



## **ANNUAL REPORT**

### **PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE**

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*Submitted by:*

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## 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. RECOMMENDATION

**Surrogate Consent for DNR/COLST:** For several years, the issue of who can give consent for DNR/COLST orders has been the subject of ongoing discussion with the Vermont 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. In 2015, draft statutory language was proposed and passed by the Senate (S.62) to address these barriers as well as to outline a process for surrogate consent for DNR/COLST orders in a comprehensive manner. It is the recommendation of the Task Force that the House Human Services Committee continues the work that was started in the Senate and move forward with passage of S.62.

## III. HIGHLIGHTS FROM 2015

**Good News for Advance Care Planning:** In October of 2015, Centers for Medicare and Medicaid Services (CMS) approved payment for voluntary end-of-life counseling as part of its 2016 Medicare physician fee schedule. According to CMS, the new policy will help seniors "make important decisions that give them control over the type of care they receive and when they receive it".

There are two current procedural terminology (CPT) billing codes for advance care planning (ACP). CPT code 99497 covers a discussion of advance directives with the patient, a family member, or surrogate for up to 30 minutes. An additional 30 minutes of discussion takes the add-on code of 99498. Medicare will pay roughly \$86 for 99497 and \$75 for 99498 when the counseling occurs in a physician's office.

Under next year's fee schedule, ACP also can be an optional — and reimbursable — element of Medicare's annual wellness visit.

For more information about the 2016 CMS physician fee schedule go to:  
<https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2015-Press-releases-items/2015-10-30.html>

## IV. LOCAL INITIATIVES

- A. Spring 2015 Palliative Care Conference:** On April 29, 2015 the Vermont Ethics Network, in partnership with the Palliative Care and Pain Management Task Force, hosted the 6<sup>th</sup> annual Palliative Care and Pain Management Conference at the Hilton Hotel and Conference Center in Burlington, VT.

The theme for the event was treatment decisions for serious or advanced illness. The goal was to focus on treatments/interventions for different types of diseases/conditions. Specifically, how to recognize when a treatment is life sustaining vs. death prolonging—what are the clinical landmarks along the disease trajectory, patient value issues, how to have conversations about prognosis, decision-making issues, etc. A primary goal was to attract practitioners from a wide range of specialties—those who typically might not attend a palliative care conference—but who could benefit from hearing about the application of palliative care for their patient population. By all accounts we achieved this goal with many new and unfamiliar faces in the audience.

Registrations came in at 193 professionals with representation from 5 of the 8 Vermont critical access hospitals. Additionally providers from facilities in New York and New Hampshire were present. Overall, this was a well-attended event. It has become a conference that health care providers of a wide range of disciplines look forward to each year. We have been fortunate to get exceptionally talented national and local presenters which have elevated the content of our programs. Our challenge each year is how to surpass what we did the previous year.

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

**Medical Decision-Making Education** – A primary focus for VEN has long been to improve understanding of best practices in medical decision-making and appropriate use of available decision-making tools. Since the 2014 IOM Report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, advance care planning has been highlighted as a national priority for quality patient-centered care. This report emphasized the need for advance care planning, for improved conversations between patients and health care providers, for improved systems for documenting wishes for end-of-life care, for more education for health care professionals and patients, and for greater accessibility to advance care planning opportunities. In addition to the IOM recommendations, the Institute for Health Improvement and The Joint Commission have identified advance care planning as both a quality care issue and a patient safety issue. VEN has responded to these recommendations by increasing our educational efforts surrounding advance care planning, advance directives and DNR/COLST orders for community members and providers alike. Our goal is to see greater integration of advance care planning practices into the system of care delivery throughout Vermont.

**Act 39: Patient Choice and Control at the End-of-Life** - VEN continues to respond to requests for training and information for health care providers, facilities and the general public on the topic of physician assisted death.

**Vermont Advance Directive Registry (VADR):** Starting in November of 2015, VEN assumed responsibility from the Vermont Department of Health for all inquiries related to the VADR. The goal of this shift is to create a more centralized and seamless mechanism for responding to the advance care planning needs of Vermonters and Vermont health care facilities.

### **C. VNA's of Vermont:**

**Palliative Care Demonstration:** All ten hospice organizations in Vermont were selected as pilot agencies for the Medicare Care Choices Model (MCCM) demonstration grant which will allow the agencies to provide extensive palliative care and care management services to patients who qualify for hospice care but chose not to enroll in the hospice program. The model provides Medicare beneficiaries who qualify for coverage under the Medicare Hospice Benefit and dually eligible beneficiaries who qualify for the Medicaid Hospice Benefit the option to elect to receive supportive care services typically provided by hospice and continue to receive curative services at the same time.

The program will provide home-based care management, care coordination, and palliative care services to eligible beneficiaries with emphasis on patients with Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD) and diabetes.

The Center for Medicare and Medicaid Innovations plans to phase in the program starting this January. The second phase will start January 1, 2018. Hospices were randomly assigned to phase 1 or phase 2. Eight of the 10 Vermont hospices were selected for phase 1.

The patients who will be served in this program are at highest risk of repeated medical crises, hospitalization, symptom distress, family caregiver stress, and unnecessary medical expenditures.

Participating hospices will provide services under the model that are currently available under the Medicare hospice benefit for routine home care and respite levels of care, but cannot be separately billed under Medicare Parts A, B, and D. Services will be available around the clock, 365 calendar days per year and CMS will pay a per beneficiary per month fee ranging from \$200 to \$400 to participating hospices when delivering these services under the model. Services will begin starting January 1, 2016 for the first phase of participating hospices and in January 2018 for the remaining participating hospices.

Individuals who wish to receive services under the model must fall into certain categories:

- Must be diagnosed with certain terminal illnesses (e.g., advanced cancers, chronic obstructive pulmonary disease, congestive heart failure and human immunodeficiency virus/acquired immune deficiency syndrome);
- Must meet hospice eligibility requirements under the Medicare or Medicaid Hospice Benefit;
- Must not have elected the Medicare or Medicaid Hospice Benefit within the last 30 days prior to their participation in the Medicare Care Choices Model;
- Must receive services from a hospice that is participating in the model; and
- Must have satisfied model's other eligibility criteria.

**Vermont Hospice Study:** To explore more deeply why the hospice utilization in Vermont is among the lowest in the nation, the Visiting Nurse Association (VNA) of Chittenden and Grand Isle Counties' Madison-Deane Initiative commissioned the Vermont Hospice Study, with support from the VNAs of Vermont and Coverys Community Healthcare Foundation.

This study was guided and overseen by a Study Advisory Committee that included physicians, hospice agency staff, policy makers, consumers, and faith communities. Committee members from diverse backgrounds and regions of Vermont were recruited to include perspectives on local cultural norms and healthcare.

A brief report highlighting the findings from the six-month Vermont Hospice Study conducted between April 1 and September 30, 2015 can be accessed at: <https://www.vncares.org/wp-content/uploads/2015/10/VHS-Brief-Report-10.20.15-.pdf>

- D. BAYADA:** BAYADA Hospice is caring for 150 patients across the state and has over 500 families and loved ones receiving bereavement support.
- From January 1<sup>st</sup> 2015 through September 31<sup>st</sup> they provided 37,546.68 hours of hospice care-plus 1,698 volunteer hours.
  - BAYADA is participating in a 5 year CMS demonstration project beginning January 1 2016. Medicare Care Choices Model (MCCM) is an initiative developed by the Centers for Medicare & Medicaid Services to explore ways to improve care options for beneficiaries by allowing greater flexibility and choice “in deciding between hospice care and curative treatment, when faced with life-limiting illness.”
  - BAYADA continues to work with all health service area (HSA) groups on increasing access to hospice care.
- E. University of Vermont (UVM) Palliative Care Service:** UVM's program is expanding. A new Division Chief, Dr. Robert Gramling was hired and will start in May 2016. He will work to expand UVM's services—particularly in the areas of research and clinical education.

**F. Rutland Regional Medical Center (RRMC) Palliative Care Program:** 2015 was a year of steady growth for RRMC's Palliative Care Program. With 780 patient referrals, there was sufficient evidence to allow for an increase in staffing from 2.5 to 3.0 FTEs. In collaboration with the ICU physician team, a new protocol was developed and is now in trial which allows the Palliative Care Team to screen all ICU level patients for possible referral. There has also been an increasing inclusion of palliative care in the Emergency Department. RRMC has been chosen as a pilot site for a Joint Commission testing of the Certification Program for Palliative Care (PAL) quality measures. This pilot will continue through the end of January 2016.

RRMC is a member of the Center for the Advancement of Palliative Care (CAPC) and continues to submit data to the National Registry. According to the most recent report generated from the Registry from 2014, RRMC ranks in the top of the 4<sup>th</sup> Quartile for palliative care penetration rate of 12.5% of hospital admissions as compared to the mean 4<sup>th</sup> Quartile rate of 8.5% and a national mean of 4.4%.

**G. 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 2015, the program had received over 80 referrals and provided services to over 50 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. To date, there are 38 children currently enrolled.

Highlights this past year include analytics of learner surveys after attending "Pediatric Palliative Care 2.0: Improving Care and Advancing Delivery" on September 16, 2014; a collaboration between Vermont Department of Health, Vermont Children's Hospital, and VNA's of Vermont. The curriculum included an innovative approach to learning, utilizing simulation and role play during which learners practiced palliative care interview skills in a safe and facilitated environment. Surveys showed remarkable improvement both in skills and comfort conducting such interviews 6 weeks after the session compared to before. Responses to the learning day were overwhelmingly positive, and plans to organize another conference in 2016 are under way.

The program's move from Vermont Health Access to Children with Special Health Needs (CSHN), part of the Maternal Child Health Division at Vermont Department of Health in September 2014, has allowed for improved continuity of care and collaboration for Vermont children with complex medical needs. Specifically, the current state of nursing capacity and retention at the community level continues to be one of our greatest challenges, which impacts not only the PPCP, but many most home-based services. Having all programs for CSHN unified, provides opportunity to approach this challenge from a more global purview, but also prioritize resources and support families who have limited access in certain regions.

The advisory committee reconvened in November 2015 and collectively identified both strengths and challenges of the program and identified goals moving forward. Goals for this coming year include strengthening relationships with pediatric

palliative care teams at both UVMMC and DHMC support the community level interdisciplinary teams and families enrolled. As always, the needs of children and families are the driving force of this work, so in addition to annual family satisfaction surveys, referring provider surveys will begin this year. Program operations improvements revolve around enhanced assessment of service delivery and ongoing collection of data, which will inform some recommended changes in program structure to increase effectiveness. Lastly, VDH/MCH is supporting the education of the first trained Pediatric ELNEC (End-of-Life Nursing Education Curriculum) nurse in the state to build our local expertise.

**H. Vermont Medical Society (VMS):** VMS shined a spotlight on hospice this year with three articles in their August/September 2015 Newsletter, *The Green Mountain Physician*. (<http://www.vtmd.org/sites/default/files/files/AugSept2015.pdf>)

In addition, they hosted a panel discussion with Dr. Zail Berry, Dr. Robert Macauley, and Helen Riess (Director, Empathy & Relational Science at Massachusetts General Hospital) at their Collaborative Multi-Specialty Annual Meeting. The topic of the program was *Supporting our Patients in Aging*. Helen Riess provided the keynote address at VMS's annual meeting emphasizing the importance of empathy. Finally a panel presentation on *Opioids in Chronic Pain Management – a Best Practice Approach* with Dr. Carlos Pino was also offered.

## V. ACTIVITIES PLANNED FOR 2016

- A. Annual Spring Palliative Care/Pain Professional Conference:** Planning for the spring conference is underway. The broad theme for this event is, “Challenges in Palliative and End-of-Life Care”. The Task Force invited Dr. Atul Gawande to provide the keynote address. Regrettably he was not able to accept our invitation and we are in the process of inviting other potential speakers of similar caliber. Following a broad keynote address, additional topics to be covered at the conference include: challenges associated with palliative care and end-of-life when there is underlying psychiatric/mental illness; issues of substance abuse, palliative care and pain management; overcoming barriers in accessing palliative and end-of-life care in rural settings; how to have meaningful conversations about code status; hospice referrals and prognostication—when is it too early; and a topic from a pharmacist on the rational use of expensive medication for hospice patients and issues of polypharmacy.
- B. Community Education:** Increasingly it appears that the general public has a limited understanding of common end-of-life interventions (i.e. CPR, ventilation, feeding tubes, dialysis, etc.) yet routinely they are asked to make decisions about these treatments. There is a desire to create educational brochures on these topics and then to work with Channel 3 and the *Across the Fence* program to feature 15-minute TV segments to further disseminate accurate information about frequently deployed life-sustaining technologies.
- C. Additional Initiatives:** A subset of the Task Force is working to develop a survey to determine who is providing palliative care services across the state, and then to

develop a repository of this information by county so that we have a better sense of who is doing what, where. This work is in the beginning stages.

**D. Ongoing Medical-Decision Making, Ethics and End-of-Life Education:**

Requests for training on medical decision-making, end-of-life options and resolving ethical challenges are on the rise 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*. 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 also be prioritized throughout Vermont's health care system. VEN and a large group of stakeholders are embarking on an initiative similar to DHMC to address advance care planning needs at the community, inpatient and outpatient levels. Greater commitment from state agencies directed at furthering this work is necessary.



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

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