



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

Professional Development for Health Care Practitioners on Serious Illness

Communication: As Vermonters age, optimal management of serious and age-related illness is integral to the health of patients and their caregivers. Ensuring that health care practitioners have the skills necessary to communicate effectively with patients and families about serious illness and disease progression is paramount. Policy decisions that promote and support the integration of these specialized communication skills are recommended.

Access to Appropriate Pain Management for Patients with Serious Illness and Those at End-of-Life:

The use of opioids remains a necessary and important tool in the management of some symptoms for patients with serious illness and/or at end-of-life. As Vermont continues its work to address the complex issues surrounding opiate use and abuse, it remains of critical importance that any revisions to current policy and any future proposed policies protect access to appropriate pain medication for hospice and hospice-eligible patients.

III. BACKGROUND INFORMATION

In 2014, the Institute of Medicine's report, *Dying in America: Improving Quality and Honoring Individuals Preferences at the End of Life*, prompted a shift in health care toward systemic improvements in advance care planning and clinician-led conversations about goals, values and care preferences for patients with serious and life-limiting illness.ⁱ Today, evidence of these conversations are the hallmark of high quality, patient-centered care. Numerous studies confirm 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-concordant care, and reduced costs. The preferred and endorsed practices for palliative and hospice care by the National Quality Forum (NQF) and the National Consensus Project for Quality Palliative Care state that communication, shared decision making, and advance care planning are central to quality care for people with serious illness.ⁱⁱ In light of these recommended and preferred practices, palliative care educational efforts in Vermont are directed at these core elements of communication and advance care planning.

IV. STATEWIDE & REGIONAL EFFORTS

- I. **Statewide Palliative Care Conference:** In May of 2019, the Vermont Ethics Network hosted the 10th annual Palliative Care and Pain Management Conference. The event, *Listening, Language & the Power of Truth-Telling* was held at the DoubleTree by Hilton in

South Burlington and was attended by 118 interdisciplinary professionals from across Vermont and New Hampshire. The primary learning objectives for attendees for this event were:

- To understand the elements of effective listening and communication;
- To gain insight into how the language providers use impacts what patients and families hear and understand;
- To improve provider ability and comfort in sharing difficult prognoses and in handling emotions and/or denial; and
- To improve provider skill level in navigating open and honest conversations about illness and disease progression with both adult and pediatric patients.

The conference featured two national experts:

- **Danielle Ofri, MD, PhD, D.Litt, FACP**, an internist at the medical clinic of Bellevue Hospital, the oldest public hospital in the country. She is a founder and Editor-in-Chief of the *Bellevue Literary Review*, and is on the faculty of New York University School of Medicine. Her newest book is *What Patients Say; What Doctors Hear*, an exploration of doctor-patient communication and how refocusing the conversation between doctors and patients can improve health outcomes. Dr. Ofri writes regularly for the *New York Times* and *Slate Magazine* about medicine and the doctor-patient relationship. Her essays have also appeared in the *Los Angeles Times*, the *Washington Post*, the *Atlantic*, the *New England Journal of Medicine*, the *Lancet*, *CNN* and on *National Public Radio*; and
- **Terry Altilio, MSW, LCSW, ACSW**, a palliative social work consultant with over two decades of experience. Terry lectures in post masters social work programs at NYU, Smith and California State University San Marcos. She is a recipient of a Project on Death in America Career Achievement Award and a Social Work Leadership Award. She received a Mayday Pain and Society Fellowship Award and a Social Worker of the Year award from the Association of Oncology Social Work. She lectures nationally and internationally and is co-editor with Shirley Otis-Green of the *Oxford Textbook of Palliative Social Work* and most recently with Bridget Sumser and Meaghan Lyon Leimena of *Palliative Care – A Guide for Health Social Workers* published in January 2019.

In 2020, the Vermont Ethics Network, in partnership with the Task Force, will host a conference centering on the broad theme of informed consent. Planning for the event is in process.

Vermont Ethics Network (VEN): 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.) across the state. As part of this effort, VEN has been working with a subset of the Palliative Care Task Force to revise Vermont's DNR/COLST form and submit recommendations for improvements to the Vermont Department of Health. We anticipate proposed revisions will be finalized and implemented in 2020.

Throughout 2019, the organization provided over 50 educational workshops and trainings for both community and health care providers on topics related to advance care planning, medical decision-making and care at the end-of-life. Additionally, the organization responded to over 350 calls and emails from across the state, with 4,207 new registrants added to the Vermont Advance Directive Registry during this time.

VEN worked with Governor Scott's office on a Governor's Proclamation declaring April 14-19, 2019 Vermont Advance Directive Week. In honor of that declaration, and to celebrate National Healthcare Decisions Day (NHDD) on April 16, VEN coordinated a large scale advance care planning awareness effort in partnership with more than 30 healthcare organizations across the state. Together we offered the public a total of 19 advance directive awareness events in 10 Vermont counties from April 14–19. We served 559 people and distributed almost 1,300 advance care planning brochures and forms. We are planning a similar statewide effort for April of 2020.

Highlights from local and statewide initiatives are summarized below:

Bayada:

BAYADA Hospice continues to provide hospice care to all of Vermont with offices in Norwich, Colchester, Rutland and Brattleboro with an average daily census of over 400. In 2019, they created paid positions for massage and music therapy, and have expanded their volunteer offerings. BAYADA Hospice is dedicated to continue working with CMS innovation center to inform on future models of palliative care by continuing to engage in the Medicare Care Choices Model. In 2020, they are expanding their physician and nurse practitioner services to include community based palliative care.

Central Vermont Medical Center (CVMC) Collaborative Project:

During the 2018-2019 fiscal year, the Vermont Ethics Network received a generous grant from Massachusetts Health Decisions to support the *Taking Steps Vermont* advance care planning initiative in Central Vermont.

The areas of focus for this initiative included consumer education, serious illness communication education for providers, and system documentation trainings for healthcare staff.

The work for this project was accomplished in collaboration with The University of Vermont Medical Center, Central Vermont Medical Center, Central Vermont Home Health & Hospice, BAYADA Hospice, OneCare Vermont, Central Vermont Council on Aging, BlueCross BlueShield of Vermont, Quality Improvement Organizations, Centers for Medicare and Medicaid Services, and The New England Quality Innovation Network.

Consumer Education Accomplishments

- Interacted with 362 people through 12 consumer education events in two Central Vermont counties.
- 89% of self-evaluation respondents were motivated to complete an advance directive as a result of attending a presentation.

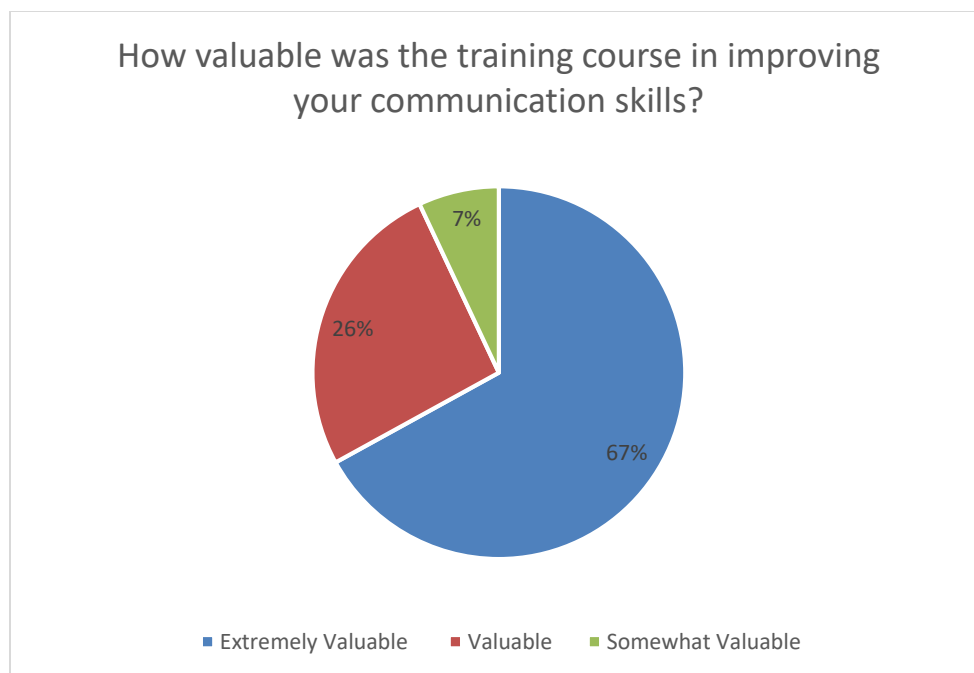
- 100% of respondents found the trainings to be useful.
- Over 1,050 advance care planning forms and related informational pieces were distributed.

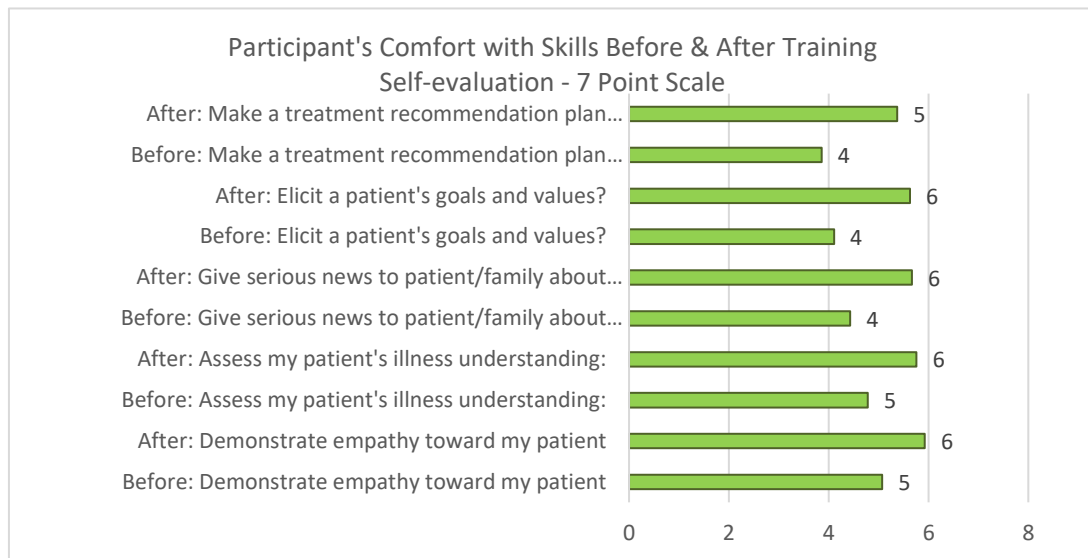
System Documentation Accomplishments

- 3 advance care planning presentations were delivered to facility staff at Central Vermont Medical Center, a nursing home/residential care facility, and Central Vermont Home Health & Hospice, reaching a total of 43 professionals.
- Hospice utilization rates during the grant period increased by 26% (average length of stay on hospice) and 38% (average daily census) respectively.

Provider Education Accomplishments

- 2 serious illness communication trainings were held using the *TalkVermont* program curriculum for a total of 28 providers.
- Serious illness communication focused CME held at Central Vermont Medical Center with 40 staff participants.
- A comprehensive survey was distributed at the close of each training. Highlights from the survey results included the following:





Department of Vermont Health Access (DVHA):

Advance Care Planning codes were approved, effective 8/15/19. The codes and rates are listed below. Provider types allowed are: physician, nurse practitioner, and physician assistant.

- 99497 - Advance care planning, including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate rate: \$70.46
 - 99498 - each additional 30 minutes rate: \$61.88 (maximum units 2 per billing date)
- 99441 - Telephone Evaluation and Management service by a physician or other qualified health care professional who may report evaluation and management services provided to an established patient, parent, or guardian not originating from a related E/M service provided within the previous 7 days nor leading to an E/M service or procedure within the next 24 hours or soonest available appointment; 5-10 minutes of medical discussion rate: \$11.52
 - 99442 - 11-20 minutes rate: \$22.32
 - 99443 - 21-30 minutes rate: \$32.94

On December 13, 2019, a presentation from Cindy Bruzzese (Vermont Ethics Network) and Dr. Stephen Berns (UVMMC Palliative Care) was provided to the Vermont Chronic Care Initiative, Clinical Operations Unit, and Pharmacy clinical staff. 29 members were present.

Mt. Ascutney Hospital and Health Center (MAHHC):

Mt. Ascutney Hospital and Health Center has established systematic processes to promote advance directives for individuals in the community at large. This work

encompasses both inpatient and outpatient settings. MAHHC staff have trained and supported community volunteers to establish two advance directive clinics, one in Windsor and one in Woodstock. These clinics make it possible for community members to register and attend multiple sessions for education and assistance in completing their advance directive. The volunteers also make copies and mail the completed forms to multiple sites including the Registry, PCP, Hospitals and Agents.

MAHHC staff are available to community groups, churches and agencies who wish to learn more about advance directives.

MAHHC has supported National Healthcare Decisions Day with a lobby table to promote the conversation.

The hospital ethics committee continues to be active and is a community resource.

Mt. Ascutney Hospital and Health Center has worked with Complementary/Alternative Medicine partners in a formal way since the mid 1990's and formed an active Multidisciplinary Functional Recovery Team, which has been active since 2016. This team is comprised of the following disciplines:

- Patient Centered Medical Home, Medical Director
- Psychiatry
- Pain Management
- Pain/Addiction Medicine
- Case Management/Spoke Staff
- Massage Therapy
- Addiction Counseling
- Therapeutic Rec. for Mindfulness training, Tai Chi and Assess Quality Of Life
- Self-Management Programs in well-being/WRAP, chronic pain, tobacco cessation, etc.
- Acupuncture
- Physical Therapy
- Aquatic Therapy
- Medical Staff
- Occupational Therapy
- Psychiatry
- Behavioral Health including CBT/DBT
- Community Health

Goals of care include:

- A. Newly Identified Patients
 - Prevent and improve loss of function.
 - Prevent and address depression and other psychosocial impacts of chronic pain.
 - Prevent reliance on large doses of opioids.

- B. Long-Term Chronic Pain Patients Dependent on Opioid Therapy
- Decrease the dosage of opioid medications taken each day.
 - Increase patient function.
 - Increase patient satisfaction and quality of life.

Individual providers are encouraged to bring challenging patients to this team that meets on a monthly basis.

Pediatric Palliative Care Program, Vermont Department of Health:

Currently, there are 60 children enrolled in the program and services are offered statewide through 9 designated home health agencies (HHAs).

Successes

Throughout the year, relationship building with providers/HHAs has been a primary focus (establishing strong interdisciplinary teams, observing/facilitating regular interdisciplinary team meetings, reviewing program operations and expectations, providing on-site 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 UVMHC/DHMC and many other providers, etc.).

To help standardize program processes and increase mastery of providers, an agency toolkit has been created to assist with the intake and needs assessment, plans of care, care conferences, and interdisciplinary team meetings. The Pediatric Palliative Care Program Family Satisfaction Survey was revised and mailed to families. Except for skilled in-home respite, the annual limits on all Pediatric Palliative Care Program services were lifted in September of 2019 and no longer require a prior approval.

Challenges

Despite extensive outreach, challenges continue with more rural regions and the availability of expressive therapy services. Additionally, the PPCP continues to research best-practice and evidence-based palliative services as they are delivered in other states. In order to provide equal and adequate services to all enrolled families, the program is seeking to expand the range of covered services.

The Pediatric Palliative Care Program is exploring alternative payment models and continues to problem-solve reimbursement challenges.

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 such a limited population of pediatric palliative care families, mastering and maintaining PPCP provider expertise is a challenge.

Plans for 2020/Current Projects

Continue to standardize processes/procedures for the PPCP specifically targeting orientation for new providers, an admission packet for families, and the bereavement process following the death of a child.

Continue to explore best practices to optimize billing/coding, problem-solve/track reimbursement challenges, and research alternative palliative care payment models.

Finalize proposal for the Global Commitment 1115 Waiver expansion of services for the Pediatric Palliative Care Program.

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.

Rutland Regional Medical Center (RRMC):

Now entering its 15th year, the Palliative Care Program at RRMC uses a nurse-led model to provide in-patient palliative care consultations with on-site support seven days a week. The current team consists of three full-time registered nurses with specialist certification in hospice and palliative care.

The Palliative Care Program has become well integrated with the usual hospital services. According to the most recent National Palliative Care Registry report, the program has one of the highest penetration rates with over 1,000 referrals per year and consultations on 15.8% of all hospital admissions. The team is included as a component of basic hospital orientation for new graduate and newly hired nursing staff and provided education to hospital staff and community on end-of-life care, pain management, caregiving support, and advance directives.

As part of the Rutland Community Collaborative's efforts to improve care and services in Rutland County, the Palliative Care Program partners with the Visiting Nurse Association and Hospice of the Southwest Region (VNAHSR) and Bayada Hospice on RCC's Hospice and Palliative Care Sub-Committee. This committee seeks to promote awareness and understanding of hospice and palliative care among both healthcare professionals and lay people in the community by offering community education events, clinical case reviews, and developing strategies to improve rates of advance directive completion and access to hospice services.

Southwestern Vermont Medical Center:

Southwestern Vermont Medical Center has maintained a palliative care program since January 2015, providing physician consultation and nursing case management in the inpatient, outpatient, SNF, and home care settings. In 2019, they expanded into regular participation with inpatient interdisciplinary rounds in the hospital. In the outpatient setting, they are participating as a test site for the RAND Health three year pilot to develop CMS quality measures in outpatient palliative care. Palliative care services are fully integrated into the SVMC Cancer Center, and they are serving a growing number of patients each year.

UVM Division of Palliative Medicine

Porter Medical Center Site

Porter's Palliative Care program began in February of 2016 consisting of 40% palliative care physician time through FY19. Consultations are done on the main floor of UVMHN Porter Medical Center and at UVMHN Helen Porter Rehabilitation and Nursing in both the post-acute and long-term care units.

The Palliative Care service has been well received and consistently busy with near doubling of target consult volumes for each year. In FY 2019 (10/1/18 to 9/30/19), 201 consults were done; 149 at Porter Medical Center and 51 at Helen Porter. In addition to direct service, the palliative care program runs educational programs, including:

- *Palliative Care Rounds* open to all Porter Medical Center staff
- *Living with Dying Partnership of Addison County* “to create a framework for end-of-life care organizations to collaborate on our common goal of providing education about dying, death and options for care”. The partnership meets monthly to coordinate efforts and also publishes a monthly column in the local Addison Independent in order to foster community education and awareness. The group has sponsored several community events related to Advance Care Planning and End of Life Care, including sponsoring a table for National Healthcare Decisions Day and sponsoring a local stop on Kimberly Paul's “Bridging the Gap” nationwide tour this past summer.
- *End of Life Services* in Middlebury is collaborating with Porter Palliative Care to create a Volunteer Program to companion those with a life threatening or life limiting diagnosis. These volunteers have a minimum of a 30-hour certified hospice training, but often additional experience such as ministerial/counseling or certification as an EOL Doula, Massage, Reiki, or Music Therapist. These volunteers will work in teams in the ARCH end-of-life suites, one-on-one with referred patients and as vigil sitters for those who are actively dying.

Given the demand and success, UVMHN Porter Medical Center leadership committed to growth of the service. In December of 2019, Porter hired an experienced Palliative Care Social Worker to join the team full time. They also approved an additional 40% physician time FTE of MD time; recruitment is underway with hopes of filling the position in 2020.

University of Vermont Medical Center Burlington Site

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, and research/innovation. The UVMHC-based team includes 6 physicians and 3 nurse practitioners with a closely affiliated chaplain, social worker, psychiatry and pharmacy team members.

During this past year, the UVMMC team was consulted more than 1,400 times to care for seriously ill hospitalized adults and children. They have been offering TeleConsult follow-up home visits, outpatient consultations at Milton Family Practice, and outpatient consultations for ALS patients at Fanny Allen. Substantial expansion of all services is planned for 2020, including establishing a new Palliative Care Unit at UVMMC and more Telehealth and Outpatient availability.

Their 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. They are preparing to launch an ACGME-accredited fellowship beginning July 2021. In the fall of 2017, the Division established the Vermont Conversation Research Lab to understand and promote high quality communication in serious illness.

Highlights of additional projects of the UVM Palliative Care Service include:

- *TalkVermont*: *TalkVermont* is a multi-component intervention to improve serious illness conversations between clinicians and patients. The UVMHN team has collaborated with *VitalTalk* to create evidence-based communication skills training programs that are engaging, interprofessional, and focused on patient values. *VitalTalk*'s methods have demonstrated success in not only improving clinician communication skills but also improving clinician resilience while simultaneously improving patient trust and connection with their clinicians. They 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. The Ariadne Labs six-part program focuses on system-level support for clinicians and has demonstrated improvement in quality and frequency of the serious illness conversations with patients.

Since 2017, the UVM team has implemented the “Mastering Late Goals of Care Conversations” course, a full-day communication skills workshop for serious illness conversations. They have already trained over 500 clinicians (physicians, nurse practitioners, nurses, social workers, and chaplains) and trainees (nursing students, medical students, and medical residents). Moreover, these courses have brought together palliative care colleagues from across the state to co-teach these important skills and create culture change at their various institutions and beyond.

In 2019, the *TalkVermont* team introduced three new courses focused on Pediatrics, Early Goals of Care and Longitudinal Conversation Skills Coaching. Over the next 2 years, they plan to reach more than 800 clinicians throughout Vermont and the Adirondack region of New York. Additionally, they plan to use the Serious Illness Care Program implementation strategies to apply early goals of care initiatives within 5 local practices by “re-engineering” the clinical environment to promote the frequency and quality of serious illness conversations in the outpatient setting.

- AI Silence Project: Systematically measuring indicators of communication quality is essential to transform how we value and incentivize clinical care. This project is using state of the art machine learning (i.e. artificial intelligence) and existing audio data from a large palliative care research study funded by the American Cancer Society to identify one clinically important indicator of human connection in serious illness conversations: compassionate silence.
- TelePresence Projects: TeleHealth (e.g. visits with a clinician by video) can increase the reach of specialty services in rural areas. Fostering a sense of "presence" is crucial for palliative care conversations but underdeveloped in healthcare telehealth technology. This project collaborates with gaming technology experts to develop the capacity for cultivating presence when serious illness conversations happen virtually. UVM has received grants to help support the expansion of Telehealth in the home and rural dialysis settings.

UVM Medical Center Adult Primary Care:

During calendar year 2019, UVM Medical Center Adult Primary Care practices reported the following increases in the percentage of patients with advance directives on file:

- General Internal Medicine: 42.8% (Dec 2018) → 50.1% (Dec 2019)
- Family Medicine: 34.3% (Dec 2018) → 41.7% (Dec 2019)

To be included in these totals, patients must be 18 years of age or older, living at the time of the report, have a Primary Care Physician in one of the departments listed above, and had an appointment in that department in the last 3 years.

For General Internal Medicine, this includes the Primary Care Practices of Burlington Adult Primary Care, Essex Adult Primary Care, South Burlington Adult Primary Care, and Williston Adult Primary Care.

For Family Medicine, this includes the Primary Care Practices of Berlin Family Medicine, Colchester Family Medicine, Hinesburg Family Medicine, Milton Family Medicine, and South Burlington Family Medicine.

Vermont Medical Society (VMS):

Palliative Care

In November of 2019, the VMS hosted a CME accredited webinar on the *Implementation of Act 39 and How to Respond to Patient Requests for Hastened Death*. This session was presented by Dr. Allen Hutcheson, M.D., a family physician from Southwestern Vermont Family Medicine and provided a comprehensive background on physician-assisted-death (PAD) and an in-depth report on how Act 39 has been implemented specifically in the State of Vermont. Dr. Hutcheson also shared specific guidelines on how to respond to patient requests for aid-in-dying aimed at fully supporting patient's needs, while ensuring that all alternatives have been considered.

Pain Management

The VMS also closely monitors the implementation of the state opioid prescribing rules to ensure that Vermont patients living with chronic conditions or needing end-of-life care have access to adequate pain management. VMS continues to provide feedback to the Department of Health on any proposed updates to the prescribing rules. The VMS supports alternative pain management options and in December of 2019 hosted a webinar, *An Integrative Approach to Treating Chronic Pain*, with presenter Dr. Jon Porter, M.D., from the University of Vermont Medical Center Comprehensive Pain Program. Dr. Porter's session focused on reframing our approach to addressing chronic pain over the last three decades in the context of patient outcomes and clinician wellbeing. In this webinar he also described the advantages of integrative, team-based, patient-centered approaches to chronic pain.

Who's Your Person... What's Your Plan? :

Between January and November 2019, this collective impact initiative of ten organizations (Age Well, BAYADA, Cathedral Square, Community Health Centers of Burlington, Howard Center, OneCare Vermont, Support and Services at Home (SASH), The University of Vermont Medical Center, The University of Vermont Health Network Home Health & Hospice, Vermont Ethics Network) working in Chittenden and Grand Isle Counties continued their grassroots-level work begun in previous years, ramped up their marketing efforts, and worked more closely with facilities and providers, including but not limited to the following accomplishments:

- Conducted 22 ACP presentations in various venues throughout the community.
- Conducted 5 trainings for health care providers/facility settings.
- Trained 24 new facilitators to conduct advance care planning presentations, increasing their facilitator network to 38 individuals.
- Developed a one-on-one advance care planning support guide training curriculum and trained 17 new guides.
- Tabled at wellness fairs, conferences, a farmer's market, and more to spread public awareness.
- Reached thousands through advertising campaigns with Green Mountain Transit, Vermont Lake Monsters, VPR, VTDigger, and more.
- Began a pilot program of providing a one-on-one support guide to Evergreen Family Health in Williston to regularly meet with patients and support them with completion of advance directives.
- Hosted a sold out public event at UVM Medical Center during National Healthcare Decisions Week with 98 attendees and 352 advance directive brochures and forms distributed. Based on evaluation results, 93% of attendees who had not already completed an advance directive were motivated to do so after this event.

They also reported the following outcomes:

- The percentage of distinct patients admitted to UVM Medical Center who indicated that they have an advance directive increased by roughly 1.5% over the

past fiscal year (791 more people) and has nearly doubled since the concept for this initiative was originally proposed, rising from 7.88% in FY15 to 14.8% of patients in FY19 (as of 8/20/19). This equates to 14,711 more people over 4 years.

- 2018-19 data from the Vermont Advance Directive Registry reflects an increase of 216 (14%) more advance directives in the Registry from Chittenden and Grand Isle Counties over roughly the same period the previous year (as of 8/31/19).
- Evaluations from their community advance care planning presentations indicate that 28% of attendees had no knowledge of advance care planning prior to attending a training and 81% were motivated to complete an advance directive afterward. Of those presentations delivered at businesses, their evaluations reflect that 96% were glad to have been offered this presentation by their employer (as of Sep 2019).

V. CONCLUSION

As Vermont continues to implement a new model of health care delivery, best practice standards in medical decision-making, advance care planning and palliative care must be embedded into the system of care for all patients at all levels of care. Sudden illness or accident does not discriminate based on age or baseline health, and we have learned that waiting to initiate conversations about treatment goals and health care priorities until a health crisis happens is too late in the care planning process. Failure to address these needs has consequences that go beyond the patient—affecting family members, caregivers and population health overall. These conversations must begin earlier and be revisited as patients age, new diagnoses occur and/or health declines. Policy initiatives that promote and support advance care planning, that focus on improving provider communication skill and comfort, and enhance both documentation and sharing of information across care settings are necessary to ensure that the care and treatment patients desire aligns with the care and treatment patients receive.

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

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ⁱⁱ Teno JM, Price RA, Makaroun LK. *Challenges of Measuring Quality Of Community-Based Programs For Seriously Ill Individuals And Their Families*. Health Affairs 26, No. 7 (2017).