook, on page 55.
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—and that 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? Whether it’s time alone in the woods, or a game with a young child or sweating it out on the basketball court, find what is meaningful and useful to you. You and your patients will be glad you did.

What We Can Do for Ourselves

- 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, making notes in a journal, an annual balloon release).
- Recognize your own emotional limits and speak of them.
- Know that compassion fatigue is a real phenomenon. Self-care and social-care measures are the best preventive actions.
- Seek assistance when needed: Talk with your clinical team manager, call Agrace’s Employee Assistance Program, and/or visit with a personal counselor for professional assistance.
- Be a part of developing organizational strategies that allow clinicians to maximize their efforts at self-care.
- Encourage your colleagues to acknowledge their feelings.
- Provide positive reinforcement and feedback regarding excellent care and outcomes you see.
- Acknowledge your personal feelings; they are OK!
- Attend to your own grieving.
- Keep work-life balance among your top priorities.