

SUMMARY OF KEY POINTS

- Withdrawal of life support is a legal and ethical option.
- Withdrawal of life support is a medical procedure and needs attention to detail.
- Once the decision to withdraw is made, all therapies that don't provide comfort should be stopped. Just turn it off unless rapid withdrawal interferes with comfort.
- Mechanical ventilation should be withdrawn through a rapid weaning process, ensuring adequate management of patient discomfort.

Integrating Palliative and Critical Care

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Definition of Palliative Care in the ICU at University Hospital:

An interdisciplinary model of care for **all** patients admitted to ICU which addresses physical, cognitive, emotional, social and spiritual needs and seeks to improve the quality of life for the ill person and his or her family.

PURPOSE OF THIS EDUCATIONAL PAMPHLET:

PROVIDE EDUCATIONAL BACKGROUND ON COMMON TOPICS CONCERNING PALLIATIVE CARE IN THE ICU.

THIS PAMPHLET INCLUDES THE FOLLOWING:

1. FREQUENTLY ASKED QUESTIONS ABOUT WITHOLDING AND WITHDRAWING LIFE SUPPORT
2. TREATMENT OF PAIN IN THE DYING ICU PATIENT
3. INTERDISCIPLINARY STAFF COMMUNICATION WITH PATIENTS AND THEIR SURROGATE DECISION MAKERS AND LOVED ONES
4. PRINCIPLES AND PRACTICE OF WITHDRAWING LIFE SUPPORT IN THE DYING PATIENT

How rapidly should mechanical ventilation be withdrawn?

Mechanical ventilation should be withdrawn through a rapid weaning process that usually takes between 15 – 30 minutes.

Full ventilatory support →→→Remove supplemental O₂ and PEEP →→→Reduce set rate or PS gradually

Titrate sedation to ensure comfort Titrate sedation to ensure comfort

Takes 5 minutes

Takes 5 minutes

Takes 5-20 minutes

Should patients be extubated after withdrawing mechanical ventilation?

There is little research evidence to guide this decision. Clinicians however often have strong opinions. Judgments should be case-based on preferences of family, the amount of secretions, and level of consciousness of patient. Many surrogates prefer to have endotracheal tube out to facilitate their being close to the patient.

The interdisciplinary team needs to be aware that, for cases of interest to the medical examiner, clinicians should not remove an endotracheal tube or any other tubes after a patient dies. However, good quality end-of-life care may involve removing such tubes *before* the patient dies and this is perfectly acceptable, even if the medical examiner is interested in the case.

Should paralytic agents be discontinued prior to withdrawal?

Yes. Paralytics should be stopped for a period of time that is sufficient to allow evaluation of patient discomfort such as grimacing, restlessness, etc.

Are there other clinical tips that experts have found helpful?

1. ICU nurses should be given wide latitude to select doses for management of discomfort.
2. IV drip of pain medication allows for rapid titration and ensures that sufficient medication is available.
3. Bolus equivalent to at least the current hourly rate should also be present at the bedside to manage rapidly emerging symptoms of distress.
4. It is important to document the signs and symptoms that necessitate a dose escalation.

PRINCIPLES AND PRACTICE OF WITHDRAWAL OF LIFE SUPPORT IN THE DYING PATIENT

What are the principles of withdrawing life support?

- The goal is to remove all treatments that don't provide comfort.
- Withdrawing is morally and legally equivalent to withholding therapies.
- Any treatment can be withdrawn if withdrawal serves the purpose of promoting comfort.

Should sedation be used when removing life-sustaining therapies?

Yes. Any discomfort and suffering caused by removal of life-sustaining therapy should be treated aggressively just as aggressively as one would treat pain associated with the underlying disease.

What drugs should be used to treat pain and other symptoms associated with withdrawing life support?

Generally, opioids (narcotics) and anxiolytics (benzodiazepines) are used and are adequate. Occasionally, neuroleptic agents may be helpful for agitation.

What is the correct dosing for treating discomfort with withdrawal of life support?

It is not possible to develop explicit dosing guidelines. Effective doses to relieve suffering depends on the patient's tolerance to opioids and the underlying condition. Importantly, no dose is too high if lower doses fail.

What process should be used to initiate withdrawal of life support?

As with any medical procedure, informed consent and education is necessary for the patient or the surrogate decision maker. In addition, the ICU team should ensure that the withdrawal is done in a proper setting, with the monitoring necessary to ensure patient comfort, adequate sedation and analgesia. The team should be prepared for complications. Surrogates often appreciate having control over timing.

How rapidly should life-sustaining therapies be withdrawn?

The only justification for slowly removing (weaning) life support is when its abrupt removal will cause discomfort. All therapies, except mechanical ventilation, should generally just be turned off. "Stuttering" withdrawal, where some therapies are withdrawn one day and others withdrawn on subsequent days, often signals confusion about the goals of therapy and should generally be avoided.

FREQUENTLY ASKED QUESTIONS ABOUT WITHHOLDING AND WITHDRAWING LIFE SUPPORT

Is withdrawing or withholding life support legal in New Jersey?

Yes. New Jersey's informed consent law gives patients, or their legal surrogates, the right to refuse any recommended therapy whether it is life sustaining or not. In addition, the New Jersey Advance Directive for Health Care Act (PL1991,201) specifically states that "competent adults have the fundamental right in collaboration with their health care providers, to control decisions about their own health care." This act explicitly includes artificially provided nutrition and hydration as a type of life-sustaining therapy that can be withdrawn.

In cases of withdrawing medical treatment, what is the cause of death?

Death occurs as a complication of the underlying disease. Similarly, the goal of comfort care is to relieve suffering in dying person, not to hasten death. Providing pain and symptom control with measures such as narcotics and benzodiazepines is legal and constitutes good quality medical care.

It is better to withhold a therapy or withdraw a therapy?

Withholding treatments is morally and legally equivalent to withdrawing them. When one life-sustaining treatment is withheld, strong consideration should be given to withdrawing other current life sustaining treatments and changing the goals of care to comfort.

What is the legal status of various options for end-of-life care?

	Is the practice legal in NJ	Does the patient have to be competent?	If the patient is not competent, can a surrogate authorize the decision?	Does the patient have to be declared "terminal" by two physicians?	Is a physician's order required?
Withholding or Withdrawing of life-sustaining therapy Def: stopping or not starting a medical therapy	Yes	No	Yes	No	Yes
Physician Assisted Suicide (PAS) Def: providing the means to commit suicide	No	NA-not legal	NA-not legal	NA-not legal	NA-not legal
Voluntary Active Euthanasia Def: both providing the means and completing the act that results in death at a person's request	No	NA-not legal	NA-not legal	NA-not legal	NA-not legal
Mercy Killing Def: killing someone to relieve their suffering	No	NA-not legal	NA-not legal	NA-not legal	NA-not legal
Terminal Sedation Def: providing adequate analgesic at the end of life to achieve unconsciousness	Yes	No	Yes	No	Yes
Stopping of Eating and Drinking Def: an individual's refusal of food and drink for the purpose of hastening their death	Yes	Yes	Yes	No	No
Adequate Pain Management Def: providing pain and symptom management to effectively alleviate pain and other symptoms	Yes	No	Yes	No	Yes

Informing:

- Nurses can translate the language of critical care (e.g., “DNR”, “inotrope”, “vent”)
- Nurses can help explain the pathophysiology of the patient’s condition and the purpose behind treatments or equipment

Preparing:

- People may need assistance to be able to speak and listen
- Affirm the need for communication
- Ask rhetorical questions to help others think aloud
- Prior to conferences with the physician, help families think about the questions they have

Supporting:

- Affirm the value of each person’s input; share other’s sorrow when hard decisions must be made
- Be present when physicians talk with families

GUIDING

Orienting:

- Help family and others to be able to function in their normal social or professional roles within the high-tech environment of critical care
- Help families to get past the technology to the patient
- Encourage family presence at the bedside to assure that families have the intimate knowledge of the patient’s situation necessary for good surrogate decision making

Directing:

- Guide others about what their social or professional role now entails, given the clinical reality
- Encourage families to create the rituals they want around the dying event
- Help family to move into a decision making role; cue families to surrogate decision-making by asking what their loved one would choose, not what they want done

Sharing:

- Offer your presence to others when they go through difficult and unfamiliar experiences
- Be present during the dying process

- Talk with the surrogates about what the patient would have wanted if she/he could talk.
- Talk with the surrogates about what the patient valued.
- Talk with the surrogates about the patient and their religious or cultural needs.
- Ask the surrogates how conferences/discussions with the health care team went.
- Inquire about disagreements among surrogate decisions makers.

When surrogate decision makers are talking with physicians, what can the interdisciplinary team do to facilitate communication?

Surrogate decision makers may have talked with team members caring for their loved one about their questions, concerns and treatment preferences. Yet during discussions with physicians, these topics may not come up. Interdisciplinary team members can facilitate communication by prompting discussion about previously expressed questions, concerns or preferences.

What are specific strategies for the interdisciplinary team to foster good communication with surrogate decision makers?

KNOWING

Understanding the patient as a whole person:

- Ask visitors to bring a picture of the patient taken before the hospitalization
- Ask about the patient’s prior interests and values
- Create a collage that helps care providers get to know the unique and loved person they are caring for

Understanding the surrogates perspective:

- Try to view the patient and the situation through the visitors’ eyes
- When confronted with a statement by visitors that are disturbing, respond in a non-judgmental manner by saying something like, “Tell me more about that.” or “I’m not sure I understand what you mean.” Please tell me more about _____.”

Understanding the perspective of other care providers:

- When you find your opinion or perspective differs from a colleagues, respond non-judgmentally by seeking more information

FACILITATING

Bringing together:

- Help arrange the logistics to bring the involved people together to talk
- Private conversations need private spaces. Find rooms where family can meet either alone or with the team to consider the situation

TREATMENT OF PAIN IN THE DYING ICU PATIENT

Note: While this pamphlet focuses on the needs of the dying patient, many of the same principles apply for *all* patients in the ICU.

What are the principles of pain management for dying patients?

The goal is to balance adequate control of symptoms with an acceptable level of cognitive function. For critically ill patients, this can be challenging. Pain management is critical to providing humane and compassionate care. Recent research has found that families report that up to 50% of patients suffer moderate to severe pain in the last three days of life.

What is the best delivery route for pain management in the ICU setting?

Since most ICU patients already have intravenous access, this route is preferred. Continuous IV drips are often better than intermittent IV dosing to insure maintenance of a therapeutic level and that adequate medication is on hand for sudden increases in symptoms. Patient controlled analgesia pumps are not recommended for actively dying patients or for patients with a diminished level of consciousness. Epidural, intrathecal, subcutaneous, oral, and rectal routes can also be used when the IV route is either unavailable or contraindicated.

INTERDISCIPLINARY STAFF COMMUNICATION WITH PATIENTS AND THEIR SURROGATE DECISION MAKERS AND LOVED ONES

It is important to remember that, if the patient is unable to participate in medical decision making, staff should identify the surrogate decision maker(s) and include them in discussions. In the State of New Jersey, the legal surrogate decision maker hierarchy goes as follows:

1. Durable power of attorney for healthcare
2. Legal spouse
3. Adult child (> 18 years of age)
4. Parent
5. Sibling

If there is more than one person at a given level, decisions should be unanimous among all persons at that level who are actively engaged. In ordinary practice, we strive to achieve consensus among all family members and loved ones, if at all possible.

The interdisciplinary team should talk with the patient and his/her surrogate decision maker(s) about end of life care as early in the hospital stay as possible. The interdisciplinary team consists of nurses; physicians; social workers; spiritual care providers; occupational, physical, respiratory, and speech therapists and others providing direct care to the patient.

As members of the health care team we should respond to questions, concerns, and needs in an honest but compassionate manner. Physicians should initially provide diagnostic and prognostic information. However, this should not discourage other team members from reinforcing this knowledge, offering emotional support, preparing patients, family members and other persons important to the patient for bad news, and assisting them with impending loss.

What does an interdisciplinary team tend to do well in their communication with family and other surrogate decision makers of patients?

Critical care providers frequently talk with the surrogate decision makers about a patient's illness and explain treatments to them. They also are likely to inquire whether the surrogates have questions and to encourage them to discuss their feelings.

What areas of communication can the interdisciplinary team improve?

Research has shown that critical care providers address the following areas less frequently:

- Tell the surrogates what to expect during a conference with the health care team.

What are the equianalgesic opioid doses for common analgesics?

Drug	IM	PO	Half-life(hr)
Morphine	10	20-30/60 ^b	2 - 3.5
Codeine	130	200	2 - 3
Oxycodone	15	30	3 - 4
Hydromorphone	1.5	7.5	2 - 3
Methadone	10	20	15 - 120
Meperidine*	75	300	2 - 3
Oxymorphone	1	10	2 - 3
Levorphanol	2	4	12 - 16
Fentanyl	0.1 ^a	4	12 - 16
Tramadol	100	120	3 - 4

*Meperidine/Demerol is no longer recommended due to a high incidence of neurotoxicity associated with its metabolite normeperidine.

^aEmpirically, transdermal fentanyl at 100 ug/hr = 2-4 mg/hr intravenous morphine.

^bDerived from single-dose studies.

How should dose changes be handled?

Many patients will require additional sedative and analgesic medication for objective signs of discomfort. Changes in dose should be documented in the medical record with the signs or symptoms that prompted the dose change.

What dose is too high when controlling symptoms in the setting of withdrawing life support?

No dose is too high if lower doses have failed to control symptoms.