ANNUAL REPORT

PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE

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Submitted by:

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in partnership with members of the Palliative Care and Pain Management Task Force

I. PURPOSE

This report is submitted per Act 25 (2009) to the House Committee on Human Services and the Senate Health & Welfare Committee regarding recommendations, progress and activities related to the work of the Palliative Care and Pain Management Task Force.

II. BACKGROUND INFORMATION

Vermont law makers have a longstanding history of supporting patient self-determination and ensuring access to quality end-of-life care services. The Palliative Care Task Force was created in 2009 with a goal of coordinating palliative care initiatives across the state, providing ongoing education to health care clinicians and consumers about palliative and end-of-life care, as well as ensuring access to those services when needed. Additionally, when barriers to access or gaps in services are identified, it was intended that the Task Force would make the legislature aware of such issues and, where appropriate, propose solutions.

III. RECOMMENDATIONS

Make Permanent Remote Witnessing and Explaining of Advance Directives: The COVID pandemic necessitated numerous modifications to health care delivery and gave rise to the development of improved telehealth services. It also prompted an increase in conversations about future health care needs should an individual lose capacity to make decisions for themselves. Promoting meaningful advance care planning conversations and the completion of advance directive documents is a hallmark of quality patient-centered care. While remote witnessing and explaining of advance directives was initially intended to be a temporary provision to ensure uninterrupted access to advance directive completion, the success of this option, as it relates to expanded access to document completion, leads the Task Force to recommend this become a permanent provision of Vermont's advance directive statute.

Include Remote Witnessing and Explaining for Ulysses Clause: Under the existing statute an individual may include a provision in their advance directive that permits their health care agent, in the event that the principal lacks capacity, to authorize or withhold health care over the principal's objection (i.e. Ulysses Clause). [See 18 VSA §9707(h)]. This can be an important component of an advance directive for individuals with certain health care considerations. To be valid this provision necessitates additional signing, witnessing and explaining. In the original remote witnessing and explaining permissions, the inclusion of a Ulysses Clauses was not explicitly addressed or included. In making permanent the option to execute an advance directive via remote witnessing and explaining, the Task Force recommends the legislature make explicit that this shall also apply to the completion of a Ulysses Clause provision.

Allow for Electronic Signatures for Advance Directive Completion: In conjunction with remote witnessing and explaining, the Task Force is recommending the allowance of e-signing of advance directive documents to further enhance access to document completion and submission to the Vermont Advance Directive Registry.

The remainder of this report provides highlights from local, regional, and statewide agencies/initiatives directed toward advancing these efforts.

IV. STATEWIDE & REGIONAL EFFORTS

Statewide Ethics & Palliative Care Education: Given the success of last year's virtual ethics series, the Vermont Ethics Network once again hosed a series of presentations on ethics topics to address frequently recurring question. Sessions included:

- **October 4, 2022: Patient Safety and the Dignity of Risk** - *Adira Hulkhower, JD MS, Chief of the Bioethics Consult Service at Montefiore in the Bronx.* Hospitals have both a regulatory and ethical mandate to establish safe discharge plans for all patients. Through the lens of dignity of risk this session will provide a case-based exploration of how to expand conceptions of safety, risk and beneficence to better meet patient needs.

- **October 11, 2022: Can Long Term Care Facilities Really Say NO to Taking Patients Back?** – *Zail S. Berry, MD, MPH.* Complex patient needs combined with staffing and bed shortages have placed increased strain on the system of care delivery. Examining how different sectors of the health care system have responded can shed light on how this quandary has come about and may suggest new ways to work toward meeting the multidimensional needs of these vulnerable patients and their families.

- **October 19, 2022: Ethical Management of Clinician-Patient Conflict in the Hospital** – *Tim Lahey MD, MMSc. Director Clinical Ethics, UVM Medical Center.* This session will provide a case-based discussion about the ethical uncertainty that arises when the hospital becomes the default setting to manage non-acute and chronic health needs. Issues of behavior management, time off unit policies, discharge over objection and resource allocation will be addressed.

- **November 1, 2022: Covert Medications: Is this Ever Okay?** – *Bob Macauley, MD. Director of the OHSU Doernbecher Bridges Program. Former Director of the UVM Department of Ethics.* This session will explore the ethics of covert medications and contemplate a framework for when it may be permissible to surreptitiously give an incapacitated patient medications they have been declining.

- **November 9, 2022: Mounting Pressure in the Emergency Department – Are there ethical and legal solutions? –** *Shireen Hart, JD. Shareholder and health law attorney for Primmer Piper Eggleston & Cramer PC.* This session will offer a case-based review and solution-oriented approach to navigating some of the common challenges currently encountered in emergency departments.

- **November 16, 2022: Medical Professionalism & the "Hateful Patient" -** *William Nelson, MDiv, PhD, Director of the Ethics and Human Values Program and Professor in The Dartmouth Institute for Health Policy and Clinical Practice (TDI), and*

Departments of Medical Education and Community and Family Medicine, Geisel School of Medicine at Dartmouth. What does it mean to be a health care professional? Drawing from the famous 1978 article by James E. Grove, MD "*Taking Care of the Hateful Patient*", this session will be an interactive discussion exploring contemporary challenges in care delivery and the importance of maintaining and exemplifying professionalism during stressful ethical tensions and resource constrained times.

Recordings of the presentations and access to copies of the power point slides can be found at: **https://vtethicsnetwork.org/presentation-recordings-ven-fall-2022-ethics-education-series.** Registration and attendance at each presentation ranged from 50 – 115 people. At the conclusion of each session, post-event evaluation surveys were sent to all registered participants.

ORGANIZATION & PROGRAM SUMMARIES

Vermont Ethics Network (VEN)

There continues to be heightened interest in both completing and updating advance care planning documents (advance directives, DNR/COLST orders), and increasing numbers of Vermonter are submitting their advance directives to the Vermont Advance Directive Registry (VADR). The state currently has 47,997 total registrants in the Vermont Advance Directive Registry. To reduce impediments to the completion of advance directive documents during the pandemic, VEN once again worked with the Vermont legislature and other statewide stakeholders to extend remote witnessing and explaining of advance directive documents for another year (March 2023).

VEN continues to promote best practice in medical decision-making and appropriate use of advance care planning tools (i.e. advance directives, DNR/COLST orders, the Vermont Advance Directive Registry, etc.). In partnership with members of the Palliative Care Task Force, VEN worked to revise and improve the Vermont DNR/COLST form. Those improvements were finalized in early 2022. In preparation for a June 1, 2022 launch, VEN hosted a series of statewide educational offerings for health care clinicians and other stakeholder groups who interact with these portable medical orders. During these trainings, clinicians were able to review the new form, discuss the changes and re-visit best practices. The same training was also offered to EMS personnel. A recording of one session and an accompanying slide deck are available on the VEN website for free download. Summarized below is the registration data for each session:

- 4/14/22 – Clinician DNR/COLST Information Session 1: 95 registered
- 4/26/22 – Clinician DNR/COLST Information Session 2: 118 registered
- 5/10/22 – EMS DNR/COLST Information Session: 78 registered
- 5/11/22 – Clinician DNR/COLST Information Session 3: 115 registered
- 5/26/22 – Clinician DNR/COLST Information Session 4: 97 registered

In June VEN finalized translation of the health care agent form and the advance directive short form, as well as the Vermont Advance Directive Registry submission/change form into the following languages:

1. **Arabic**	2. **Bosnian**	3. **Burmese**	4. **Chinese(Simpl.)**
5. **French**	6. **Kirundi**	7. **Nepali**	8. **Farsi**
9. **Somali**	10. **Spanish**	11. **Swahili**	12. **Vietnamese**

We also embarked on a project in collaboration with advocates for the deaf and visually impaired and have finalized video translations of these resources into American Sign Language (ASL). All translated forms are now available on the Vermont Ethics Network website here.

Bayada

BAYADA Hospice is a mission-driven nonprofit organization with 4 offices in Vermont: Colchester, Rutland, Brattleboro, and Norwich.
BAYADA Hospice's interdisciplinary team provides in-home hospice services 24 hours a day, 7 days a week wherever a patient calls home.

We collaborate with the patient's primary care provider, or practitioner of choice to provide individualized, whole-person support services to both patient and family. Each family works with a consistent team that is flexible and responsive to meet changing end of life needs. Services are covered 100% by most insurances.

Bayada Hospice 2022 Data:
Patients admitted to Bayada hospice services in past 12 months: **1324**

- Burlington Area:487
- Rutland and Bennington Area: 249
- Brattleboro Area: 228
- Norwich Area: 360

Vermont residents currently receiving Bayada bereavement support: **2683**

- Ongoing bereavement groups held in Burlington, Rutland and Norwich area communities.
- One on one bereavement meetings available as well as mail and phone outreach
- Statewide "Hope For The Holidays" event hosted by zoom

Community Educational Offerings: **46**
Topics include:

- Understanding Hospice and Palliative Care
- Understanding Dementia
- Medical Aid in Dying and Voluntary Stopping of Eating and Drinking
- Advance Care Planning
- Ordering Your Affairs
- End of Life Conversation Group

- EOL Film Series

Events held in Senior Centers, Assisted Living Facilities, Skilled Nursing Facilities and Community Centers.

Brattleboro Area Hospice Program

Brattleboro Area Hospice (BAH) is an independent, community based, nonprofit volunteer hospice organization. We receive no insurance, state or federal funding. We provide non-medical help to terminally ill people and their families, bereavement support to anyone grieving the loss of a loved one, education to the community on issues of loss, death and dying, Advance Care planning support and bereavement and caregiver support groups. We serve Windham County and bordering New Hampshire towns.

Our trained volunteers and staff work with patients and their families to address the physical, emotional, spiritual and existential needs that are associated with death, dying and bereavement. Our non-medical assistance can be provided in homes, assisted living facilities, nursing facilities or hospitals.

Our Hospice program is for anyone with a terminal illness and a prognosis of up to one year.

Our Early Care Program is for anyone with a prognosis of up to 2 years, even if they are receiving curative treatment.

Our Bereavement Program is for anyone in the community who is bereaved, whether or not they have used hospice services.

We have a community-based volunteer hospice choir, Hallowell, which sings at the bedsides of the ill and dying.

We have a lending library with over 650 books, offer free Advance Care Planning support as well as community events such as *Death Cafes* and *Kitchen Table Conversations* to support folks in talking about death and issues related to death and dying.

Department of Vermont Health Access (DVHA)

United Way and The Robert Larner, M.D. College of Medicine Public Health Project has partnered with the Department of Vermont Health Access (DVHA) to determine feasibility of offering palliative care services in the community setting. Medical students will do a literature review to assess current evidence-based recommendations. Structured interviews or in-person surveys/interviews with specific community partners.

Pediatric Palliative Care Program (PPCP)

Currently, we have 58 children enrolled in the program and services are offered statewide through 9 designated home health agencies (HHAs).

Successes:

- Following 2.5 years of the pandemic, re-establishing program operations and relationships with providers, HHAs, and families has been a primary focus (establishing strong interdisciplinary teams, facilitating regular interdisciplinary team meetings, reviewing program operations and expectations, annual eligibility re-evaluations, providing technical assistance, holding a statewide PPCP call for program leads, supporting providers via co-visits with families, identifying and addressing educational needs, providing targeted outreach to UVMMC/DHMC and many other providers, etc.).
- The PPCP mentored two cohorts of UVM senior nursing students for their Public Health Nursing Clinical. The students worked with the PPCP Program Coordinator to revise the family satisfaction survey and the resource list. The PPCP Family Satisfaction Survey was mailed to families and the PPCP website was updated with the new resource list.
- The UVMMC has developed a Pediatric Advanced Care Team that provides consultation to the PPCP via a support grant written by VDH, bridging gaps in communication and access across the system of PPC in Vermont.
- The PPCP offered monthly virtual education to its statewide providers, covering a variety of topics from ethics to communication.
- The PPCP secured a small amount of funding for HHAs to purchase "comfort cart" supplies targeted at legacy creation, psychoeducational supports, comfort enhancements, and coping toys.
- The PPCP presented a program overview on a national level, providing virtual education on the PPCP to the Catalyst Center and the PPC Statewide Coalitions Networking Call.
- In December, the PPCP Program Coordinator and the UVMMC PACT RN participated in the ELNEC Train-the-Trainer course.

Challenges:

Despite extensive outreach, challenges continue with more rural regions and the availability of staffing, specifically nursing, counseling, and expressive therapy services. The PPCP continues to research best-practice and evidence-based palliative services as they are delivered in other states.

Outreach and education are consistent program goals targeted to decrease resistance to palliative care and increase awareness of the Pediatric Palliative Care Program in Vermont. In addition, with a limited population of pediatric palliative care families, mastering and maintaining PPCP provider expertise is a challenge.

Plans for 2023/Current projects:

- Continue to standardize processes/procedures for the PPCP specifically targeting orientation for new providers, the bereavement process following the death of a child, and grief resources throughout the state.
- The PPCP provider education day scheduled for Friday, March 17th, 2023 with a focus on provider wellness, resource fair, and clinical education.

- The PPCP is working with DVHA to improve access to the PPCP skilled respite benefit. Presently, the Skilled Respite benefit is edited to be used exclusively by Vermont Home Health Agencies. The PPCP is working to the provider type for PPCP skilled respite to include ICFs capable of caring for eligible PPCP enrollees.
- Identify strategic solutions to improve access to the PPCP services across the state.
- Continue to research community-based palliative care measurement best practices to demonstrate value to stakeholders, manage program operations, and perform continuous quality improvement.
- ELNEC trainers will plan ongoing education for statewide providers serving PPCP families.

Southwestern Vermont Medical Center (SVMC) - Bennington, VT

SVMC offers palliative care services, also known as the supportive care service, based in Southwestern Vermont Regional Cancer Center, and providing consultation and support in the inpatient, outpatient, skilled nursing, and home care settings.

- Our services are offered to patients with a serious life-threatening illness. We see patients along all points through the treatment trajectory which include prior to and during treatment.
- The referral process can be initiated by physician referral, tumor board discussion, or hospitalist IDR at the hospital. Appointments for outpatients are scheduled at the Cancer Center, at local long term care facilities, and in the home setting. We also see patients while they are inpatient at the hospital.
- The supportive care service is led by a physician board-certified in palliative care. During 2022, we are transitioning from an RN to an NP as a second member of the team to expand services.
- There is a priority on follow-up across care settings in regards to symptom management and goals of care.
- We coordinate additional care and support for our patients that will assist them to achieve better quality of life. This coordination of interdisciplinary care involves initiating home health, physical therapy, nutrition services, social work services, and hospice. We also identify community resources that may be appropriate for our patients such as Council on Aging, SASH, Lifeline, assistance with insurance authorization for medications. We collaborate with Physicians, Case Managers, and Ancillary Services to ensure continuity in the plan of care in relation to patient's goals of care.

Ongoing Initiatives:

- We continue to have the goal of expansion and access for the Supportive Care Service. This includes clinician education, nurse orientation, and support for the bioethics group.
- In 2022 and 2023, SVMC is serving as a rural site rotation for Palliative Care fellows from UVM.

UVM Health Network Department of Family Medicine / Division of Palliative Medicine

TalKVermont and Serious Illness Communication Training for All Clinicians: In 2020, the UVM Health Network funded the highly successful *TalkVermon*t Program to expand the reach and integration with Network practices over the next five years. Begun in 2017, *TalkVermon*t is a multi-component intervention to improve serious illness conversations between clinicians and patients. The Division has collaborated with *VitalTalk* to create evidence-based communication skills training programs that are engaging, interprofessional, and focused on patient values. We have also partnered with Ariadne Labs (of Harvard School of Public Health) to create changes to the electronic health record and clinical workflows to facilitate serious illness conversations for clinicians and patients. Since 2017, we have conducted more than 42 day-long workshops in "Mastering Late Goals-of-Care Conversations", "Mastering Early Goals-of-Care Conversations" and "Mastering Pediatric Serious Illness Conversations throughout Vermont and the Adirondack Region of New York. In 2022, we offered both in-person and virtual courses for participants. We also continued to do a yearly longitudinal champion coaching course for workshop graduates to finetune their skills in serious illness conversations and offered an Advanced Course in the fall of 2022 to cover topics like navigating conflict and requests for hastening death in Serious Illness Conversations. To date, *TalkVermont* has trained more than 1000 clinicians (physicians, nurse practitioners, nurses, social workers, and chaplains) and trainees (nursing students, medical students, and medical residents) throughout the UVM Health Network. During the coming five years, *TalkVermon*t anticipates training more than 1,000 additional clinicians and implement practice re-design interventions for clinical sites throughout our Network to support seriously ill patients, their families and their clinicians engaging each other in meaningful, vitalizing and timely conversations.

Increasing the Network Palliative Care Work Force: There is a growing need for specialty-trained HPM physicians. As effective treatments for many illnesses emerge and life expectancy increases, Vermont, and the rest of the nation, is confronted with great numbers of people with chronic, debilitating, and life-limiting illnesses. A growing evidence base demonstrates that specialty palliative care, as delivered through inpatient or outpatient consultation services or a dedicated inpatient unit, improves the quality of care, patient and family satisfaction, and the cost effectiveness of care for adult and pediatric patients especially when provided early in the course of serious illness. In the fall of 2020, we were approved by the UVMHN to build a hospice and palliative medicine fellowship. The goals of this fellowship program are to develop Hospice and Palliative Medicine physicians with a strong foundation in symptom management, including pain management, and to work within interprofessional teams to provide evidence-based and values-based medical care to patients (and their families) living with serious medical conditions. Additionally, this fellowship program seeks to train future clinicians who will help promote and build an expertise in rural-based hospice and palliative care. This past summer, we began our fellowship with two fellows and in the fall of 2022, we matched our second fellowship class that will begin in July of 2023.

The University of Vermont Health Network, Porter Medical Center Palliative Care is a specialty interdisciplinary program comprised of physician and social work disciplines. Palliative Care services are available at Porter Medical Center and at Helen Porter Health and Rehabilitation Center. In the last year, our part time service increased coverage from 4 to 5 days a week. In FY2022 the Palliative Care service completed 286 new consults with 276 follow up visits. In this past year, we have completed the integration of the former End of Life Services Program into Porter's Palliative Care Department. Expanding the former hospice volunteer framework into the Palliative Care population is a unique, valuable opportunity for Porter. We currently have 60 active volunteers who offer Palliative Support, Vigil Sitting, Singers, and Bereavement support. The Palliative Care team holds regular educational sessions for our Volunteers who are currently active at Porter Medical Center and Helen Porter. We are beginning to offer Volunteer Services at continuing care facilities, through Primary Care offices and in the community at large. Our volunteers helped to develop and support an annual Community Story Telling event around Grief and Bereavement. We have updated our training materials and are now offering grief support groups for the community.

University of Vermont Health Network, UVM Medical Center in Burlington: Since establishing the Division of Palliative Medicine within the Department of Family Medicine at UVM in 2016, the program has been growing in clinical services, teaching programs, population health innovations and research. The UVMMC-based team includes 8 physicians and 3 nurse practitioners. During this past year, the UVMMC team was consulted for around 1000 new patients in the inpatient setting and over 100 in the outpatient setting. We continued to care for patients in the outpatient setting in the ALS clinic, the Heart Failure Clinic, and our General Palliative Medicine Telehealth Clinic. In partnership with the UVM Cancer Center, we began to embed palliative care services in two ways: 1) we expanded an outpatient palliative care clinic in the cancer center 2) we created a second palliative care team to collaborate with the medical and hematologic oncology services. Additionally, we have started Serious Illness Conversations in the ED with an embedded palliative care nurse once a week with hopes to expand this Monday through Friday.

University of Vermont Larner College of Medicine: Our formal teaching programs reach more than 300 learners each year and include inpatient observerships for first-year medical and nursing students, elective clinical rotations for medical students and residents, and a required 40-hour Palliative Medicine course for medical students during their 3rd year. We launched an ACGME - accredited physician fellowship in July 2022 and welcomed our first two fellows. The Vermont Conversation Research Lab (vermontconversationlab.com) continues to advance the science of human connection in serious illness, including recent completion of the successful *StoryListening Project*, an EOL Doula-facilitated intervention for families, friends and healthcare professionals who experienced the death of a person during the COVID pandemic to share the story of that experience with an engaged, non-judgmental listener.

Vermont Department of Corrections (VT DOC)

The VT DOC Health Services Division has been working with our health care vendor Vital Core Health Strategies to ensure incarcerated individuals have access to the same palliative services available to the community as a whole. The DOC has identified certain challenges that surfaced due to COVID and staffing shortages: specifically the need to hire traveling nurses that may not have had much training in palliative care. Additionally, the lack of advance care directives upon admission to an infirmary setting poses a significant challenge. To address these issues the DOC has focused on scheduling specific evaluations to identify palliative needs as well as continued training and education of medical staff.

Vermont Medical Society (VMS)

The Vermont Medical Society shared updated resources and information with member physicians and physician assistants in several formats this year. The VMS included information about the updated POLST/COLST forms and related VEN webinars in its member e-newsletter; distributed information in its e-newsletter about the VEN fall ethics series; had a speaker at the VMS fall membership meeting on "Updates in Caring for Patients at the End of Life;" and worked with VEN to add a new chapter on "End of Life Considerations" to the popular resource the Vermont Guide to Health Care Law. The updated Guide can be found here: https://vtmd.org/vermont-guide-to-health-care-law.

Visiting Nurse and Hospice for Vermont and New Hampshire (VNH)

Visiting Nurse and Hospice for Vermont and New Hampshire provided service to 5,942 patients and their families in 2021, 753 of which were hospice patients.

White River Junction, VA Medical Center (WRJ VAMC)

The White River Junction (WRJ) VA Medical Center (VAMC) has palliative care team providing consultative support around inpatient and outpatient veterans. Full time staff consists of 1 physician, 1 nurse practitioner, 1 nurse case manager, and 1 social worker. The consult team receives some additional part time physician and nurse practitioner support while also maintaining a close affiliation with chaplaincy, psychiatry, and health psychology. Outpatient in-person consult services are provided at the WRJ VAMC as well as at the Burlington Lakeside Clinic (BLC). Additional, outpatient consult services can be provided by the consult team though video telehealth.

V. CONCLUSION

There continues to be a strong commitment to robust advance care planning, palliative care, and hospice programming across the state. Vermont Ethics Network, in partnership with the Palliative Care Task Force, will continue to advance this important work and is grateful for the ongoing support of the Vermont Legislature and their

interest and openness to recommendations that promote alignment of state policy, Vermonters values and clinical best practice.

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

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