GOAL-ALIGNED CARE
Even in the last hours of life, the goal may be life prolongation. It’s important to clarify whether care should be entirely aimed at medical (physical, emotional, spiritual, and/or social) and/or if the patient also prefers treatments to extend life. These are not mutually exclusive and so clarity is essential for avoiding distress for the patient, family, and care team.

FAMILY SUPPORT
• Prepare the family for uncertainty. (See below section for description of death) The exact timing of death can be unpredictable and when it takes longer than anticipated families can worry that they should not have withdrawn or forgone life-sustaining treatment. Emphasize gratitude for what time they have.
• When possible, it is helpful to ask patients and families what they envision as good end of life care.
• Specific issues around feeding, hydration and medication should be addressed. There is no evidence that hydration and feeding extend life to the final days; however, these are culturally sensitive issues and cultural and religious traditions should be elicited and respected. In the last hours of life, fluid can contribute to volume overload and dyspnea symptoms.
• Permit unlimited visitation.
• Provide a quiet space.
• Ensure that seats, food, and other comfort items (photos, music) are available.
• Consider transferring the patient outside of the ICU, unless they require intensive comfort measures, are physiologically unstable, or have a social situation that makes the ICU a more appropriate location.
• Encourage the family to connect with their loved one by touch or speech.

WITHDRAWAL OF LIFE-SUSTAINING TREATMENT
Avoid use of the phrase "withdrawal of care." Patients and families are vulnerable and need to be assured of non-abandonment by the medical team. Withdrawing and withholding medical treatment are ethically equivalent.

COMPASSIONATE EXTUBATION
• Premedicate the patient to maximize comfort and reduce anxiety.
• Suction prior to endotracheal tube withdrawal.
• Position the patient for comfort and to reduce secretions.
• Address dyspnea with opiates as needed.
• Discontinue alarms that the patient and family may hear.
• Discontinue vasopressors and inotropes.
• Premedicate the patient to maximize comfort and reduce anxiety.
• Suction prior to endotracheal tube withdrawal.
• Position the patient for comfort and to reduce secretions.
• Address dyspnea with opiates as needed.
• Discontinue alarms that the patient and family may hear.
• Discontinue vasopressors and inotropes.
• Premedicate the patient to maximize comfort and reduce anxiety.
• Suction prior to endotracheal tube withdrawal.
• Position the patient for comfort and to reduce secretions.
• Address dyspnea with opiates as needed.
• Discontinue alarms that the patient and family may hear.
• Discontinue vasopressors and inotropes.

WHAT DOES DEATH LOOK LIKE?
The medicalization of death means that many families and even many clinicians are inexperienced with the final phase of life. It is important to prepare the family for physiologic changes they may observe to minimize distress.

SWALLOWING IMPAIRMENT may contribute to the “death rattle” which is caused by secretions pooling in the back of the mouth and can be managed with desiccants.

Conversely, patients may have dry mouth and thirst, which can be managed with oral care and sponge sticks that loved ones can provide.

Conjunctiva can be dry and there is loss of the retro-orbital fat pad, making it difficult to close eyes. This can be managed with eye drops or lubricant.

Family members need to be prepared for changes in breathing which may include periods of apnea and shortness of breath.

Skin will become cold and mottled.

Dyspnea may be managed with opiates. Bedside cooling fans may provide comfort.

• Neurologic changes include confusion, terminal delirium, incontinence, and the inability to close eyes. Lack of sphincter control is not uncommon in the final hours.
• The patient is bed bound.
• Lack of interest in food and liquid.
• Physical weakness and fatigue.

CARE OF THE DYING PATIENT
• Patients who are actively dying should not receive CPR as it is not beneficial and can risk harm for caregivers.
• Deactivate pacemakers and ICDs.
• Eliminate tubes and implants if they cause discomfort. Urinary catheters may bring dignity and comfort if you are in the process of turning; feeding tubes may be painful to remove and may provide good access for medications in some cases.
• Oxygen can be discontinued for patients who do not have distress. Nasal cannula is typically more comfortable than masks.
• Pulmonary edema can be addressed with diuretics if not contraindicated.
• Intravenous lines may provide access for medications and should not be discontinued unless they cause discomfort.
• Opiates are preferred for analgesia.
• Oral medications are preferred because intravenous opiates have a short half life.
• Continuous infusion is a more reliable approach for intravenous meals.
• Medications should be prescribed as scheduled for intravenous medications and not regular intravenous medications may not be appropriate for patients unable to ask for them.
• Doctrine of Double-Effect: If the stated goal is comfort, it is ethically permissible to prescribe opiates even if it is understood that the side-effects may hasten death. It is not appropriate to prescribe with the intention of hastening death outside of Medical Aid in Dying (MAID).
• Delirium can be very distressing for families.
• Caregivers should be encouraged to provide gentle redirection and a calming presence.
• Haloperidol is appropriate if patients have agitation or hallucinations.
• Lorazepam can be used for persistent agitation when it might otherwise be contraindicated.
• Seizures can be controlled with lorazepam. In patients who have a history of seizures, anti-seizure medication should be continued.
• Antimicrobials can be continued if they do not add discomfort (e.g., volume overload) and the patient and family wish to treat infection.
• Mucosal buildup should be wiped from eyes and mouth.
• The “death rattle”: Pooling secretions are distressing to hear, turning and repositioning may help, as may minimizing hydration. Avoid deep suctioning. Glycopyrrolate can minimize secretions without contributing to sedation. Scopolamine may also cause sedation.
• Remember that an unresponsive patient does not feel a sensation of choking and does not suffer. Prognosis after onset of the death rattle is a few hours to a few days.
WHERE TO HANG:
- Surgeon Lounge
- OR Locker Room
- Resident Workroom
- ICU Workroom

Need additional copies?
Send an email to aast@aast.org with the subject header: Goals of Care, with mailing information.