



Hospice &  
Palliative Care  
Federation of Massachusetts

**ACCESS TO HOSPICE CARE**  
*A report on the Admitting Practices of  
Massachusetts Hospices*

A report of  
the Standards/Best Practices Committee  
Hospice & Palliative Care Federation of MA  
January 2004

*This best practice paper is offered as guidance and not as legal authority.*

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This policy is provided as a sample or guideline that hospices may use for adaptation within their own program.

Appendix A

### Hospice and Palliative Care of Metropolitan Washington

<b>Name of Protocol:</b>	<b>DISCONTINUING OF VENTILATOR SUPPORT</b>
<b>Responsibility:</b>	Clinical Staff
<b>Purpose:</b>	To ensure the patient's right to discontinue life-prolonging medical therapies, including mechanical ventilation, to assure that symptoms of breathlessness and anxiety that accompany vent discontinuation are controlled, to maintain patient comfort and dignity, and to allow the patient and family flexibility in choosing the site of ventilator withdrawal.
<b>Original Date:</b>	1999
<b>Revision Date:</b>	05/2001, 06/2001

#### CRITERIA FOR PATIENT SELECTION:

1. The patient or legitimate proxy has made an informed decision, free from active or passive coercion, to discontinue ventilator support.
2. If the patient is cognitively impaired, terms of any existent living will or previously expressed wishes of the patient are consonant with the decision.
3. The patient has been formally evaluated for the presence of clinical depression and in the judgement of the interdisciplinary group (IDG), found not clinically depressed. If depression is present, it will be addressed therapeutically and its role in the decision making process will be assessed. This will confirm the judgement that the decision to discontinue ventilator support is not primarily a manifestation of treatable depressive illness. This is not necessary in the case of a comatose patient.
4. The team members of the IDG will form a firm therapeutic relationship with the patient and family before the discontinuation of the ventilator. The nurse, social worker, physician, and chaplain services will all be offered to the family and at least two members of the IDG should be working with the family. It is necessary that a minimum of one medical and one counseling member be present. These members will be present to care for the patient and family during the ventilator removal.
5. The patient's family will be instructed and express understanding of:
  - a. The procedure

**NOTE:** This policy is provided with the permission of the Hospice & Palliative Care of Metropolitan Washington. It has since been updated and is available through the Federation.

- b. The intended and unintended effects of the procedure
  - c. All foreseeable possible outcomes, including the possibility of patient survival.
6. The patient and family have come to consensus in support of discontinuing the ventilator. The ethics committee will mediate any conflicts within the family.
  7. The primary attending physician has been actively involved in the discussion and has ordered discontinuation of the ventilator in accordance with HPCMW protocol. In the event that the primary physician disagrees with the decision, the patient/family has the option of choosing a different physician and/or to receive a palliative consultation from a Hospice physician. The primary attending physician can request this consultation if desired.
  8. The patient or legal surrogate decision maker, if the patient is not competent to make a decision will sign an informed consent.

**PROCEDURE/PROTOCOL:** The procedure is a framework to be adapted to the individual patient's needs and circumstances. If ventilator removal is to be done in a facility, HPCMW staff will follow the policies and procedures of the facility related to discontinuing ventilatory support.

**NO EMPLOYEE OF HPCMW WILL BE REQUIRED TO PARTICIPATE IN DISCONTINUING VENTILATOR SUPPORT FOR A PATIENT IF DOING SO WOULD CONSTITUTE A VIOLATION OF PERSONAL VALUES OR BELIEFS.**

#### **PART 1 – PREPARATORY VISITS AND TASKS**

1. A discussion will be first held about overall goals in light of the patient's medical condition. The role of artificial ventilation in achieving those goals should then be considered. All parts of this discussion will be documented.
2. Visits will occur before the planned intervention visit. The team will determine the number of visits necessary before the intervention at the time of the first visit.
3. The IDG members who make these visits should be the members who will be present at the intervention.
4. The roles of the IDG members at this (these) visit (s) are as follows:
  - a. The physician will:
    1. Describe the procedure.
    2. Explore the range of outcomes that may occur.

3. Order appropriate parenteral access for medication delivery.
  4. Write CADD pump orders as needed.
  5. Assess the patient for the presence of clinical depression.
- b. The nurse will:
1. Ensure that the patient and family understand the therapeutic options, their intended effects, and possible side effects or unintended outcomes.
  2. Ensure that the patient and family understand the procedure that will be followed.
  3. Describe what will happen before, during, and after the extubation or ventilator removal.
- c. The social worker will:
1. Assess for the presence of clinical depression and explore its possible effect on decisional capacity.
  2. Screen for the presence of overt or covert coercion upon the patient in the decision making process.
  3. Ascertain the feelings and likely emotional and psychological impact of the decision to end ventilator support on the patient, family, and significant others.
  4. Assess the availability of ongoing support from the community for the family.
  5. Inform the family of the availability of bereavement services from HPCMW.
  6. Facilitate closure in personal relationships between the patient and significant others.
  7. Help the patient and family with funeral planning.
- d. The chaplain will:
1. Provide a safe environment to discuss problems identified by the patient and family in accepting the decision to discontinue therapy and to discuss their current belief systems.
  2. Facilitate the expression of the patient's and family's spiritual beliefs.
  3. Provide usual and customary support to the patient, family, and team.
  4. Assist with funeral as requested, making sure the plans are completed before the protocol proceeds.
- e. The Clinical Manager will:
1. Ensure that all appropriate team members who are involved are aware of, and have had the opportunity to have input into, the impact on the team of the decision to discontinue ventilator support. (e.g. CNAs, volunteers, ancillary therapists).
  2. Notify the VP Communications and the COO that the protocol is being implemented.
  3. Arrange for the ventilator to be maintained by another agency while the patient is in our program.
  4. Assess the willingness, the competencies, and experience of the involved team members.
  5. If the RN is unfamiliar with the ventilator, arrange a respiratory therapy consultation to ensure the protocol proceeds as anticipated.

6. Arrange for the delivery of the equipment needed.
7. Arrange to have equipment removed from the patient's home as quickly as the family requests.
8. Arrange a forum for the staff to have input and express concerns, if present. The chairperson of the ethics committee should be consulted as necessary.
9. Provide a safe environment for the staff involved to debrief after the procedure either immediately or in a few days.

## **PART 2 – PROCEDURES DURING VISIT TO DISCONTINUE VENTILATOR SUPPORT**

**THE RN AND AT LEAST ONE OTHER MEMBER OF THE HOSPICE IDG SHOULD BE IN ATTENDANCE.**

1. **Educational, psychological, and spiritual preparation of the patient and family**
  - a. By the MD and/or RN:
    1. Describe the procedure in clear, simple terms and answer any questions as fully as possible.
    2. Assure the patient and family that the patient's comfort is of our primary concern.
    3. Inform the patient and family that breathlessness may occur but can be managed, and that the appropriate medications are available to manage the patient's discomfort.
    4. Inform the patient and family that a state of sleep may need to be induced.
    5. Assure the family that involuntary movement or gasping may occur, but do not reflect the presence of suffering in a properly sedated or comatose patient.
    6. Caution the patient and family that, although death is expected, it is not certain. If death does not occur Hospice will continue with palliative care. (Data shows that around 10% of ventilator dependent patients survive removal.)
    7. Remind the family that the Hospice staff will not have the equipment available to replace a removed endotracheal tube.
    8. Establish the level of sedation desired by the patient and family (conscious but calm, light sleep, heavy sedation).
  - b. By any IDG member:
    1. Explain ways in which the family can show love and support through presence, touch, and gentle words of caring and reassurance.
    2. Encourage the family to manipulate the environment to be conducive to comfort and reassurance for the patient (favorite music, pictures, readings etc).

3. Offer and/or facilitate rituals and prayers as appropriate.

**2. Physical Preparation of the Patient:**

- a. A member of the team (RN, MD, or respiratory therapist) should supervise that all monitors and alarms in the room are turned off.
- b. Ensure that staff is assigned to override alarms that cannot be turned off.
- c. Remove NG tube and any other needlessly disfiguring or unnecessary device that may be crowding the bedside.
- d. Maintain IV access (when present) for administration of palliative medications.

**3. Discontinuing the ventilator: [The Hospice IDG will identify roles and tasks prior to the visit.]**

**a. Establish adequate symptom control prior to extubation:**

1. Patient who is opiate and benzodiazepine naïve:
  - Bolus with 2 –10 mg. of Morphine IV or SQ to prevent breathlessness.
  - Follow with a continuous infusion at 50% of initial bolus dose/hour either IV or SQ.
  - Titrate the infusion dose to maintain the desired effect.
  - Also bolus with 1-2 mg. midazolam (Versed) IV or SQ.
  - Begin continuous infusion at 1 mg/hr IV or SQ.
  - Titrate dose as necessary to minimize anxiety and achieve the desired level of sedation.
  - Set the FiO<sub>2</sub> on the ventilator to 21% and observe the patient for signs of respiratory distress.
  - Adjust opioids and benzodiazepines to relieve distress before going further.
2. Patient who is not naïve to opiates and benzodiazepines:
  - Will require individualization of dosages.
  - Consult with a Hospice Medical Director for proper dosing.
  - Generally, they will require at least 50% above their maintenance dose to start.
  - Alternative/additional medications: Lorezepam (Ativan), diazepam (Valium), pentobarbital (Nembutal), phenobarbital, or thorazine can be used as well.
  - Set the FiO<sub>2</sub> on the ventilator to 21% and observe the patient for signs of respiratory distress.
  - Adjust opioids and benzodiazepines to relieve distress before going further.

**b. Remove from Endotracheal Tube:**

- Be sure the patient appears comfortable first.
- May try a few moments of "no assist" before removing endotracheal tube (ET).
- Deflate ET cuff.
- *Tip – Someone should be assigned to silence, turn off the ventilator and move it out of the way.*

- Remove the ET under a clean towel, catch any secretions in the towel and keep the tube covered with the towel.
- Suction excess secretions from the oropharynx or trachea as necessary.
- Encourage the family to come forward to be with the patient.
- Encourage them to hold the patient's hand and provide assurances to their loved one.
- Family and staff should have tissues available to wipe away extra secretions or dab tears.

**OR**

**b. Removal from ventilator with tracheostomy;**

- Establish level of comfort with sedation, as above
- Lower FiO<sub>2</sub> to test comfort with medications
- Silence and remove the ventilator from the tracheostomy.
- Encourage the family to stay close to the patient.
- Suction any excess secretions.

**4. After Death**

- Allow time for the staff and family to talk about what happened and how they feel.
- Allow the family time alone with the patient.
- Provide acute grief support.
- Follow HPCMW procedures as customary at the time of death visit.
- Notify the attending physician, if not present, of the death.
- Follow procedure established by supervisor for the removal of the ventilator and equipment.

**PART 3 – FOLLOW-UP FOR FAMILY AND STAFF**

- All staff present work with MSW to complete a bereavement assessment.
- Offer HPCMW bereavement services to the family.
- Inform the family of the availability of community services for support.
- One or more of the IDG members should place at least one follow up call to the family.
- A sympathy card and/or attendance at a memorial service can be considered but are optional.
- The IDG should be offered the opportunity to debrief after involvement in discontinuing ventilator support for a patient, especially if there were complications or unexpected occurrences.


**Competencies:**

- MD:
1. Comfort with involvement in the procedure.
  2. Ability to work cooperatively with the interdisciplinary group.
  3. Knowledge of principles of conscious sedation.
- RN:
1. Comfort with involvement in the procedure.
  2. Familiarity with ventilator (if respiratory therapist is unavailable).
  3. Able to deflate cuff and remove endotracheal tube.
  4. Able to program continuous infusion pumps.
  5. Able to access intravenous site for medication administration.
  6. Able to place subcutaneous site.
- MSW:
1. Comfort with involvement in the procedure.
  2. Experience in counseling around end of life issues.
- PC:
1. Comfort with involvement in the procedure.
  2. Experience in providing spiritual support at end of life.
  3. Knowledge of cultural and faith based differences in expressions of spirituality.

**Equipment:**

- Continuous suction machine with yankeur and straight catheters
- Syringes of various sizes for medication administration
- 2 CADD pumps - 1 with midazolam, 1 with morphine sulfate (to evenly control the level of medication to patient's desired level of comfort).
- Bofus doses of midazolam and morphine for PRN use
- Gloves
- Clean towels or chux
- Gauze pads (4x4)
- Tissues
- Subcutaneous set

**Approved by:**

  
\_\_\_\_\_  
Mary E. V. Frank, RN, MSN, FAAN  
Senior Director, Hospice/Home Health

JUNE 21, 2001  
\_\_\_\_\_  
Date



Review Dates: \_\_\_\_\_  
\_\_\_\_\_

**References:**

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VNA/HOSPICE ALLIANCE

▲ DARTMOUTH-HITCHCOCK · COOLEY DICKINSON

NOTIFICATION OF NON-COVERAGE FOR MEDICARE SERVICES

Patient's Name \_\_\_\_\_ Date of Determination \_\_\_\_\_

Medicare # \_\_\_\_\_ Patient ID# \_\_\_\_\_

Start of Care Date \_\_\_\_\_

Dear \_\_\_\_\_:

The item checked below explains that all or part of the Hospice Service which the Medicare beneficiary received, or was to receive from this Agency, are not covered by Medicare.

Services not covered:

1. The medical information available at the time of, or prior to, start of care show that certain specific services to be furnished by this hospice do not meet the requirements for coverage under Medicare. However, should you request us to file a claim with Medicare, you will receive a formal determination from the Medicare intermediary as to the non-coverage of the hospice services. You can do that by calling the Hospice office at (413) 586-8288.

2. The Medicare Intermediary advises that the type or level of services furnished no longer qualify, as covered under Medicare beginning \_\_\_\_\_  
The Medicare Intermediary will send you formal determination as to the non-coverage of the Home Health service.

The Medicare Fiscal Intermediary servicing this Agency is ASSOCIATED HOSPITAL SERVICE OF MAINE, 2 Gannett Drive, South Portland, Maine 04106.

3. We regret that this may be your first notice of the non-coverage of the Hospice Services under Medicare. Our efforts to contact you earlier in person or by telephone were unsuccessful.

4. You are receiving services under another provider. These services are not part of the hospice plan of care. Therefore, you are financially responsible for the services.

Signature of VNA/Hospice Staff \_\_\_\_\_

VERIFICATION OF RECEIPT OF NOTICE

A. This is to acknowledge that I have received this notice of non-coverage of the services under Medicare on \_\_\_\_\_

Signature of Patient/Patient Representative \_\_\_\_\_

B. This is to inform you that you were advised of the non-coverage of the services under Medicare by telephone/mail on \_\_\_\_\_

Signature of VNA/Hospice Staff \_\_\_\_\_

NO ACTION ON YOUR PART IS REQUIRED

Please see page 2.

VNA/HOSPICE ALLIANCE

▲ DARTMOUTH-HITCHCOCK • COOLEY DICKINSON

Patient's Name \_\_\_\_\_ Date of Determination \_\_\_\_\_

ID # \_\_\_\_\_

RE: Services/items not paid for by Hospice

Dear \_\_\_\_\_

This letter is to inform you of the items or services listed below which are not part of the Hospice plan of care and are not paid for by the VNA/Hospice Alliance.

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If you have any questions, please call the hospice office or speak to your hospice staff.

Signature of Patient \_\_\_\_\_ Date \_\_\_\_\_

\_\_\_\_\_  
Date \_\_\_\_\_

Signature of Family Member/Patient Representative(if patient unable to sign)

Relationship to patient \_\_\_\_\_

ATTEST \_\_\_\_\_ Date \_\_\_\_\_

Agency Representative



### Membership Survey

In the spring of 2002, the Board of the Hospice & Palliative Care Federation set forth five goals in a strategic plan. One of the goals is to *“Provide opportunities for examining standards, competencies and make recommendation to members that will improve end of life care.”*

Carla Braveman, past president of the Federation and Executive Director, VNA Hospice/Alliance will chair this important committee.

The Federation’s role will be to:

- review existing standards
- determine the variation among providers
- develop educational materials/training that would encourage consistency and uniformity

#### I. ACCESS to HOSPICE CARE (All responses will be confidential.)

##### Would your hospice admit a patient....

- Without a DNR
- On IV hydration
- On ventilator support
- With no primary caregiver
- Receiving anti-viral medications for AIDS

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- Receiving blood products
- Receiving enteral therapy
- Receiving palliative chemotherapy
- Receiving palliative IV therapy for symptom management
- Receiving palliative radiation
- Receiving TPN

**II. OTHER ADMITTING PRACTICES**

**Do you.....**

- Have a free care policy?
- Have a sliding scale policy?
- Allow "outlier" services for non-Medicare patients
- Have the capability for translation services?  
Which languages? \_\_\_\_\_
- Can you admit a patient seven days a week/24 hours a day?  
If no, what are your hours for admission?

**III. BEST PRACTICES**

The Committee is interested in developing best practice models for areas of interest to the members. Please check the ONE topic that would be of the most interest to your hospice.

- Bridge programs
- Criteria for general inpatient stay
- Short length of stay models
- Respiratory distress
- Intractable pain
- Anxiety and restlessness at end of life
- Terminal sedation/palliative sedation therapy
- Other:

**IV. CONTACT INFORMATION**

Name \_\_\_\_\_ Hospice \_\_\_\_\_  
Telephone \_\_\_\_\_ Email \_\_\_\_\_

- Please check if you would be interested in joining this committee

**Please FAX your completed survey to H&PCFM at 781-255-7078.**