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. RECOMMENDATIONS

Extend Remote Witnessing and Explaining of Advance Directive Until June 2023 and Consider Making Provision Permanent: The COVID pandemic has resulted in numerous modifications to health care delivery. It has also given rise to increasing conversations about future health care needs should an individual lose capacity to make decisions for themselves. Given the community prevalence of the virus and the emergence of more contagious strains, even if there is no longer a declared state of emergency, some settings may feel the need to maintain restrictions of in-person visitation due to heightened risk of contracting/spreading disease or developing severe illness. As such, we anticipate continued need for remote witnessing and explaining of advance directives beyond the current sunset date of June 2022. The Task Force recommends extending remote witnessing and explaining for at least another year and encourages consideration by the legislature to make this option a permanent provision of Vermont's advance directive statute.

Support of Changes to Vermont's Medical Aid in Dying Law as Proposed in S.74: As introduced S.74 would:

- Enable telemedicine access to medical aid in dying by removing the "in the physical presence" requirement as it presently exists. Vermont is the only state in which physical visits are required for aid in dying requests. In all other MAID states, aid-in-dying is accessible via telemedicine when appropriate.
- Clarify that health professionals acting in accordance with the law would be immune from civil or criminal liability. At present, Vermont's law only provides explicit immunity for the prescribing physician, leaving the liability protections for other professionals (i.e. pharmacists, certifying second physician, etc.) necessarily involved in the process unclear.
- Maintain the mandated 15-day waiting period between the two oral requests but would remove the arbitrary and potentially burdensome additional 48-hour delay before the prescription can be written.

Given that Vermont policy makers have determined that medical aid in dying shall be a legally available option for qualifying patients and physicians who voluntarily choose to participate, removing unnecessary barriers to the process while maintaining essential safeguards consistent with the practices and processes in other states is recommended.

III. 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.

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 Conference: In light of the current COVID pandemic and the inadvisability of large group gatherings, the Vermont Ethics Network chose to host a fall 2021 virtual ethics series on a range of topics that generate frequent questions from health care professionals. The following topics were presented over the course of five-weeks:

- Tangled Terminology: Avoiding the Ethical Pitfalls of Misnomers in Decision-making Language. Presented by: Cindy Bruzzese, MPA, MSB, HEC-C: Executive Director & Clinical Ethicist, Vermont Ethics Network; Clinical Ethicist, UVM Medical Center. Course description: Medical decision-making terminology can be confusing and sometimes the words we use convey a meaning that was not intended (i.e. a preference for CPR in an advance directive is not equivalent to a DNR order). This session will untangle the acronyms and terms, highlight potential pitfalls, and underscore the importance of language when it comes to health care decisions.

- Exceptions to the Rule: When Minors Get to Make Their Own Medical Decisions. Presented by: Bob Macauley, MD, FAAP, FAAHPM, HEC-C: Cambia Health Foundation Endowed Chair in Pediatric Palliative Care, Oregon Health and Science University. Course description: While 18 is the "age of majority," there are several situations where patients younger than that are authorized to make their own medical decisions. This session will explore the minor treatment statutes, emancipation, and the mature minor doctrine, as well as current challenges relating to vaccination of minors without their parents' consent.

- Determining Capacity on the Frontlines. Presented by: Evie Marcolini, MD, FAAEM, FACEP, FCCM: Associate Professor of Emergency Medicine and Neurology; Vice Chair of Faculty Affairs, Department of Emergency Medicine, Geisel School of Medicine at Dartmouth. Course description: Decisional capacity is fundamental to the autonomous rights that patients have to make decisions about their health care. While capacity is presumed, it is not uncommon to encounter patients who have limits to decision-making capabilities. This session will review the basics of capacity assessment and the challenges to care management when there is uncertainty about decisional capacity.

- What I Hate About Advance Directives: A Panel Discussion. Presented by: Linda Hurley, MS, RN: Nurse Educator, Psychiatry DHMC and Belle Matheson, APRN: Palliative Care UVM Medical Center. (Panel Discussion facilitated by Cindy Bruzzese). Course description: Through discussion of case studies, we will highlight and explore wording commonly used in health care directives that is potentially ambiguous and may lead to misunderstanding of patient goals and wishes.

- Let's Talk Refusals. Presented by: Sally Bliss, RN, MSB, HEC-C: Clinical Ethicist, UVM Medical Center, Adjunct Assistant Professor, UVM Larner College of Medicine; Erika Smart, JD: Legal Risk Manager, UVM Medical Center and Stas Amato, MD, MSc, General Surgery Resident, PGY-Research, Clinical Ethics Fellow, UVM Medical Center. Course description: We are obligated to provide our very best care to the patients we see. Yet sometimes, patients disagree with our recommendations and refuse what is being offered. This session will discuss the ethical obligations and legal framework for addressing patient refusals in a variety of clinical situations.

The video recordings and slide presentations for the entire series can be found here. A combined palliative care and ethics conference is being planned for spring of 2022.

Vermont Ethics Network (VEN)

Since the start of the COVID pandemic, VEN has seen a heightened interest in both completing and updating advance care planning documents (advance directives, DNR/COLST orders), as well as submissions to the Vermont Advance Directive Registry (VADR). In order to reduce impediments to completion of advance directive documents during the pandemic, VEN worked with the Vermont legislature and other statewide stakeholders to extend remote witnessing and explaining of advance directive documents for another year (June 2022).

In partnership with members of the Palliative Care Task Force, VEN has been working to revise and improve the Vermont DNR/COLST form. In December of 2021 that process was completed and proposed changes to the form have been approved by the Vermont Department of Health. Starting in January of 2022, VEN will be working to provide statewide education to health care clinicians and other stakeholder groups who interact with these portable medical orders. The goal will be to transition to the new DNR/COLST form in March/April of 2022.

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.). The state currently has 45,783 total registrants in the Vermont Advance Directive Registry (VADR). To further promote the benefit and utility of this resource VEN published a printable brochure which answers commonly asked questions about the Registry, benefits of registering an advance directive, how to register, and how to update an existing advance directive in the Registry. Health care facilities and providers are encouraged to utilize this brochure when

explaining the Registry to patients and clients, and individuals are encouraged to review this brochure prior to registering or updating their advance directive. In July 2021, the VADR began accepting new registrations and updates to existing accounts via email. Along with the launch of email submissions, an improved administrative form to streamline the submission process was implemented for all registrants. A combined Registration Agreement/Authorization to Change form is now being utilized for initial submissions, updates and revisions to VADR accounts. Detailed instructions are available within the form and on the VEN website.

Building from a previous advance care planning (ACP) collective impact project, VEN has formalized a process to support individuals who are championing local community advance care planning efforts. VEN organizes regular *ACP Champion* calls through which information is shared to address recurring questions and provide resources in support of local efforts. In addition, periodic *ACP Champion* emails are distributed containing policy updates, tips, best practices, new research in the field, and relevant articles.

Southwestern Vermont Medical Center (SVMC) - Bennington, VT

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

- Services are offered to patients with a serious illness. Patients are seen 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 consists of a physician board-certified in palliative care and a registered nurse certified in hospice and palliative care.
- The top three diagnoses are cancer, cardiac disease, and lung disease.
- There is a priority on follow-up across care settings in regards to symptom management and new or changed medications to ensure patients are having relief from symptoms.
- 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:

- In 2021, participated with COVID related care such as symptom control, goals of care, and family support.
- Continued goal of expansion of their Supportive Care Service.

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

Continued Network Support for COVID Response: The Division continues to provide specialty consultation for both bedside patient-facing care and clinician coaching, on-demand education sessions, and updated enduring resources to support our Network community affected by COVID. The updated *Palliative Care COVID-19 Toolkit* quick reference guides and webinar resources are available to Network professionals at https://www.uvmhealth.org/coronavirus/for-medical-professionals.

Network Support for Serious Illness Communication Training: 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 39 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 2021, we offered both in-person and virtual courses for participants. Despite the pandemic, we taught an additional longitudinal champion coaching course for workshop graduates to finetune their skills in serious illness conversations. To date, *TalkVermont* has trained more than 750 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 were approved by ACGME to form the fellowship and successfully recruited two fellows to begin in July of 2022 as our inaugural fellowship class.

The University of Vermont Health Network, Porter Medical Center Palliative Care is a specialty interdisciplinary program comprised of physician and social work disciplines providing daytime coverage 4 days per week. Over this past year, the Palliative Care service completed 291 new consults and 230 follow up visits for seriously ill people admitted to the Medical/Surgical floor at Porter Medical Center and at Helen Porter Health and Rehabilitation Center (most often on the post-acute unit). This year the UVMHN Porter Medical Center will continue to expand services to people living with serious illness to increase physician availability to every weekday and via the integration of End-of-Life Services into medical center operations. End-of-Life Services is a robust community organization that supports patients, families, and caregivers before, during and after the dying process by providing highly trained volunteers, bereavement, and education. In April 2021, the board of End-of-Life Services determined they could not continue in their current form and began the search for a path forward that would continue their mission and volunteer services in the community. The official transition of End-of-Life Services from their previous form to UVMHN Porter Medical Center was effective December 27th.

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 7 physicians, 3 nurse practitioners, 1 nurse and 1 chaplain with closely affiliated social worker, psychiatry and pharmacy team members. During this past year, the UVMMC team was consulted more than 1,000 times to care for seriously ill hospitalized adults and children. We have also provided TeleConsult follow-up home visits and outpatient consultations at the Fanny Allen campus for people with ALS. From August 2020 and August 2021, we have been providing additional clinical coverage for Miller-McClure Respite House in collaboration with UVM Home Health & Hospice. Substantial expansion of all services is planned for 2022, including new outpatient services in both adult and pediatric oncology at UVMMC and establishing palliative care consultation in the Emergency Department setting.

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 are preparing to launch an ACGME- accredited physician fellowship beginning July 2022. The Vermont Conversation Research Lab (www.vermontconversationlab.com) continues to advance the science of serious illness communication. Part of this work includes developing scalable interventions to help reduce the public health burden of grief and loneliness. In 2020, the VCL began the *StoryListening Project*. The experience of

caring for and about people who have died during the social distancing context of the COVID pandemic can be isolating and distressing for family, friends and clinicians. Telling the story of one's experience to an engaged listener can help decrease the sense of isolation and loneliness and, consequently, improve quality of life for people who are grieving. Conducted by trained listeners from the UVM End-of-Life Doula Program (https://learn.uvm.edu/program/end-of-life-doula-at-uvm/end-of-life-doula-certificate/), this study evaluates the aspects of storytelling and storylistening that are most beneficial to quality of life. More than 50 participants have enrolled in the *StoryListening Project* and will continue to enroll through the Spring of 2022.

Visiting Nurse and Hospice for Vermont and New Hampshire:

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.

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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