



VERMONT
ETHICS
NETWORK

ANNUAL REPORT

PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE

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Submitted by:

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members of the Palliative Care and Pain Management Task Force

I. PURPOSE

This annual report is submitted per requirement of Act 25, Section 18 to the house committee on human services and the senate committee on health and welfare regarding recommendations, progress and activities related to the work of the Palliative Care and Pain Management Task Force.

II. RECOMMENDATIONS

From a systems standpoint, in an effort to support patient autonomy and improve seamless transitions of care between settings, as well as to increase access to palliative care and hospice services, the members of the Palliative Care and Pain Management Task Force recommend:

1. **Legislative action to proceed with standardizing the tools used for out-of-hospital Do-Not-Resuscitate (DNR) orders and DNR identification.**

Currently the advance directive statute and accompanying rules allow for the use of out-of-hospital DNR orders and a DNR identifier. Neither the statute nor the rules stipulate any specific form or identifier be used, only that whatever is used, comply with the requirements outlined in the law. The Clinician Orders for Life Sustaining Treatment (COLST) form is recommended but is not the only permissible form. This lack of standardization in the form and identifier is problematic. Different forms and identifiers being used by different facilities interferes with seamless transitions between settings. The goal is not to change practice around use of DNR, but to standardize the tools so that there is greater continuity and ability to follow patients as they transition from one setting to another. The Task Force recommends that the COLST form and one DNR identifier be mandated by the state for use by all health care providers and facilities in Vermont.

2. **Legislative action to proceed with expanding simultaneous eligibility for Choices for Care and Hospice Services.**

As discussed in the Department of Aging and Independent Living (DAIL) report to the Legislature (January 2010), the issue of simultaneous eligibility is one that has been periodically reviewed. In July of 2005, DAIL revised its policy to allow participants who are already enrolled in Choices for Care, and have a terminal diagnosis, to simultaneously enroll in hospice. However, the current policy is “one-way”. That is, people already served by Choices for Care can add hospice, but people already served on hospice cannot add Choices for Care. Hospice providers conducted a three-month survey (which concluded in September of 2010) to collect data to determine the extent of need for Choices for Care by patients already enrolled in hospice and the projected cost. That data was gathered, aggregated and given to DAIL for review. Preliminary review of the data showed that it was not likely to have a large financial impact as not that many people would be using it. However, for the patients who do need it, it would make a huge difference in the quality of their care and provide them with the necessary supports to remain at home. It is the recommendation of the Task Force that the current “one-way” policy be amended to function “two-ways”, thus ensuring that Vermonters with terminal illness can receive the care that they need while spending their final days at home, regardless of which program is accessed first.

3. Legislative support and participation in efforts to bring together private payers in Vermont to discuss an expanded hospice benefit for adults, similar to the Aetna pilot project. In 2004, Aetna implemented a specialized care management program for their Medicare Advantage and commercially insured members, and removed barriers to hospice care. Trained nurse care managers provided care management services to meet the comprehensive needs of patients with terminal illness. For entry into hospice, one group of participants adhered to the standard hospice benefit requirements (i.e. terminal illness with life expectancy of 6 months or less and cessation of all curative therapies). The second group was allowed “enhanced hospice access”. For the latter group, Aetna expanded the hospice benefit requirements (i.e. patients with terminal illness and a life expectancy of **12 months** and **continuation of curative therapy** while on hospice). Results showed:

- Hospice utilization increased in both groups with high patient and family satisfaction.
- There was a decrease in the use of acute care, intensive care, and ER services, particularly in the Medicare group.
- For those in the commercially insured group, the increase in hospice utilization and decrease in acute care represented a net cost decrease of 22%. In the Medicare Advantage group, there was a substantial reduction in utilization of acute care services, suggesting cost reductions for this group. However, an accurate impact on total cost could not be determined because CMS paid directly for the hospice services.

Based on these results, Aetna now provides terminal illness care management to all members eligible for care management services, and has expanded the hospice benefit for a large portion of commercial members. They have also proposed a demonstration pilot project to CMS to expand the hospice benefit for their Medicare Advantage members.

Given the demonstrated quality improvements and cost reductions, the Task Force strongly recommends that Vermont insurers move forward along a similar proven path to expanded access, improved quality and reduced costs.

III. PROGRESS AND CURRENT INITIATIVES

A. **Rural Palliative Care Network (RPCN):** Fletcher Allen Health Care is now providing a Rural Palliative Care Network to support the palliative care efforts of community hospitals in Vermont and upstate New York. Their program offers the following services:

- 24/7 Hotline Service
- Telemedicine Palliative Care Consult Service
- Telemedicine Case Review every Wednesday at noon (free CME credits)
- Mentorship Program Opportunities
- Discussion Group on the RPCN Website (goal to be functional by mid-February 2011)

- Site Visits

Dr. Allan Ramsay is the contact person for questions and further information.

B. Hospice Focus Groups: From May 13 to June 8, 2010 five state associations held five hospice focus group sessions. The focus groups included physicians, hospice and home care staff, nursing home and hospital representatives, and advocates. The goal was to determine what works now in hospice, to identify the concerns about current hospice services, and to develop strategies to resolve these concerns. In addition, a meeting with 11 family members of patients on hospice was held August 18, 2010. Results of these focus groups are summarized on the Vermont Assembly of Home Health Agencies website. The executive summary can be reviewed at <http://www.vnavt.com/Hospice%20focus%20Group%20Executive%20Report.htm>

C. Pediatric Palliative Care Waiver: The Department of Vermont Health Access (DVHA) submitted a report in November 2009 on the programmatic and cost implications of a Medicaid waiver amendment allowing Vermont to provide concurrent palliative and curative care to Medicaid children with life-limiting illness. The 2010 legislature included a provision in the SFY11 appropriations bill requiring AHS to submit a waiver request to the federal Centers for Medicare and Medicaid Services (CMS), either as part of the Global Commitment for Health waiver renewal or as an amendment following renewal, to allow such a program to be implemented in Vermont.

AHS has chosen to submit the request as a waiver amendment following renewal of Vermont's Global Commitment for Health waiver. In preparation for the waiver amendment request, DVHA convened an advisory group consisting of doctors, nurses, parents, ethicists, directors of other state children's programs, home health agency staff, family support organizations, and other stakeholders to present program design recommendations. This group met on September 17, 2010 to discuss the program design and offer feedback.

DVHA has not yet been able to submit the waiver amendment request to CMS due to a protracted negotiation process for the Global Commitment (GC) waiver renewal. Originally they had anticipated the GC renewal would be approved by the end of September, but it was not approved until the very end of December. DVHA will be exploring carefully whether they can operate this program under the GC waiver without an amendment, and if not, submit the amendment request as quickly as possible. DVHA expects to ask for funds to operate the program in its SFY12 budget submission.

D. Dartmouth Hitchcock Medical Center (DHMC) Palliative Care Service: Beginning in September, DHMC began its Peer Observership Program. This is a tuition free opportunity for providers to spend 1 – 2 weeks with the DMHC Palliative Care Service. It provides one-on-one mentorship for a person working in hospice or palliative care. It is geared mostly toward MD's and RN's but they are encouraging other disciplines to attend in the future. They have grant funding to make this a tuition free opportunity for the next 2 years.

- E. Community Resources:** The Madison-Deane Initiative (MDI) has developed *Vermont Palliative & End-of-Life Resource Connections*, www.vtpcrc.org, as an online resource for information related to end-of-life care services in Vermont. It is Vermont's first website specifically designed for people facing life-threatening illness. Vermont Ethics Network (VEN) has redesigned their website, www.vtethicsnetwork.org, to include expanded content related to Palliative Care and Pain Management.
- F. Partners in Palliative and Home Care:** Partners in Palliative and Home Care has been established in conjunction with Porter Medical Center in Middlebury. Their program represents an innovative, patient-centered approach that focuses on the special needs of homebound patients with serious and chronic illnesses and their families.

Program Overview:

- Focus on individuals with life-limiting illness and those who need end-of-life care
- Patients seen exclusively in their place of residence
- A deliberative and considered approach will be taken regarding treatment, testing, hospitalization, procedures, and medication
- Coverage will be provided 24 hours per day, 7 days per week to assure continuity and consistency of care
- The comfort and convenience of old fashioned house calls will be combined with up-to-date technologies including electronic medical records, laptop computers, cell phones, GPS, and clinical outcome tracking.
- Coordination with community resources such as community care homes, Helen Porter Rehab Center, Helen Porter Nursing Home, Addison County Home Health and Hospice, Hospice Volunteer Services, and the families of patients.

- G. Rutland Regional Medical Center Palliative Care (RRMC PC) Program:** The RRMC PC Program is staffed by two full-time hospice and palliative care certified (CHPN) nurses, and serves patients in all in-patient units and the emergency room.

Recently, the critical care/palliative care interface has become a focus of the RRMC Intensive Care Unit (ICU). Two new initiatives have been developed that incorporate early integration of palliative care as part of the ICU care plan. RRMC PC program is working with Vermont Program for Quality in Health Care to evaluate the impact and effectiveness of this nurse-led program model for physicians, patients and families.

The PC program has also created a team of specially trained volunteers to offer support to patients and families in the inpatient setting and they are offering opportunities to increase education and awareness of palliative care for professionals and community members.

IV. NEW PROJECTS AND ACTIVITIES FOR 2011

- A. Statewide Pain Conference:** In response to feedback from the March 2010 Statewide Summit on Palliative Care and Pain Management, Vermont Ethics Network, in partnership with the Palliative Care and Pain Management Task Force, will be hosting a statewide conference for primary care providers on *Managing the Needs of the Chronic Pain Patient*. This conference is currently in the planning phase and a date in early June is expected. The goal of this conference will be to address the complex needs and challenges of managing chronic pain patients in the primary care setting.
- B. Training Opportunity for Nursing Home and Residential Care Facilities on Advance Care Planning and Hospice Care:** As a result of the summer Hospice Focus Groups and the feedback that was collected during those sessions, providing further education and training on issues related to advance care planning, advance directives, DNR/COLST, medical decision-making and hospice care for Nursing Home and Residential Care staff would be beneficial. On January 27th, the Vermont Health Care Association is offering a half-day workshop on these topics for staff working in nursing homes, residential care and assisted living facilities.
- C. Across the Fence Community Awareness/Education Segments:** In an effort to provide information to the public on issues related to palliative and end-of-life care, we have been given the opportunity to tape three segments that will appear on Across the Fence in 2011. The topics to be covered include:
- **Palliative Care in Rural Communities**
 - **Coping with Loss (Grief and Bereavement)**
 - **Shared Decision-Making:** Airing will coincide with National Health Care Decisions Day on April 16, 2011.
- D. Addison County Pilot Project on COLST (for providers and community):** All too often we hear from providers and family members of a patient who filled out an advance directive providing information about their wishes regarding resuscitation and/or intubation. However frequently in the nursing home or at home, CPR is initiated, the patient is transported to the hospital, intubated and put on a ventilator because there is uncertainty in the moment about what to do and the proper medical orders related to resuscitation, intubation and transfer were either not filled out or not readily accessible. The result is that the family is distraught because this was not what the patient wanted and subsequently the family has to go through the painful process of withdrawing supports. This is frustrating for health care providers and often devastating for patients and families.

The Vermont Ethics Network, in cooperation with the UVM Center on Aging and the Fletcher Allen Health Care Ethics Committee is embarking on a comprehensive systems approach to education and training for providers, hospitals, nursing homes, residential care facilities, home health and hospice programs, EMS and community members on the DNR/COLST form in Addison County. The goal is improve continuity of care between settings when patients have expressed preferences related

to DNR and other life sustaining treatments. Success of this project will inform the development and implementation of similar educational programs, tailored to address the specific needs of each region, across the state.

- E. **Community and Provider Education Opportunity:** The Madison-Deane Initiative is bringing Diane E. Meier, MD, FACP to Vermont on March 28, 2011 to present: *Palliative Care: A Remedy for Unnecessary Suffering*. Dr. Meier is Director of the Center to Advance Palliative Care (CAPC), a national organization devoted to increasing the number and quality of palliative care programs in the United States. Under her leadership the number of palliative care programs in U.S. hospitals has more than doubled in the last 5 years. She is also Director of the Lilian and Benjamin Hertzberg Palliative Care Institute; Professor of Geriatrics and Internal Medicine; and Catherine Gaisman Professor of Medical Ethics at Mount Sinai School of Medicine in New York City. The community presentation will be held at the Doubletree Hotel in South Burlington on March 28th, followed by a Grand Rounds presentation at Fletcher Allen Health Care on March 29th.

This Report was prepared in consultation with:

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