



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 health committee regarding recommendations, progress and activities related to the work of the Palliative Care and Pain Management Task Force.

II. RECOMMENDATIONS

- 1. Rule-Making for DNR Identification.** Per 18 V.S.A. § 9708, uniform minimum requirements for DNR identification shall be determined by rule by the Department of Health no later than July 1, 2014. This rule has not been completed and the Task Force is recommending it be addressed as soon as possible. Presently, Vermont law requires an informed consent process for DNR which includes statutory requirements for what constitutes a valid order. An advance directive that expresses a preference to not receive CPR is not sufficient to prevent EMS from initiating CPR should it be medically indicated. Thus, patients who are certain that they would not want CPR are required to have a DNR/COLST form signed by their clinician that is readily accessible. EMS will not honor an advance directive but must see a completed DNR/COLST form, otherwise CPR, if indicated, will be attempted. A physician can also issue a DNR identification for a patient who has a COLST form and EMS will honor that in place of the paper form. However, it is necessary that a system be implemented to ensure that anyone who obtains a DNR identification has a signed DNR/COLST order on file to ensure that the statutory requirements have been met.
- 2. Surrogate Consent for DNR/COLST:** For several years, the issue of who can give consent for a DNR/COLST order has been the subject of ongoing discussion with the legislature. Per Act 127, on or before July 1, 2016 the Department of Health is required to adopt by rule, criteria for individuals who are not the patient, agent or guardian but are giving informed consent for a DNR/COLST order. In previous years access to health information and immunity for surrogates were identified as legal barriers to rulemaking for surrogate consent for DNR/COLST. These barriers still exist. Draft statutory language was initiated in 2013 to address this issue in a more comprehensive manner. It is the recommendation of the Task Force that the statutory issues surrounding surrogate consent for DNR/COLST be addressed this legislative session.

III. HIGHLIGHTS FROM 2014

On September 17, 2014 a consensus report from the Institute of Medicine (IOM), *Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-Life*, was released indicating that improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end-of-life, but may also contribute to a more sustainable care system. The IOM Report recommended:

- All insurers should cover comprehensive care for individuals with advanced serious illness who are near the end of life;

- Quality standards should be developed for clinician-patient communication and advance care planning;
- Appropriate provider training, certification and licensure should be developed to strengthen palliative care knowledge and skills of all clinicians;
- All insurers should integrate the financing of medical and social services to support quality care consistent with patients' values and preferences; and
- Fact-based public education that encourages advance care planning and shared informed medical decision-making should be provided.

Palliative care and advance care planning were repeatedly mentioned throughout the report as essential in providing high quality care for people who are nearing the end-of-life. Of particular interest and relevance to the work of the Task Force were the recommendations that:

- All people with advanced serious illness should have access to skilled palliative care or, when appropriate, hospice care in all settings where they receive care (including health care facilities, the home and the community).
- All clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management.
- All individuals, including children with the capacity to do so, have the opportunity to participate actively in their health care decision-making, and receive medical and related social services consistent with their values, goals and informed preferences.
- Clinicians initiate high-quality conversations about advance care planning and integrate the results of those conversations into the ongoing care plans of patients.
- Clinicians continue to revisit advance care planning discussions with patients because individuals' preferences and circumstances may change over time.
- Financial incentives should be provided for improved shared decision making and advance care planning that reduces the utilization of unnecessary medical services and those not consistent with a patient's goals for care.
- The required use of interoperable electronic health records that incorporate advance care planning to improve communication of individuals' wishes across time, settings, and providers, documenting (1) the designation of a surrogate/decision maker, (2) patient values and beliefs and goals for care, (3) the presence of an advance directive, and (4) the presence of clinician orders for life-sustaining treatment (COLST) for appropriate population of unnecessary medical services and those not consistent with a patient's goals for care.

System improvements designed at integrating palliative care and advance care planning practices into health care delivery in Vermont is both necessary and overdue. Additional education and resources on advance care planning will be essential in improving the quality of care for Vermonters living with advance serious illness and those who are approaching the end-of-life.

To read the IOM Report:

<http://www.iom.edu/~media/Files/Report%20Files/2014/EOL/Key%20Findings%20and%20Recommendations.pdf>

LOCAL INITIATIVES FURTHERING THIS WORK

- A. Spring 2014 Palliative Care Conference:** On April 9, 2014 the Vermont Ethics Network, in partnership with the Palliative Care and Pain Management Task Force, hosted its fifth statewide palliative care and pain management conference, *When Cure is No Longer Possible: Prognosis, Hope and Professional Responsibility*, at the Hilton Hotel and Conference Center in Burlington.

Interest among health care professionals related to having difficult conversations and improving communication about end-of-life continues to grow. The spring conference was our largest event to date with over 200 health care professionals from a range of disciplines and health settings in attendance. Keynote presentations were provided by national speakers David Weissman, MD, founder of the Medical College of Wisconsin Palliative Care Center, and Chris Feudtner, MD, Director of Medical Ethics and the Pediatric Advanced Care Team at Children's Hospital of Philadelphia. In addition, presentations from local experts included topics on prognostic awareness, how to stop failing therapies and advanced communication skills in conflict management.

- B. Vermont Ethics Network (VEN) Initiatives:**

Medical Decision-Making Outreach - In addition to VEN's work with the Palliative Care and Pain Management Task Force, VEN conducted numerous workshops and trainings for both professionals and the community on advance care planning, advance directives and DNR/COLST orders.

Act 39: Patient Choice and Control at the End-of-Life - With the passage of Act 39 and absent an implementation organization at the time that could respond to questions and provide education and training, VEN took on the responsibility initially for this education. In 2014 and ongoing, VEN continues to respond to requests for training and information for health care providers, facilities and the general public on this topic. Per our last inquiry with the Department of Health, five (5) sets of paperwork have been completed and submitted indicating the intent to prescribe a lethal dose of medication.

Ethics Committees & Ethics Education - The role of ethics committees and expanding access to ethics expertise and resources has been a focus of VEN's work for the past several years. Despite a long-standing recognition of the importance and benefit of ethics committees, and the requirement by the Joint Commission for health care facilities to have a mechanism to address ethics conflicts, ethics committees are still primarily found in larger urban hospitals. Further, many Vermont health care facilities possess limited formal resources, training and/or processes to address ethical issues that may arise in care delivery. A number of multi-facility ethics committee trainings were conducted in 2014 with credentialed faculty from Vermont Ethics Network, University of Vermont Medical Center and the Dartmouth Policy Institute. Participants at these trainings received an individualized ethics curriculum to address site specific needs and concerns.

C. Supportive Care Benefit Program and UVM Medical Center: In 2014, VNAs of Vermont, BCBS of Vermont, and University of Vermont Medical Center (UVMCC) piloted a Supportive Care Program for persons who have been diagnosed with a serious, chronic or life-limiting illness. The program provides comprehensive palliative care in the home setting to manage pain and symptoms, reduce burden to family caregivers, and support coordination of care and care options consistent with the patient’s goals. The population for this pilot included active, enrolled members in the UVMCC medical plan/benefit (representing approximately 11,000 employees and their family members).

During this initial plan year, only 4 patients were admitted to the program. The low use was primarily attributed to lack of awareness of the program and its benefits. The demographics of the plan members who were eligible for this program may have also played a factor. Members are young, actively working individuals employed by a major health care organization.

Due to this low utilization, the program partners agreed to continue the program another year with an added focus of expanding awareness to eligible participants and health care providers. BCBS of Vermont is also exploring the option of expanding the program to other plans they manage.

D. Supportive Care Program and Rutland Regional Medical Center: See Attachment A.

E. Bayada Palliative Care Update: BAYADA has applied and is awaiting response from CMS regarding the concurrent care demonstration project. Regardless of the decision, Bayada plans to broaden their community based palliative care program providing physician and advanced practice nursing visits at home. Many of Bayada’s home health social workers have received training on goals of care discussions and advanced care planning to better support transitions to hospice care when appropriate.

F. Pediatric Palliative Care Program (PPCP): Launched September 2012 in Chittenden County, the Pediatric Palliative Care Program (PPCP) has been available statewide to eligible children and families since January 2014. As of December 2014, the program had received over 60 referrals and provided services to over 45 children and families ranging from birth to 20 years old with a variety of diagnoses such as neuromuscular disorders, congenital anomalies, cancer, and brain injury. In September 2014, the PPCP, which had previously resided under Department of Vermont Health Access, moved to Children with Special Health Needs (CSHN), part of the Maternal Child Health Division at Vermont Department of Health, in an effort to improve continuity of care and collaboration for Vermont children with complex medical needs.

“Pediatric Palliative Care 2.0: Improving Care and Advancing Delivery” was held in Montpelier on September 16, 2014 and attended by over 50 providers from throughout Vermont. The curriculum was based on PPCP provider surveys, and

catered specifically to meet their educational needs and goals. Taught by both national and local experts and including innovative teaching techniques such as simulation and role play, the evaluation and feedback was exceedingly positive. In collaboration with UVM Medical Center's Vermont Children's Hospital, ongoing data is being collected to assess the conference's impact on change in practice over time. Preliminary data should be available as early as spring 2015.

Provider education and capacity building continue to be the priorities in terms of program improvement and evolution. Family satisfaction surveys were implemented in February 2014 to ensure the needs of children and families are always our driving force. Preliminary results are very positive, with constructive and helpful feedback to guide our focus moving forward. Goals in 2015 will center around assessment of service delivery, data collection and gaps in care specific to the program, which may lead to recommended changes in program structure to improve delivery of care.

G. Hospice and Palliative Care Council of Vermont: In 2013 Vermont Hospices cared for more than 2345 hospice patients and their families—an increase of about 5% over the previous year, and there have been similar increases for the past 3 years. Most of our hospice programs are part of the local not-for-profit home health or Visiting Nurse Associations, two volunteer hospices work closely with their local agencies, and a privately owned hospice provides services in many areas of Vermont. This is a unique collaboration and safety net for the critically ill, the dying and their families in our state. New restrictions this year by Medicare in defining what is a terminal diagnosis have again led to fewer patients receiving Hospice Care in recent months in Vermont. Deaths in hospitals have spiked recently, and many nursing home residents and their families do not know they can access hospice care wherever they reside. Recent articles and research efforts are being used to address the gaps.

Several times a year members of the Hospice & Palliative Care Council of Vermont (which includes all but one hospice organization) gather from all corners of the state to exchange ideas, brainstorm problems and share up-to-the-minute insights into patient care, family support, government and insurance issues that impact care. Specialty sub-groups—clinicians, volunteer coordinators, and bereavement coordinators meet to offer peer support, problem-solve difficult issues, share best practices, mentor new staff, and expand expertise. In June of 2014, two hundred people gathered at Lake Morey for the HPCCV Annual Conference, which explored ethics, Act 39, pediatric palliative care, veterans' issues, dementia, spiritual care and grief support for families and hospice workers.

IV. ACTIVITIES PLANNED FOR 2015

A. Spring Palliative Care and Pain Management Conference: The Palliative Care and Pain Management Task Force has scheduled the spring conference, *One Size Does Not Fit All: Treatment Decisions for Advanced Serious Illness*, on May 4, 2015 at the Hilton Hotel and Conference Center in Burlington. The goal of this conference is to focus on interventions for different disease conditions and how to recognize when a treatment is life sustaining vs. death prolonging—what are the clinical

landmarks along the disease trajectory, advance care planning considerations, patient value issues, how to have the conversation, etc. A primary goal is to attract practitioners from a wide range of specialties, including those who typically might not attend a palliative care/ethics conference, but who could benefit from hearing about the application of palliative care and proactive disease specific advance care planning for their patient population.

The event will feature national experts:

- **Douglas White, MD, MAS:** Dr. White directs the University of Pittsburgh Program on Ethics and Decision Making in Critical Illness. His first talk will be on a topic related to critical care and responding to requests for potentially inappropriate treatment. His second talk will focus on surrogate decision-making for critically ill patients
- **Muriel Gillick, MD:** Dr. Gillick is a staff physician at Harvard Vanguard Medical Associates and a Professor of Population Medicine at Harvard Medical School/Harvard Pilgrim Health Care Institute. She also provides consultation to patients at the Brigham and Women Hospital, a major Harvard teaching hospital. The major focus of Dr. Gillick's work is caring for patients near the end of their lives. She is particularly interested in helping patients and their families figure out what approach to medical care makes the most sense for them, given their underlying health status, their values, and their goals. Her presentations will focus on frailty and dementia.
- **Michael Germain, MD:** Dr. Germain, is Professor of Medicine at Tufts University in Boston, an Attending Physician at Baystate Medical Center, a nephrologist with Western New England Renal & Transplant Associates, and physician affiliated with Holyoke Medical Center. His presentations will focus renal palliative care and the elderly frail chronic kidney disease patient.

B. Madison-Deane Initiative Hospice Study: The VNA of Chittenden and Grand Isle Counties is preparing to design and conduct a study that will hopefully reveal the reasons behind Vermont's low hospice utilization and provide the basis for developing approaches to address this issue. The study has been commissioned by the Madison-Deane Initiative, the educational arm of the VNA's end-of-life care services, with support from VNAs of Vermont. The goal is to better understand why hospice use in Vermont is among the lowest in the nation, how and where Vermonters are dying if not in hospice, and what barriers are keeping Vermonters from utilizing the hospice services available throughout the state.

The intent is to inform strategies for increasing hospice utilization and quality of care at the end of life for Vermonters. The knowledge gained will also help Vermont's hospice providers to project future demand for hospice care and plan accordingly. It is anticipated that the study will be conducted in spring and findings released in late summer/early fall of 2015.

- C. Ongoing Medical-Decision Making, Ethics and End-of-Life Education:** The need for ongoing training about medical decision-making, health care ethics and end-of-life options are critical as our population ages and as our health care resources become more constrained.

In the fall of 2014 Dartmouth Hitchcock Medical Center initiated their *Honoring Care Decisions Program*. This is a new program with the goals of improving and supporting advance care planning at Dartmouth-Hitchcock and in their communities. Dartmouth-Hitchcock has already established a reputation for promoting shared decision-making, helping patients make decisions based on medical evidence in the context of their goals and values. *Honoring Care Decisions* brings this to the next level for patients to plan ahead for possible and probable scenarios for a time when they cannot speak for themselves. This new program will develop and continuously improve a system of care that supports good decision-making and that honors those decisions during serious illness and at the end of life.

Continued efforts to support shared decision-making through proactive advance care planning, completion of advance directives, appropriate utilization of DNR/COLST orders and understanding of options available at the end-of-life must be prioritized throughout Vermont's health care system as well. VEN and the University of Vermont Medical Center will be embarking on a pilot program to address advance care planning systems issues both at the inpatient and outpatient levels. More active participation and commitment from state agencies directed at furthering this work is both desired and necessary.



This report was prepared in consultation with members of the Task Force:

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Diana Barnard, Fletcher Allen Health Care - Palliative Care Service
Kristin Barnum, Bayada Hospice
Monica Ogelby, Pediatric Palliative Care Program -VT Chronic Care Initiative

Attachment A

Supportive Care Program

A Joint Collaboration between Rutland Area Visiting Nurse Association & Hospice (RAVNAH) and Rutland Regional Medical Center (RRMC)

Goals of the Program

- Integrate supportive care and end-of-life decision making **earlier in the disease process**
- Expand upon collaborative approaches with primary care, RRMC and the Rutland Community Health Team to facilitate patient care **decisions based upon patients' own values**
- **Avoid unnecessary hospitalization** and/or re-hospitalization for patients with complex conditions and needs
- Improve symptom management and **quality of life for the patient and caregivers**
- Promote **earlier referrals** to hospice *
- Support the **Blueprint for Health goals** for improving care for patients with chronic illness *

Patient Population

All Payer Sources, Non-Homebound Patients, No Home Care Services with:

- Heart Failure
- Chronic Lung Disease

Who Have Had:

- More than 2 hospitalizations/ED visits in the past 6 months
- ICU admissions unrelated to surgical or interventional procedures in the past 6 months

Or Experience

- Impaired or declining in function for the prior 6 months
- Dyspnea (or more than 2 other symptoms rated moderate/severe)
- Cognitive impairment
- Caregiver stress (or lack of availability)

Services

- Comprehensive **assessment** in the home **of palliative care needs** for the patient and caregiver(s) related to physical, social, emotional, spiritual elements;
- **Identify** patient/caregiver goals and **formulate** a care plan to address the patients' needs with the patient and caregiver(s);
- **Facilitate patient decision making** around advance care planning, establishing patient and family/caregiver goals through the use of proven tools (Start the Conversation, Speak Sooner);
- **Collaborate and coordinate** with other community medical, social and volunteer resources as needed, especially to **assist and support transitions of care** or referrals for services;
- **Make a recommendation** to the primary care provider when the patient is appropriate for hospice.

Consult

The first home visit with the nurse and social worker is scheduled based on patient urgency anywhere from 1 day to 4 weeks (on average 2 weeks).

- Includes a comprehensive supportive care assessment and introduction of planning tools, namely Start the Conversation and Speak Sooner.

Discussion will center on patient and family understanding of:

- Their condition
- Expectations and goals for care
- Symptoms
- Nutritional, functional, and cognitive status
- Fall risk
- Psychological distress
- Practical needs (home environment and safety, neighborhood safety, access to transportation)
- Caregiver availability, confidence, and the burden
- Ability to afford medications, equipment or other medical care
- Medication management.

Ongoing team-based consultations are available

- Consultations range from one to twelve visits weekly, bi-weekly, monthly or a combination thereof to suit the patient and caregiver(s).

The RN will be responsible for:

- Changes in disease status, symptoms, medication adherence, and communication with the primary MD.

- The SW will be responsible for:

- Psychological distress (depression screenings), and linking the patient with appropriate community-based services - transportation, medication/equipment pick-up, medication education, etc.

- A care plan is **developed with the patient and family/caregiver based upon individual needs and values, in conjunction with the primary care provider.** Patient and family review of, and agreement with, the care plan culminate the provision of services.
- Program access 24/7 will be available by telephone for off-hours crises, in keeping with the mission to prevent 911 calls and unnecessary ED visits. Staff will be available Monday through Friday 8 am-4 pm for home visits and telephone calls.

Standard Ravnah referral Process- May use Palliative Care Referral tool and fax to Ravnah at 747-0021.