



ANNUAL REPORT

PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE

JANUARY 2017

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. RECOMMENDATION

The Task Force has no specific policy recommendations at this time. We do wish to highlight two important areas for consideration and inclusion in any future proposed healthcare policy.

Advance Care Planning and Serious Illness Conversations: The Institute of Medicine has called for systemic improvements in advance care planning and clinician-led conversations about goals, values and care preferences for patients with serious and life-threatening illness. Studies suggest that appropriately timed advance care planning conversations are associated with improved quality outcomes for patients and their families, including: better quality of life, reduced use of non-beneficial medical care near death, enhanced goal-consistent care, and reduced costs. As the state continues to work toward improved access and quality health care for all Vermonters, best practice in medical decision-making must be embedded into the system of care delivery at all levels. Policy initiatives to ensure that conversations occur and preferences of patients are known and carried out throughout disease progression are both encouraged and necessary.

Access to Opioids for Patients at End-of-Life: The use of opioids remains a necessary and important tool in the management of some symptoms at end-of-life. As Vermont works to address the complex issues surrounding opiate use and abuse, it remains of critical importance that any proposed policies continue to protect access to appropriate pain medications for patients with serious and advanced illness and/or those at end-of-life.

III. LOCAL INITIATIVES

Spring 2016 Palliative Care Conference: the Vermont Ethics Network in partnership with the Palliative Care and Pain Management Task Force hosted the 7th annual Palliative Care and Pain Management Conference, *Practical Solutions: Addressing the palliative, pain management and end-of-life care needs of seriously ill patients*, on May 6, 2016 at the Sheraton Hotel and Conference Center in Burlington. Approximately 150 interdisciplinary health care professionals attended this event.

We were fortunate to have two national presenters: Dr. Thomas Strouse, Medical Director of the Resnick Neuropsychiatric Hospital at UCLA, who presented on decision-making capacity and clinical management strategies in palliative care patients with co-occurring psychiatric illness; and Mary Lynn McPherson, PharmD, who teaches extensively in the Doctor of Pharmacy program at the Maryland School of Pharmacy and presented on medically futile and irrational medication regimes at end-of-life, as well

as on pain management in the setting of addition and serious life-limiting illness. Local experts were also featured and presented on topics ranging from code status discussions and do-not-resuscitate orders, to care transitions and hospice lengths of stay.

A. Vermont Ethics Network (VEN) Initiatives:

Best Practice in Medical Decision-Making: A primary focus for VEN has long been to improve understanding of best practices in medical decision-making and appropriate use of advance care planning tools. Obligations to provide high quality patient-centered care necessitate shared decision-making and conversations about individual goals and values in the context of personal health. Studies continue to show that advance care planning is a preventive ethics tool best implemented in stages, where discussions are appropriately aligned with patient needs and readiness. To encourage best practice efforts, VEN has launched the *Taking Steps* Vermont initiative with accompanying educational materials that outline a step-wise approach to advance care planning. This initiative is being piloted in Chittenden and Grand Isle as part of a collective impact project entitled “Who’s Your Person...What’s Your Plan”. Since illness and injury can happen at any time, regardless of age or health status, our goal is to engage the community at large and normalize advance care planning conversations as an essential component of patient-centered, high quality health care.

Vermont Advance Directive Registry (VADR): Starting in November of 2015, VEN assumed responsibility from the Vermont Department of Health for all consumer and provider inquiries related to the VADR. In July of 2016, VEN assumed responsibility for the management of the contract with US Living Will Registry, the vendor for the VADR. The goal is to streamline efforts and create a centralized and seamless mechanism for responding to the advance directive and advance care planning needs of Vermonters and Vermont health care facilities.

Surrogate Consent of DNR/COLST: Efforts to educate health care providers and facilities about Vermont’s law on surrogate consent for DNR/COLST orders, which goes into effect in January of 2018, are underway.

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.

B. American Cancer Society: The American Cancer Society collaborates with national and state partners to promote palliative care as part of cancer treatment for patients and their families at any age and any stage. Through its partnership with the National Palliative Care Research Center (www.npcrc.org), initiated in 2007, the Society invests millions of dollars in palliative care and symptom management research grants designed to help improve the quality of life and quality of cancer care for patients, survivors, and their families. This partnership is also building up and supporting the community of palliative care researchers and opportunities for collaborative research projects among them. At the same time, American Cancer Society staff in Vermont work with area hospitals, cancer centers, and other health

systems to expand the reach of palliative care services. We also provide cancer patient supportive services that focus on relieving suffering and improving quality of life for patients and their families, including:

- **The Hope Lodge in Burlington:** Cancer patients getting treatment at the UVM Medical Center, who live more than 40 miles from Burlington, can stay at the Hope Lodge for free. This eliminates some of the physical, emotional and financial burdens of traveling long distances to receive treatment. One caregiver can stay with the patient as well. Many community volunteers donate home-cooked meals which are shared family style, which provides a community of support for these patients.
- **The National Cancer Information Center:** The NCIC provides information and support 24 hours a day, 365 days a year to those facing cancer. Trained cancer information specialists are available via phone, or live chat, providing accurate, up to date cancer information to patients, family members, and caregivers and connecting them with valuable services and resources in their communities.
- **Patient Navigators:** Often cancer patients struggle with the financial and emotional realities of their diagnosis by themselves. Our patient navigator at UVM Cancer Center can help direct them to social workers and counselors and help them find a way to pay for their treatment and prescriptions, as well as other services.
- **Road to Recovery:** Our volunteers provide free transportation to cancer treatment.
- **Look Good Feel Better:** This program helps with appearance-related side effects of cancer treatment. Trained volunteer cosmetologists teach women how to cope with skin changes and hair loss using cosmetics and skin care products donated by the cosmetic industry.
- **American Cancer Society Cancer Action Network** (the Advocacy Affiliate of ACS) ACS CAN advocates for policies that improve the lives of cancer patients by making treatment of pain and other symptoms as well as coordination of their care standard protocol throughout their treatment for cancer, starting at the point of diagnosis. Specifically, in 2016, ACS CAN in Vermont took an active role in providing comments on the Opioid and Vermont Prescription Monitoring System (VPMS) legislation and ensuing regulations. We urged the legislature and the Vermont Department of Health to exempt chronic pain associated with cancer or cancer treatment; palliative care; end of life or hospice care from prescribing limits and VPMS query requirements.

C. BAYADA: BAYADA continues to provide high quality hospice care statewide across Vermont. In addition to traditional hospice care, in 2016 BAYADA began participating in the Medicare Care Choices Model (MCCM) which provides hospice-like services to those still seeking curative care. The program, BAYADA Support is led by Toni Apgar, RN. BAYADA Support received 53 referrals of which 25 were admitted to the program. The 33 not taken under this new care model did not meet the strict MCCM criteria. 15 of the MCCM admissions have since been transferred to the traditional Medicare Hospice Benefit. Also in 2016 BAYADA launched a

specialized palliative care program for end-stage heart disease in the Brattleboro area. BAYADA clinicians received advanced training and certification in how to manage end-stage heart disease in the home. The goal in 2017 is to spread this program to other areas of the state. Finally, in 2017 BAYADA will launch a provider led community based palliative care program. Our community based palliative care will offer MD, NP and licensed social work services in traditional homes and assisted living facilities.

- D. Chittenden County Regional Clinical Performance Committee (RCPC):** End-of-life improvement efforts by the Chittenden County RCPC included:
- a. Educational sessions on hospice at 5 primary care sites jointly led by representatives from both VNA and BAYADA
 - b. Development of a pocket card and poster for providers on when to consider a hospice consultation.
 - c. Systems improvements which include the addition of palliative care consult order to the inpatient admission order set for congestive heart failure admissions. Also provided is a hyperlink to information on when to consider a palliative care consult in congestive heart failure.
- E. VNA & Hospice of the Southwest Region:** In 2016, VNA & Hospice of the Southwest Region, prioritized focused education and training on palliation and end of life care. Out of five eligible Hospice & Palliative care nurses, four successfully achieved their Certification in Hospice and Palliative care. This emphasis will continue into 2017 as more staff become eligible to sit for the exam.

Rutland Area VNA and Hospice continued their Vermont Health Care Innovation Project which began in 2015. This Supportive Care Grant Program provides supportive services to patients in Rutland County with a diagnosis of CHF or COPD who were not eligible for home care based on skill requirements or homebound status. The goals of the program are to promote earlier referrals to hospice, avoid unnecessary hospitalizations and integrate end-of-life decision making earlier in the disease process. Over the course of the program, sixty-three patients have been referred and forty-nine enrolled in the program. These patients receive assistance with symptom management, social and financial assistance, short and long-term care planning as well as assistance with advanced directives. Forty-five percent of the patients enrolled in the program completed their advanced directive and twenty-nine percent transitioned into either a palliative or hospice program. With consideration of the success of the program, as well as ongoing health care changes in Vermont, expansion of the program in the future remains a possibility.

Also in 2016, internal collaboration between homecare and hospice departments was and continues to be a priority. The focus is to identify patients in homecare that may be more appropriate for palliative care or hospice and begin conversations with those patients and families sooner in their disease process. Several tools and techniques are being implemented internally to assist with this effort.

Lastly, in Rutland County in 2016, RAVNAH and BAYADA joined together to provide provider education and community outreach about the hospice benefit. The

goal of these sessions was to provide education, dispel any myths or misconceptions and improve relationships in the community. While there is no official data to date, both organizations report positive outcomes from this effort. Going forward into 2017, the collaborative is going to be reaching out to more provider offices in Rutland County and also plans to extend into Bennington County.

F. Vermonters Taking Action Against Cancer (VTAAC): In March of 2016, VTAAC hosted its 10th Annual Meeting at the Capitol Plaza in Montpelier, VT. The meeting launched the 2016-2020 *Vermont Cancer Plan: A Framework for Action*, which was formally recognized by the legislature with a bi-partisan resolution to support the plan. For the past year, VTAAC leaders and members have promoted the new cancer plan at conferences and meetings across the state, working to implement goals and strategies specific to reducing the impact of cancer. One of these goals is “To improve access to optimal palliative care among Vermont cancer patients and survivors.” Strategies include raising awareness of the broad application to increase use of palliative care by all, promoting funding of Vermont educational programs on palliative care, and supporting Commission on Cancer accredited programs working to achieve palliative care standards.

G. Wake Up To Dying Project: During the week of July 12–17, 2016, the Wake Up to Dying Project traveling exhibit returned to Burlington, VT, to present their innovative end-of-life traveling exhibit for the second year in a row. More than 900 attended to explore what death, dying and life means to them. Many local end-of-life organizations sponsored the event and cooperatively presented 13 different workshops and community chats over the six days. Workshop topics ranged from how to prepare end-of-life planning documents to exploring what living well and dying well means to each of us.

As a result of attending this event more than 60% of those surveyed said they are more likely to consider using hospice services, 56% are more likely to consider using palliative care services, just over 60% said they are more likely to complete end-of-life planning documents, 82% said they are more likely to have a conversation about end of life with a family member and 78% plan to make changes in the way they live their life.

IV. TASK FORCE ACTIVITIES PLANNED FOR 2017

A. Annual Spring Palliative Care/Pain Professional Conference: Planning for the spring 2017 conference is underway. The broad theme for the event is, “Suffering and Consciousness at the End-of-Life”. Given the interdisciplinary nature of palliative care, the planning committee is excited to offer an educational event that addresses both the physical and the existential aspects of suffering and consciousness; and appropriate strategies for pain and symptom management at end-of-life for patients of different faith/belief backgrounds.

The theme arose from concerns expressed by some in the Buddhist community about the possible over-reliance on morphine for pain management during the dying process and the resultant impact this may have on a patient’s ability to remain

conscious throughout their end-of-life experience. We are hoping to increase the understanding of hospice and palliative care practitioners about the importance of consciousness in the dying process for some Buddhist practitioners and others, as well as to provide opportunities for understanding of the role that different faith beliefs may play in patient's goals at end-of-life. Additionally, we will provide sessions on best practice approaches to pain management offering strategies that go beyond the use of morphine.

- B. Additional Work Planned:** The Task Force will be working with community stakeholders to create fact-based information and messaging about hospice and palliative care for patients and providers, as well as to develop a statewide resource that will describe what and where palliative care is available across the state.

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

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