

Guidelines for Care following the Withholding or Withdrawal of Life-Sustaining Treatments

Division of Critical Care Medicine Medical-Surgical Intensive Care Unit Children's Hospital Boston

Purpose: These guidelines are intended to assist the clinicians providing end-of-life care in the Medical-Surgical Intensive Care Unit at Children's Hospital Boston with information on how to coordinate and deliver more effective and cohesive care.

The Clinical Team Huddle

- Prior to the withholding or withdrawal of life-sustaining treatments, the attending physician, charge nurse, fellow, NP, bedside nurse, medical resident and respiratory therapist at a minimum, and preferably including other members of the clinical team such as clergy and psychosocial experts, should huddle. The huddle should review the issues covered in this guideline.

What treatments may be withheld or withdrawn?

- It is ethical and legal to withhold or withdraw any medical treatment when the patient's family, as informed by a recommendation from the clinical team, determines that the burdens of such treatments outweigh the benefits.
- Any medical intervention, from ECMO and pacemakers to the use of physiologic monitors, may be withheld or withdrawn from the dying patient in the ICU.
- We never withdraw care, only treatments and interventions.
- A guiding concept in determining what treatments to continue and what treatments to withhold or withdraw is that any intervention that appears to promote the patient's comfort or dignity (as well as ameliorate emotional, psychological, or spiritual concerns) should be continued. Those that do not appear to promote the patient's comfort or dignity should be withdrawn.

How should mechanical ventilation be withdrawn?

- An artificial airway may be removed (extubation), or the patient may have supplemental oxygen and/or positive pressure ventilation gradually reduced (terminal wean with no plan for extubation). The method of withdrawal should be guided by the specific circumstances of the patient.
- A patient likely to experience significant hemoptysis, for example, may benefit from a terminal wean with the gradual reduction in FIO₂ and/or ventilator rate at a pace not faster than pharmacologic sedation is administered to treat objective signs of distress from the effects of hypoventilation and hypoxia.
- Studies suggest that the most rapid descent into unconsciousness with the least agitation occurs when hypoxia is allowed to progress in the face of normocarbia.
- Many parents will request that mechanical ventilation be withdrawn by having their child extubated. In this case, the abrupt removal of respiratory support will likely lead to the abrupt escalation in symptoms of respiratory distress. In this case the patient generally should receive sedation or analgesia prior to extubation in anticipation of respiratory distress, with subsequent doses titrated to the patient's level of discomfort.

- It is not a violation of the medical examiner policies to withdraw the endotracheal tube as the means to withdrawing life-sustaining treatment in the ICU at the request of informed and responsible parents.

Preparation of the Family

- After the clinician huddle, preferably the senior physician and bedside nurse should huddle with the family to provide clear and explicit explanations about the process of withdrawal of life-sustaining treatments, and assurance that symptoms of patient suffering will be treated. A huddle with the family is essential in guiding them on what to expect, may alleviate some of their anxiety around the process.
- Avoid making firm predictions about the patient's clinical course after withdrawal of mechanical ventilation or other forms of life-sustaining treatment as they are often inaccurate, and may result in a substantial loss of credibility when predictions about death or the timing of death are in error. In answer to questions about what will happen it is better to say, for example, "We think it is unlikely that your son will survive after the ventilator is withdrawn, but whether he breathes only for a short time or for a very long time we can assure you that we will treat symptoms that appear to be causing him discomfort."
- At times it will be necessary for the clinicians to anticipate, ask, and answer questions that the family appears to be afraid or unable to verbalize. "Sometimes after the ventilator is withdrawn patient's experience a change in skin color, or unusual breathing noises, and this is to be expected and our job is make sure that your child does not experience symptoms of suffering or discomfort. If we see signs of discomfort, we will treat them."
- Families should have the opportunity to be helpful and invited to participate in activities to relieve discomfort, such as mouth care, bathing, and repositioning. They should be encouraged to participate in assessment of the patient's pain and suffering and they should that the family could also be encouraged to provide other means of comfort to the patient that were important to them before, such as holding or rocking, their child, wrapping the child in a special blanket, giving their child a massage, etc.)

How should signs of apparent discomfort be treated?

- Treatment of discomfort may include pharmacologic and nonpharmacologic strategies. Palliative measures should be comprehensive, and not rely solely on sedation and analgesia. For example, simple positioning or massage may be effective.
- Assessment of breathing patterns can be complicated in dying patients. Irregular breathing patterns are a natural part of dying and may not be uncomfortable for the patient. Unfortunately, the irregular pattern that accompanies dying is often referred to as "agonal," which may imply to the family and other clinicians that the patient is in "agony."
- Gasping is a medullary reflex and can occur in the absence of consciousness. Similarly, noisy respirations from airway secretions (the "death rattle") are more likely to be distressing to the family and other observers than they are to the patient. All gasping does not need to be treated with escalating doses of sedatives or narcotics, ideally the decision should be made on a consensus between the family and clinicians at the bedside on whether the patient activity appears to be causing, or is a manifestation of, suffering.
- In general, the clinician's obligation is to treat objective signs of discomfort as experienced by the patient. The distress of the family should be addressed by continued reassurance and emotional support.

Neuromuscular blockade and the withdrawal of mechanical ventilation

- Neuromuscular blocking drugs have no sedative or analgesic properties and may mask symptoms of suffering at the end of life. As a general rule, therefore, pharmacologic paralysis should be avoided at the end of life.
- In most cases, the effect of these agents can be reversed or allowed to wear off within a short period of time, allowing for the withdrawal of mechanical ventilation in the absence of the confounding effects of paralysis. Patients who have been receiving NMBAs chronically for management of their ventilatory failure occasionally can present a more difficult ethical dilemma. In some situations, restoration of neuromuscular function may not be possible for several days or even weeks. When faced with this problem, the clinician must choose between withdrawal of the ventilator while the patient is paralyzed vs. continuation of life support well beyond the point at which the patient and family have determined that the burdens of such treatments outweigh the probable benefits. In this circumstance, it may be preferable to proceed with withdrawal of life support despite the continued presence of neuromuscular blockade.

How much is too much sedation and analgesia?

- Current ethical and legal guidelines place importance on the intentions of clinicians in administering analgesics and sedatives at the end of life. Specifically, clinicians should administer doses that *are intended to relieve pain and suffering but not intended to directly cause death*. We cannot, however, give more sedation than what the patient needs to be comfortable (be prepared for the request, “Please, can’t we just get this over with”).
- Because intentions are essentially subjective and private, the only way to infer the nature of a clinician’s intentions are by self-report and by an analysis of his or her actions. Accordingly, documentation of one’s intentions in the patient’s chart is an important part of providing end-of-life care. When “p.r.n.” orders are written for analgesics and sedatives, the indication for administration should be stated clearly (e.g., pain, severe upper airway obstruction). This reduces the likelihood of misinterpretation or abuse.
- With regard to actions, when a clinician titrates morphine in doses of 1, 5, or 10 mg every 10 or 20 mins, it is plausible to conclude that the clinician intends to make the patient comfortable and not to directly cause the patient’s death. On the other hand, when a clinician administers 2000 mg of morphine acutely to a patient who is not profoundly tolerant, it raises the concern that the clinician may have primarily intended the death of the patient.
- Sedation and/or analgesia should be titrated to effect, and the dose should not be limited solely on the basis of “recommended” or “suggested” maximal doses. In most cases, patients who do not respond to a given dose of an opioid or benzodiazepine will respond if the dose is increased—there is no theoretical or practical maximal dose.
- The concept of “anticipatory dosing” (as opposed to reactive dosing) also should guide clinicians in the use of sedation and analgesia at the end of life. The rapid withdrawal of mechanical ventilation is an example of the need for anticipatory dosing. At the time of ventilator withdrawal, the clinician can anticipate that there will be a sudden increase in dyspnea. It is not sufficient simply to respond to this distress with titrated doses of an opioid (reactive dosing). Rather, clinicians should anticipate that the abrupt withdrawal of assisted breathing will trigger increased respiratory distress and therefore they should provide adequate sedation or analgesia beforehand (anticipatory dosing). As a general rule, the doses of medication that the patient has been receiving hourly should be increased by two- or three-fold and administered acutely before withdrawing mechanical ventilation.

What is the goal in using sedatives and analgesics in this context?

- The goal of titrating sedatives and analgesics after withdrawal of mechanical ventilation is only to treat objective signs of discomfort that evolve; it is not to bring about a certain outcome. Stated another way, the target is to make the patient comfortable, the target is not some arbitrary maximum dose and the target is not the death of the patient.
- If there are no objective signs of discomfort and the patient breathes effectively after extubation, despite our prediction that death would immediately follow withdrawal of ventilation, there should be no panic among the clinicians that something is wrong and further sedatives or analgesics must be administered. If the patient is unexpectedly breathing comfortably after extubation, continue all other non-medication measures of palliative care and provide ongoing and comprehensive support for the family.
- On the other hand, it may take multiple boluses of escalating doses of sedatives and analgesics to treat clear signs of discomfort after extubation in order to keep the patient comfortable.
- Either way, our frame of mind before the withdrawal of life-sustaining treatments is that we accept that patient's will proceed at their own time and place. We respond to what evolves, but it is not our intention in administering sedatives and analgesics to ensure that a certain outcome evolves.
- Our sole focus is only that a patient for whom life-sustaining treatments have been withheld or withdrawn not be left with untreated, objective, signs of suffering.

What basic documentation is essential?

- A brief description must be placed in the patient's medical record of the decision making process that led to the withholding or withdrawal of life-sustaining treatment, and the palliative care provided.
- For example, when describing the decision making process, one should note the date and time of the family meeting, those present, and some statement that conveys that there is "agreement between the family members and the clinician team that the burdens of life-sustaining treatments outweigh any remaining benefit and that the decision has been made to withdraw life-sustaining treatments at this time."
- In describing the palliative care measures provided, it is important to briefly document the rationale used to titrate sedation and analgesia, if administered. For example, "Signs of suffering were noted with the onset of gasping respirations and increased work of breathing after the patient was extubated. Morphine and versed were ordered by Dr. Burns and administered by L. Pixley RN and titrated to treat these signs of patient suffering. The patient's signs of suffering were relieved after three boluses over 20 minutes and the patient expired at 3:45 PM."

What else do we need to know?

- After the patient expires the physicians need to complete the "Report of Death" paperwork. This can be found in the file cabinet at the front of the MSICU, the administrative assistant on duty can get it for you.
- Attached to this report is also a checklist on all the agencies and individuals who must be notified (the medical examiner for any death of a patient under 18 years; the New England Organ Bank as every cadaver is potentially a tissue donor of corneas, skin, heart valves and bone; the pediatrician and others).
- Autopsy consent forms are also found at the front desk. Note, Massachusetts regulations require that the family understands that an autopsy is the removal and retention of organs by the hospital and that patient's next-of-kin has the legal right to refuse or restrict the autopsy.
- The Care after Death protocol can be found in the Nursing Policy and Procedures manual, and CHB eLibrary: "Bereavement Check list: when a patient dies" and "Honoring Patient Preferences".