PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #35
INFORMATION FOR PATIENTS AND FAMILIES ABOUT VENTILATOR WITHDRAWAL

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Introduction This is Part 3 of a three-part series on ventilator withdrawal. *Fast Fact* #33 reviewed a protocol for removing the ventilator; *Fast Fact* #34 reviewed medications for symptom control. Physician-counseling of families is a critical aspect of care for the dying patient who is to be removed from a ventilator. Ideally the family will be involved in the decision to withdraw the ventilator and thus apprised of the goals of care. Before withdrawal, the following issues should be discussed.

Potential outcome of ventilator withdrawal
Assuming all other life-sustaining treatments have been stopped, including artificial hydration and nutrition, there are several potential outcomes: rapid death within minutes (typically patients with sepsis on maximal blood pressure support), death within hours to days, or stable cardiopulmonary function leading to a different set of care plans, including potential hospital discharge. If the latter possibility is realistic, future management plans should be discussed prior to ventilator removal, since some families may desire to resume certain treatments, notably artificial hydration/nutrition. Generally, by the nature of the underlying illness and the established goals, it is fairly easy to predict which category will be operative, but all families should be prepared for some degree of prognostic uncertainty (see *Fast Fact* #30).

The procedure of ventilator withdrawal
Never make assumptions about what the family understands; describe the procedure in clear, simple terms and answer any questions. Families should be told before-hand the steps of withdrawal and whether or not it is planned/desired to remove the endotracheal tube. In addition, they should be counseled about the use of oxygen and medications for symptom control. Assure them that the patient's comfort is of primary concern. Explain that labored breathing and signs of breathlessness may occur shortly after the extubation, but that they can be managed. Confirm that you will have medication available to manage any discomfort. Ensure they know that the patient will likely be asleep and that involuntary moving, noisy or irregular breathing, or gasping do not reflect suffering if the patient is properly sedated or in a coma. Some families may wonder if leaving their loved one intubated and on the ventilator may be more comfortable. Explain that ET tubes are a source of discomfort and anxiety for most patients and therefore are not recommended at the end of life when comfort is the primary goal.

Explain how the family, clergy and others can be at the bedside before, during and after withdrawal. If asked, explain that they can show love and support through touch, wiping of the patient's forehead, holding a hand and talking to him or her.

Support the decision
Even though a family is able to make a definite decision for ventilator withdrawal, such a decision is always emotionally charged. Families may constantly second-guess themselves, especially if the patient appears to linger following ventilator withdrawal. Physician support, guidance and leadership are crucial, as the family will be looking to the physician to ensure them that they are "doing the right thing." Furthermore, it is common for families to have concerns that their decision constitutes euthanasia or assisted suicide—explicit counseling from a physician will be needed. Finally, support needs to continue following death during the bereavement period (see *Fast Fact* #22).

References

1. Adapted from: Emanuel LL, von Gunten CF, Ferris FF, eds. Module 11: Withholding and Withdrawing Therapy. *The EPEC Curriculum: Education for Physicians on End-of-life Care.* Chicago, IL: The EPEC Project; 1999. http://www.EPEC.net.
2. Rubenfeld GD, Crawford SW. Principles and practice of withdrawing life-sustaining treatment in the ICU. In *Managing Death in the Intensive Care Unit*. Curtis JR and Rubenfeld GD, eds. New York, NY: Oxford University Press; 2001: pp127-147.

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