



ANNUAL REPORT

PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE

JANUARY 2024

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

Approve H.469 – An act relating to remote and electronic processes for executing an advance directive. This bill was introduced during the 2023 legislative session, passed in the House and is currently in the Senate Health and Welfare Committee. The bill seeks to:

- **Make permanent the ability for remote witnessing and explaining of advance directive (AD) documents through live, interactive, audio-video connection or by telephone.** 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 and patient self-determination, necessitates this become a permanent provision of Vermont's advance directive statute.
- **Allow for the use of digital signature for signing, witnessing and explaining of AD Documents.** In conjunction with remote witnessing and explaining, the allowance of e-signing of advance directive documents will further enhance document completion and submission to the Vermont Advance Directive Registry.
- **To clarify the process for completing a Ulysses clause provision in an AD document.** 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. As it relates to the Ulysses Clause provision, H.469 provides that:

- When completing a Ulysses Clause for the first time, the clinician consent process and the explainer portion must be completed in person (not remotely).
- For any future updates to a previously completed AD document that contained a Ulysses Clause, the individual who is updating their document could update the Ulysses Clause provision remotely and the clinician and explainer roles need not be in person but could fulfill their obligations through the use of live, interactive, audio-video connection only. Not via telephone.
- The bill further clarifies that:
 - The agent/co-agent/alternate agent named in the advance directive who is/are required to sign the Ulysses Clause provision documenting acceptance of the responsibility, need not be in person when signing, need not sign when the others involved are signing, and can be signed digitally.
 - The informed consent process by the clinician and their signature can be done at a separate time from the explainer portion (and vice versa) and signed digitally.
 - Makes explicit that all parties that need to sign as part of a Ulysses Clause provision need not all be present at the same time or on the same day.

The Task Force recommends approval by the Senate and passage of H.469.

The remainder of this report provides highlights from local, regional, and statewide agencies/initiatives directed toward advancing advance care planning, palliative and end-of-life care initiatives.

IV. STATEWIDE & REGIONAL EFFORTS

Statewide Palliative Care Education: Building on the success of our fall virtual ethics series, the Vermont Ethics Network (VEN), in conjunction with the Palliative Care Task Force, beginning on April 18th and running through May 24th offered a 6-part palliative care virtual series on a range of palliative care topics. Registration and attendance for each session ranged from 103 - 200 interdisciplinary professionals. The series covered the following topics:

- **April 18, 2023.** *They Just Don't Get It: Serious illness communication strategies, skills, opportunities and pitfalls* – Diana Barnard, MD – Palliative Medicine, Porter Medical Center. (177 registrants)
- **April 25, 2023.** *Mining the Language Gap: The words we use may not always convey the meaning we intend* – Steve Berns, MD - UVM Medical Center; Kacey Boyle, MSPC,

RN, CHPN - UVM Medical Center; Jennifer Hauptman, MSW, LICSW - UVM Medical Center (103 registrants)

- **May 4, 2023.** *Uncertain End of Life Trajectory: Care implications for patients with severe psychiatric illness.* Steve Runyan, DO – UVM Medical Center & Belle Matheson, NP – UVM Medical Center (163 registrants)
- **May 9, 2023.** *Clear as Mud: The nuances of hospice eligibility & financial issues at end of life.* Joyce Dobbertin, MD – Northeastern Medical Center. (150 registrants)
- **May 17, 2023.** *Use of Opioids in Serious Illness: Inpatient and outpatient considerations.* Allen Hutcheson, MD - Southwestern Vermont Medical Center. (137 registrants)
- **May 24, 2023.** *Medical Aid In Dying Update: Recent Changes to Act 39 & Non Resident Access.* Diana Barnard, MD – Porter Medical Center & Patient Choices Vermont, and Toni Kaeding, MS, RN – Patient Choices Vermont. Moderated by Cindy Bruzzese, MPA, MSB, HEC-C - Vermont Ethics Network. (200 registrants)

Recordings of the presentations and access to power point slides can be found at: <https://vtethicsnetwork.org/presentation-recordings-spring-2023-palliative-care-series>

ORGANIZATION & PROGRAM SUMMARIES

Vermont Ethics Network (VEN)

There remains heightened interest in both completing and updating advance care planning documents (advance directives, DNR/COLST orders), and an increasing numbers of Vermonter are submitting their advance directives to the Vermont Advance Directive Registry (VADR). As of December 31, 2023, Vermont has 51,268 total registrants in the Vermont Advance Directive Registry.

VEN continues to serve as the primary liaison for inquiries and communications between consumers and providers and the VADR. The organization receives packets of 30-40 documents from the registry approximately every two weeks with advance directive (AD) submissions that the VADR is unable to process--requiring further follow up from VEN. In addition to the correspondence pertained to failed submissions, VEN receives additional inquiries via phone/email averaging 15-20 calls/emails per week (780 – 1040 calls annually). Questions come from both the public and professionals including physicians, nursing staff, case managers, attorneys and ombudsmen, who are looking for clarification about medical decision-making principles, medical aid in dying, end-of-life planning, advance care planning tools, DNR/COLST procedures, guardianship proceedings, etc.

As the number of registrants increases each year, the demand for VEN and the registry to deliver high quality customer service via mail, phone, and email communication continues to grow. To better manage the needs of customers, VEN is working with the registry to build a more robust electronic submission option, streamline our handling of improperly completed documents, and decrease our reliance on paper communications.

In addition to customer support, VEN is also working to improve access to the registry for health care providers. Staff turnover in many health care settings has been incredibly high over the last three years, and maintaining authorized user accounts has become a priority. This is an opportunity for VEN to re-educate about best practices and the benefits of registration and assist healthcare practices in utilizing the VADR to support their own electronic records. We have been working closely with UVMMC to integrate the VADR into their EMR, and efforts like this will continue in FY24 as we plan to offer virtual trainings for authorized user administrators in the Spring/Summer of 2024.

Our efforts to improve access to ethics expertise in rural settings is also gaining traction both in and outside of Vermont. Development of a more robust system capable of responding to the increased need for ethics education and consultation across all areas of Vermont's health care system remains. Increased demand amidst finite supply seems to be one of the greatest and ongoing challenges VEN faces—the more education provided the greater the awareness about the importance of the ethics lens in clinical decision-making. This leads to increased requests for ethics expertise and consultation to assist with complex care decisions. Ensuring that facilities and providers have access to ethics when needed should be a priority for Vermont's health care delivery system.

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.

BAYADA collaborates 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 2023 Data:

Patients served by Bayada Hospice in past 12 months: 1296

- Brattleboro – 299
- Colchester – 416
- Rutland – 224
- Norwich – 359

Central Vermont Home Health & Hospice (CVHHH)

CVHHH is a full service, not-for-profit Visiting Nurse Association committed to providing high quality, medically necessary home health and hospice care to all Central Vermonters, regardless of their ability to pay. For over 100 years, CVHHH has continued to innovate to incorporate new technologies, treatments and best practices in order to meet the changing needs of the communities we serve in Washington and Orange Counties.

In 2023, the Hospice program provided care to 331 patients, providing 9,583 visits. The Bereavement program made 1,188 visits and calls, along with 422 clergy visits. Additionally, an estimated 2,300 hours of volunteer services were provided under the hospice program. Hospice focuses on meeting a person's physical, emotional, and spiritual needs, as well as the needs of their family and caregivers, by bringing expert medical treatment, pain and symptom management, and emotional and spiritual support to people at home. CVHHH hospice care is available to Central Vermonters wherever they reside – at home, in a skilled nursing facility, an assisted living facility, a hospice inpatient facility, or hospital.

In the Spring of 2023, CVHHH launched its Palliative Care Consultative Service (PCCS), led by Dr. Kelley Elwell, DNP, APRN, FNP-BC, Palliative Care Nurse Practitioner. The PCCS was created to help the population of patients who are challenged with living with serious or life-limiting illnesses. Receiving referrals directly from patients, hospitals or patients' physicians, Dr. Elwell works hand-in-hand with each person's care team, including their PCP, specialists, family members, spiritual or faith counselors, and social workers, to ensure they get the care necessary to manage pain and symptoms, achieve optimal quality of life and understand the nature of their disease progression. She helps patients explore their health care wishes and long-term goals of care, including helping them with preparing advance directives and providing navigational support for those pursuing hospice care. This allows her to be a consistent provider throughout a patient's care continuum and end-of-life journey.

As a nurse practitioner, Dr. Elwell has also been able to serve as patients' attending provider for hospice care, on an as-needed basis, enabling care for those patients without a PCP. This provides a readily available resource to address changes in condition that, in some cases, could result in preventable ER visits or hospitalizations. During its inaugural year, CVHHH's PCCS provided care to 149 patients.

Dr. Elwell conducts educational presentations and visits with community groups, health care facilities and medical providers, to increase awareness and understanding of palliative care and hospice, and chronic diseases and their progression, throughout CVHHH's service area. The CVHHH PCCS program is paid for by Medicare Part B, Medicaid, VA benefits and private insurances.

Department of Vermont Health Access (DVHA)

United Way and The Robert Larner, M.D. College of Medicine Public Health Project partnered with the Department of Vermont Health Access (DVHA) to determine feasibility of offering palliative care services in the community setting. Medical students did a literature review to assess current evidence-based recommendations. Structured interviews or in-person surveys/interviews with specific community partners also occurred. In July a presentation was given to DVHA senior leadership on improving access to adult home-based palliative care via Vermont Medicaid coverage expansion. Internal discussions are on-going about the feasibility of implementing a palliative care Medicaid service.

Pediatric Palliative Care Program (PPCP)

Currently, the PPCP has 56 children enrolled in the program and PPCP services are offered statewide through 9 designated home health agencies (HHAs).

Successes:

- The UVMHC Pediatric Advanced Care Team (PACT) continues to provide consultation to the PPCP via a support grant written by VDH, bridging gaps in communication, increasing pediatric hospice enrollment and access to quality PPC across the system of care in Vermont.
- The PPCP offered monthly virtual education to its statewide providers, covering a variety of topics from spirituality to hospice.
- The PPCP continues to access funding for HHAs to purchase “comfort cart” supplies targeted at legacy creation, psychoeducational supports, comfort enhancements, and coping toys. This funding expanded to include the purchase of sibling bereavement kits and other bereavement supports.
- In collaboration with the PACT RN, the PPCP Program Coordinator provided a half-day training to UVMHC titled, “Perinatal Palliative and Neonatal End-of-life Education.”
- The PPCP held a statewide provider education day on Friday, March 17th, 2023 with a focus on provider wellness, resource fair, and clinical education.
- Previously, the PPCP Skilled Respite benefit was edited to be used exclusively by Vermont Home Health Agencies. The PPCP worked with DVHA to open the provider type for PPCP skilled respite to include ICFs capable of caring for eligible PPCP enrollees.

Plans for 2024/Ongoing Initiatives:

- 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.
- In collaboration with the PACT RN, the PPCP Program Coordinator will offer a second half-day training for UVMHC titled, “Perinatal Palliative and Neonatal End-of-life Education.”
- The PPCP Program Coordinator and PACT RN will offer the complete End-of-life Nursing Education Consortium (ELNEC) training. This training is for statewide pediatric palliative care providers interested in becoming ELNEC certified.
- 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.
- The PPCP Program Coordinator is working to secure funding for the *TalkVT* Peds training customized for the statewide pediatric palliative care providers.

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 regard 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.
- SVMC continues to serve as a rural site rotation for Palliative Care fellows from UVM.

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

The Division of Hospice and Palliative Medicine at the University of Vermont Health Network officially became a network wide program this year with the goal to streamline palliative care services across all 7 clinical campuses within the health network. Dr. Robert Gramling has continued to serve as Division Head and the Holly and Bob Miller Endowed Chair for Hospice and Palliative Medicine, helping to guide our academic and clinical missions. Below are updates to our clinical and education wide programs. We are proud to have continued our great work across the health network for the seriously ill and have had small successes in the realm of education. Unfortunately, we still have limited staff and, cannot keep up with the clinical work—with low penetration rates at most of our hospitals. Although we have been able to add to some of our team at the University of Vermont Medical Center, the recent decision by the Green Mountain Care

Board has led to the health network not being able to support any growth in palliative care both in the inpatient and outpatient settings. We hope that as the health network becomes more fiscally stable and we continue our switch towards population health, palliative care can successfully grow to meet the demands of our patients and their families.

The University of Vermont Health Network Porter Medical Center Palliative Care continues to offer Interdisciplinary care with a program composed of 1.0 FTE Physician time, a 0.8 FTE Licensed Clinical Social Worker and 1.0 FTE Manager of Palliative Support Services; an innovative volunteer program with over 100 active volunteers who put in 2,700 Volunteer hours in FY2022. Palliative care consultation are available at Porter Medical (PMC) and at Helen Porter Rehabilitation and Nursing (HP). In FY2023, we completed 275 new consults with 395 follow up clinical MD/SW visits. Our volunteer program offers vigil sitting, bereavement support, and ongoing companionship for those navigating serious illness. In 2024 we offered 4 8-week grief support groups, 1 6-week volunteer training, and 1 6-week bereavement companion trainings. We held our first countywide death café in September with monthly cafes planned for FY2023. We held our second story telling event around the subject of grief and healing. The palliative medicine fellowship was launched this year with each of the two fellows spending 8 weeks each at the PMC/HP campus. Porter Medical Center was poised to expand its services up to a 1.5 FTE MD positions until budgetary cuts placed this expansion on hold. One of our part time physicians also left at the end of FY2023. We are currently recruiting for a 1.0 FTE physician to hold services steady this year with the upcoming departure of our remaining part time physician.

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. We recently hired 1.5 chaplains and 1 social worker to join our team. During this past year, the UVMMC team was consulted for around 1250 new patients in the inpatient setting and outpatient settings. This small growth occurred despite us cutting back our clinical hours on the weekend due to staff shortages. We continue to care for patients in the outpatient setting in the ALS clinic, the Heart Failure Clinic, the UVM Cancer Center, and our General Palliative Medicine Telehealth Clinic.

University of Vermont Larner College of Medicine: Our formal teaching programs reaches more than 400 learners each year and includes 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 who recently graduated—one staying within our health network and the other working in New Hampshire to be closer to family. We currently have two fellows enrolled in our program, a primary care clinician from Wisconsin and an Emergency Medicine physician from Vermont. 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.

TalkVermont and Serious Illness Communication Training for All Clinicians: In 2020, the UVM Health Network funded the highly successful *TalkVermont* Program to expand the reach and integration with Network practices over the next five years. Begun in 2017, *TalkVermont* 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 60 day-long workshops in “Mastering Tough Conversations”, “Foundations in Serious Illness Conversations” and “Mastering Tough Conversations in Pediatrics” throughout Vermont and the Adirondack Region of New York. In 2022, we offered both in-person and virtual courses for participants. We also continue to do a yearly longitudinal champion coaching course for workshop graduates to finetune their skills in serious illness conversations and offer an Advanced Course that covers topics like navigating conflict, working with colleagues, and requests for MAID in Serious Illness Conversations. This year we are putting together a “Mastering Tough Conversations in Oncology” course that will be launched in February 2024. To date, *TalkVermont* has trained more than 1800 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, *TalkVermont* 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. We are currently working on reworking our Electronic Health Record to better capture these conversations.

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

Visiting Nurse and Hospice for VT and NH (VNH) is a mission-driven nonprofit organization with our main office located in White River Junction, VT. VNH’s hospice interdisciplinary team provides in-home hospice services 24 hours a day, 7 days a week. We are dedicated to delivering outstanding home health and hospice services that enrich the lives of the people we serve, in more than 140 towns in Vermont and New Hampshire.

As the area’s foremost team of home health care experts, we deliver hospice services with proven effectiveness, integrity, and compassion. We are driven by a focus on excellence and a spirit of innovation, from improving systems of care to improving individual lives. Our relationship with each client is rooted in respect — for the families

whose homes we are privileged to enter, for the communities we are honored to serve, and for all the lives we touch.

VNH Hospice 2023 Data:

- Patients admitted to VNH hospice services in past 12 months: 240
- Total number of patients receiving hospice services in 2023: 302
- Total number of bereaved provided support in 2023: 941
- Ongoing bereavement groups held in Thetford, Hartland and Charlestown, NH
- Total number of hospice volunteers in 2023: 12

2023 accomplishments:

- In the significantly challenging area of healthcare staffing, successfully recruited and retained core team members in the hospice program, leading to zero utilization of contracted staff.
- Developed and implemented after hours staffing model that facilitated stabilized and consistent case management during the day.
- Continued to develop strong relationships and communication with our referring providers.
- Successfully recruited a full-time volunteer and bereavement coordinator. This has led us to provide much needed support for our patients and families after the pandemic and the PHE ending.
- Increased community educational outreach at libraries, senior centers and various patient care facilities throughout our coverage area. These offerings included topics such as Hospice 101, advanced care planning and many more.

White River Junction, VA Medical Center (WRJ VAMC)

The White River Junction (WRJ) VA Medical Center (VAMC) has a 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). Additionally, outpatient consult services can be provided by the consult team through 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.

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

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