

THREE APPLICATIONS

Example 1: Artificial Feeding and Hydration

- Difficult to discuss
- Food and water are symbols of caring

Physicians frequently perceive the discussion about whether or not to use or continue artificial feeding and/or hydration to be difficult. Successful approaches are not customarily demonstrated during medical training. Food and water are widely held symbols of caring, so withholding of artificial nutrition and hydration may be easily misperceived as neglect by the patient, family, or other caregivers (professional and volunteer). The following are key points, in addition to the general approaches described above:

Review Goals of Care

- Establish overall goals of care
 - Talk about the general medical condition
 - Evaluate the ability of artificial hydration and nutrition to help achieve those goals, before discussing specifics
 - For example, if the patient has advanced cancer, establish an understanding of the overall situation
 - What is the expected course of the cancer?
 - Is anything reversible?
 - How will artificial hydration and nutrition contribute to the overall goals of care, or improve the situation?
- Will artificial feeding and hydration help achieve these goals
- If patient and family hope to see improved energy, weight, and strength, then artificial fluid and nutrition may not help accomplish those goals
- Help the patient and family to understand the goals for which artificial nutrition and hydration would be appropriate

Address Misperceptions

During the discussion, listen for misperceptions expressed by patients and families. They may believe that lack of appetite and diminished oral intake of fluids is causing the patient's level of disability. Most then make the assumption that, "If only the patient got more fluids and nutrition, he or she would be stronger." Use clear, simple language to help them focus on the true causes of the situation: e.g., "The cancer is taking all of your strength" or, "The fact that your heart is so weak is what is causing you to lose your appetite and feel so fatigued."

- Cause of poor appetite and fatigue
- Relief of dry mouth
 - If the patient is close to dying, make sure the family knows that a dry mouth may not improve with intravenous fluids
 - Relief is much more likely with attention to mouth care and oral lubricants
- Delirium
 - Delirium may be related to dehydration, so a clinical trial of intravenous fluids may be warranted
 - However, before starting, ensure that everyone is aware that there are other causes of delirium that may not respond to fluids
 - Also, there is a risk that fluids will only increase other physical symptoms (eg, edema, breathlessness) without relieving the delirium
- Urine output
 - Urine output normally declines in the patient who is dying; it is not just an indicator of hydration
 - Urine output in the range of 300 to 500 mL/day is adequate

- The large volumes (2 to 3 liters/day) in hospitalized patients are usually the result of intravenous infusions and do not reflect normal output with oral hydration
- Both high-volume infusions and excessive urination may be a source of discomfort to the patient

Help Family with Their Need to Give Care

- Identify their feelings and emotional needs
 - Identify the emotional need that providing food and water meets
 - Don't just address issues of artificial hydration and nutrition
- Identify other ways to demonstrate caring
 - Teach the skills they need

A Part of Normal Dying

- Loss of appetite
 - Loss of appetite and diminished fluid intake are a part of normal dying
 - Trying to counteract natural trends may lead to more discomfort for the family without affecting outcome
- Decreased oral fluid intake
- Artificial food/fluids may make situation worse
 - Breathlessness
 - Edema
 - Ascites
 - Nausea/vomiting

Concerns of Patients and Families

- Suffering from thirst or hunger if the patient is not taking any fluids or nutrition?
- Help the patient and caregiving family to understand that dehydration is a natural part of the dying process
- It does not affect the dying patient in the same way as a healthy person who feels thirsty on a hot day or becomes dizzy on standing
- Let family members know that if the patient is not hungry, artificial fluids and hydration will not help him or her feel better
- Badgering the patient to eat or drink more will only increase tensions and may cause the patient to become angry, depressed, or withdrawn, if he or she cannot comply
- Make sure that family members and caregivers know that artificial fluids and nutrition may make edema, ascites, pulmonary and other secretions, and dyspnea worse, particularly if there is significant hypoalbuminemia
- Ensure that family and caregivers know that a state of dehydration in a patient who is bed-bound and imminently dying may have some benefits
 - Pulmonary secretions, vomiting, and urinary incontinence may be less
 - Dehydration may actually stimulate the production of endorphins and other anaesthetic compounds that help to contribute to a peaceful, comfortable death for many patients

Example 2: Ventilator Withdrawal

- Rare, challenging
- Ask for assistance
- Assess appropriateness of request for ventilator withdrawal
- Role in achieving overall goals of care

Techniques for Ventilator Withdrawal.

The clinician's and patient's comfort, and the family's perceptions, should influence the choice of the method to use:

Immediate Extubation (removal of the endotracheal tube)

- The endotracheal tube is removed after appropriate suctioning
- Humidified air or oxygen is given to prevent the airway from drying
- Ethically sound practice

While most authorities regard immediate extubation as ethically sound practice, some may be concerned that it is a form of direct killing of the patient. In such an action the intent becomes the primary concern. Secondary consequences can be dealt with, if they occur.

Terminal Weaning

- Rate, positive end-expiratory pressure (PEEP), and oxygen levels are decreased first
- Over 30–60 minutes or longer
- CO₂ narcosis may stimulate endorphin release and further sedate the patient
- A Briggs T piece may be used in place of the ventilator
- Patients may then be extubated

Ensure Patient Comfort

- Anticipate and prevent discomfort
- Have medication immediately available
- Titrate rapidly to comfort
- Be present to assess and reevaluate

When removing a patient from the ventilator, it is critical that the patient be comfortable throughout the procedure and afterwards. The most important and prevalent symptoms are breathlessness and anxiety.

Prevent Symptoms

- Breathlessness
 - Opioids
- Anxiety
 - Benzodiazepines

Breathlessness

Opioids (such as morphine) are the most effective medication for relieving the sense of breathlessness. They work through both central and peripheral mechanisms of action. The principle of intended vs. unintended consequences governs their use in this setting. Concerns about unintended secondary effects, such as shortened life, are exaggerated, particularly if established dosing guidelines are followed. Titrate the dose with the intent to achieve comfort. Increased doses beyond the levels needed to achieve comfort or sedation in order to hasten death would constitute euthanasia. Oxygen is helpful to correct hypoxemia, but not necessarily breathlessness.

Anxiety

Benzodiazepines (such as midazolam, lorazepam and others) are the most effective anxiolytic drugs in this setting. They are usually used in combination with opioids for severe breathlessness. Opioids only have transient and unreliable anxiolytic effects in opioid-naïve patients and should not be used for this purpose.

Symptom Management During Withdrawal

- Determine degree of desired consciousness
- If the patient is conscious, determine if he or she would like to remain conscious as the ventilator is withdrawn

- This will determine the endpoints for initial medication and guide the use of additional medication during the procedure
- If the patient wishes to remain awake, institute opioids and benzodiazepines at low doses
- Determine, with the patient and family, how and when you would decide to titrate to an endpoint of sedation
- Before withdrawing the ventilator, ensure that the patient is comfortable
- Make plans to intervene if severe breathlessness or discomfort ensues after extubation
- Have medication **immediately** available at the bedside so that it can be rapidly titrated to the level appropriate to ensure the patient's comfort
- Bolus 2–20 mg of morphine IV, then continuous infusion
 - If the patient is naive to opioids and benzodiazepines, start by giving the patient a bolus dose of 2 to 10 mg of morphine IV to prevent breathlessness
 - For children, dose the medications with advice from a pharmacist or pediatric intensivist. Follow this initial dose with a continuous morphine infusion (50% of bolus dose/hr) to maintain the desired effect
- Bolus 1–2 mg of midazolam IV, then continuous infusion
 - Also, bolus with a dose of 1 to 2 mg of midazolam IV and begin a midazolam infusion at 1 mg/hour
 - Titrate these medications to minimize anxiety and achieve the desired state of comfort and sedation
 - Lorazepam may be used as an alternative
 - If these medications have been in use routinely and pharmacological tolerance has developed, higher doses will be required
 - There is no need to increase the doses once comfort and the desired level of sedation have been achieved
- Titrate to degree of consciousness and comfort
- If distress ensues once the ventilator is withdrawn, aggressive symptom control is needed.
 - Consider using morphine 5 to 10 mg IV push q 10min and/or midazolam 2 to 4 mg IV push q 10min until distress is relieved
 - Adjust both infusion rates to maintain relief
- The doses recommended here are for patients who were not previously taking anxiolytic medication or opioids

Prepare the Family

- Ideally, family will be involved in the decision to withdraw the ventilator
- Need to understand procedure and be reassured about their roles
- Since there is uncertainty involved, it is also important to prepare the family for the range of outcomes
- Never make assumptions about what the family understands
- Describe procedure in clear, simple terms and answer any questions
- Assure family that the patient's comfort is of primary concern
- Explain that breathlessness may occur, but that it can be managed
- Confirm that you will have medication available to manage any discomfort
- Ensure they know that you may need to put the patient to sleep
- Assure them that involuntary moving or gasping does not reflect suffering if the patient is properly sedated or in a coma
- Explain how family can show love and support through touch, wiping of the patient's forehead, holding a hand and talking to him or her
- Ask family what other concerns they have
- Explain that there is always some uncertainty as to what will happen after the ventilator is withdrawn
 - Some patients die within several minutes
 - Whereas others may live for longer periods
 - Caution the family that, although death is expected, it is not certain
 - Data show that approximately 10% of patients survive and are discharged from the hospital

A Suggested Protocol for Ventilator Withdrawal: Immediate Extubation, Unconscious Patient

This protocol demonstrates how care and planning can ensure that the process of withdrawing life support maintains the dignity of the patient, and involves the family appropriately. The protocol presented is for immediate extubation of an unconscious patient, but it can be adapted for other uses. Key points are listed below.

Prior to Withdrawal

- Prior to procedure
 - Discussion and agreement to discontinue:
 - With patient (if conscious)
 - With family, nurses, respiratory therapists
 - Encourage family to make arrangements for special music or rituals that may be important to them
 - If the patient is a child, ask parents if they would like to hold the child as he or she dies
 - Make arrangements for young siblings to have their own support if they are to be present
 - Document issues, clinical findings, and care plan on the patient's chart

Protocol–Part 1

- Shut off alarms
 - The physician should personally supervise that all monitors and alarms (when possible) in the room are turned off
 - Ensure that staff is assigned to override alarms that cannot be turned off if they are triggered
- Remove restraints
- Clear a space for family access to the bedside
- Before the family comes into the room, remove NG tube and any other needlessly disfiguring or unnecessary device that may be crowding the bedside
- Family is invited into the room
- If the patient is an infant or young child, offer to have the parent hold the child
- Pressors are turned off
- Maintain intravenous access for administration of palliative medications.

Protocol–Part 2

- Establish adequate symptom control prior to extubation
- Have a syringe of a sedating medication **IN HAND**
 - midazolam, lorazepam, or diazepam
- Once initial symptom control has been established, respirator is set to FiO₂ of 21%
- Observe patient for signs of respiratory distress and adjust medications
- If a patient is likely to develop CO₂ narcosis with a decrease in ventilator settings, there may be less need for sedating medications
- The ET tube is removed
 - If the patient appears comfortable, prepare to remove the endotracheal tube.
 - Or try a few moments of "no assist" before the endotracheal tube is removed.
 - When ready to proceed, first deflate the ET tube cuff. (Tip: Someone should be assigned to silence, turn off the ventilator, and move it out of the way)
 - Once the cuff is deflated, remove the ET tube under a clean towel (which collects most of the secretions) and keep the ET tube covered with the towel
 - If oropharyngeal secretions are excessive, suction them away

Protocol–Part 3

- Invite family to come forward to a loved one whose face is no longer encumbered by medical devices
- Station a nurse at the opposite side of the bed with a washcloth and oral suction catheter, and facial tissues
- Encourage family to hold the patient's hand and provide assurances to their loved one
- Reassess frequently
- After the patient dies, talk with family and staff
- Encourage the family to spend as much time at the bedside as they require
- Provide acute grief support
- Provide the family with the physician's name and phone number, if they have any questions
- Offer follow-up bereavement support
- Send a bereavement card to family members

Example 3: Cardiopulmonary Resuscitation (CPR)

- Many physicians perceive discussion about cardiopulmonary resuscitation (CPR) to be difficult
- Successful approaches not customarily demonstrated during medical training
 - At best, the attending physician conducted such discussions alone, behind closed doors
 - At worst, these discussions were assigned to a lone medical student or resident to do after rounds

Reflect on the Language of CPR:

It is worth reflecting on the language that has developed around CPR and do-not-resuscitate (DNR) status, particularly in hospitals. Getting the DNR order is an important goal for physicians. The phrases, "She is a DNR" or, "He is a full code" betray the bizarre way in which decisions about resuscitation are sometimes treated in contemporary medical care. "Is he or she a DNR?" has become shorthand for the more pertinent question, "What are the goals of care?" Too frequently, a DNR order is interpreted to imply a whole host of other decisions that, in fact, may or may not have been made about an individual patient. One impetus to the current state of affairs is the emotional subtext related to "doing everything" for someone who is loved. It should be expected that everyone involved—patient, family, physician, health care team—wants to do everything possible to achieve the health and well-being of the patient. Cardiopulmonary resuscitation is but one medical treatment that may or may not help to achieve realistic goals related to the care of the patient.

Physician's Role:

- Facilitate the identification of those goals of care
- Help to determine the medical care that will best achieve them
 - In the setting of advanced progressive illness with limited prognosis, consider carefully whether CPR will help achieve goals that patient, family and the physician have collectively determined
 - Using this approach, discussion of CPR and DNR status become de-emphasized to the point that they almost disappear as important parts of the discussion

Discussing DNR Status

Establishing DNR status is but one example of advance care planning. When undertaking to establish DNR status, the physician may want to consider a range of scenarios, not just the one that appears to be the most pressing. This may also give the discussion a greater sense of proportion

- Establish general goals before discussing specific treatments
- Confirm patient and family understanding about the medical condition and the context
- Use understandable language
- Avoid implying the impossible is possible
- Ask about other life-prolonging therapies
- Affirm what you will be doing

Example of Possible Language for Discussion:

During the discussion, use language that is understandable, such as, "If you should die in spite of our current therapy, do you want us to use 'heroic measures'? To do CPR? To press on your chest and put a tube in your lungs to try to get your heart and breathing started again?" To a layman, when the heart and/or lungs stop, the patient dies. It may be helpful to use the word "death" to clarify that CPR is a treatment that tries to temporarily stop death from occurring. If the patient (or parent if the patient is a child) wants more information, move to specific descriptions of what is involved with CPR after the more general question is answered. The convention of initially discussing CPR as "starting the heart" or "putting on a breathing machine" implies a false sense of reversibility, or suggests those heart and lung functions are isolated problems. Avoid implying that the impossible is possible. In discussing DNR status with a patient with a life-threatening illness, avoid introducing CPR as "shocking the heart if it stops, using a breathing machine if the lungs stop." This reductionist approach fails to acknowledge the context in which CPR would be administered—to a patient who is dying of a disease. In the setting of advanced illness, circulation and breathing stop because of the relentless progression of the disease. If there were something to reverse, the medical team would do so long before the patient stopped breathing. Further, avoid describing CPR as "doing everything." It implies that not doing CPR is "doing nothing." The issue of abandonment is implicit in discussions of CPR and DNR. As part of the discussion, ask about other life-prolonging therapies. Put the discussion of resuscitation into the context of the host of life-prolonging therapies that need to be decided upon, including elective intubation and mechanical ventilation, dialysis, surgery, antibiotics, artificial fluids, etc. Consider describing various scenarios and eliciting the patient's preferences. Avoid "getting the DNR" and leaving the patient. Before ending the discussion, affirm what you will be doing for the patient. Confirm the active interventions that are or will be done for the patient. For many patients, full medical interventions to reverse disease and sustain life are appropriate even with a DNR order in place. However, if the patient dies in spite of all efforts, resuscitation will not be attempted. So-called "slow codes" or "chemical-only" codes are unacceptable approaches to the issue of whether or not to offer emergency attempts to restore airway, breathing, and circulation. Their use promotes cynical approaches to decision-making and hypocritical interactions between physicians and patients.

Write Appropriate Orders in the Medical Record

- DNR
 - CPR involves the establishment of a patent airway, effective breathing, and cardiac output through assisted ventilation and external cardiac massage
 - If this is not appropriate or desired by the patient, the physician should write a DNR (do not resuscitate) order
 - A DNR order does not address any aspect of care other than preventing the use of CPR
 - Some institutions prefer a DNAR (do not attempt resuscitation) to avoid the implication of success that DNR connotes

- DNI
 - A DNI (do not intubate) order is sometimes used for patients who do not ever want a ventilator used, even if the machine could save their lives
 - For example, patients with chronic or progressive lung diseases may choose an isolated DNI order
 - Patients who choose to have a DNR order have implied a DNI order, as CPR requires the establishment of airway, breathing, and circulation

- Do not transfer
 - Some long-term care institutions may permit a "do not transfer" order to indicate preferences not to be transferred to an acute hospital setting, in the event of clinical decline

- Others
 - Include all positive orders that relate to symptom control and those that guide intensity of care
 - Some institutions have special forms to facilitate communication and document orders

- POLST
 - Physician Orders for Life-Sustaining Treatment, which is being used extensively in Oregon

National Cancer Institute grant (R25 CA76449) to Sara J. Knight, Ph.D., at the Robert H. Lurie Comprehensive Cancer Center provided the funding for the development of this program. This material was adapted from the EPEC project (Education for Physicians on End-of-life Care).