



ANNUAL REPORT

PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE

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Submitted by:

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members of the Palliative Care and Pain Management Task Force

I. PURPOSE

This annual report is submitted per requirement of Act 25, Section 18 to the house committee on human services and the senate health committee regarding recommendations, progress and activities related to the work of the palliative care and pain management task force.

II. RECOMMENDATIONS

1. **Legislative action to address surrogate consent for DNR/COLST orders (Title 18, Chapter 231).** It is the consensus of the Task Force that establishing new authorities for surrogates to consent for DNR/COLST orders would be best accomplished through statute rather than through any future rulemaking process. Statutory changes would also include granting surrogates access to health information and immunity when providing informed consent for a DNR/COLST order.
2. **Legislative action to allow surrogates to consent for admission to palliative care and hospice.** The current lack of a comprehensive surrogacy statute in Vermont has made it somewhat unclear as to who can consent for health care services when a patient lacks capacity, has not previously appointed a health care agent and/or has no appointed guardian. The ability of a surrogate to consent for admission to hospice for a dying loved one has thus been called into question. This presents a potential barrier to accessing quality hospice and end-of-life care services. It is the recommendation of the Task Force to amend the current advance directive statute to allow surrogates to give consent for admission to palliative care and hospice services.
3. **Funding support for dual eligible expanded hospice benefit:** Per previous legislative action, the Department of Vermont Health Access has pursued permission to expand the hospice benefit for dual eligible individuals through the Global Commitment Waiver. Although they now have permission, funding is a more complex issue. DVHA is currently doing an analysis and trying to determine the budgetary impact of providing an enhanced hospice benefit. Any budgetary proposal to implement the enhanced benefit will require legislative approval. The Task Force is recommending that the legislature approve a budget proposal for this enhanced hospice benefit.
4. **Inclusion of coverage for expanded access to palliative and hospice services for state regulated insurance policies.** The Vermont legislature has taken proactive steps to ensure that children with life limiting illness have access to enhanced comprehensive palliative care services, and dually eligible enrollees have access to expanded hospice services. In October of 2013, the Vermont Department of Financial Regulation released a bulletin stating that the purpose of Act 39 is to provide patients with choice at the end of life and services contemplated by Act 39 shall not be excluded from insurance coverage. The Task Force is further recommending the legislature ensure that state regulated insurance plans will provide palliative care and expanded hospice services to all individuals with serious illness that

would not otherwise qualify for hospice or home care services due to homebound status, clinical criteria, or their prognosis.

III. HIGHLIGHTS FROM 2013

- A. Spring 2013 Palliative Care Conference:** On April 3, 2013 the Vermont Ethics Network in partnership with the Palliative Care and Pain Management Task Force hosted its fourth statewide palliative care and pain management conference, *A Bridge to Healing: Insights into the Management of Pain and Suffering*, at the DoubleTree Hotel in South Burlington.

This was the largest event with over 175 health care professionals in attendance. Keynote presentations were provided by national speakers Janet Abraham, MD and Eric Cassell, MD. In addition, presentations from local experts included topics on symptom management, integrative chronic pain management, palliative sedation and the use of opioids in patients with non-terminal chronic pain.

B. Vermont Ethics Network (VEN) Initiatives:

Medical Decision-Making Outreach - In addition to VEN's work with the Palliative Care and Pain Management Task Force, VEN conducted numerous workshops and trainings for both professionals and the community on medical decision-making, advance directives and DNR/COLST orders in 2013.

Act 39: Patient Choice and Control at the End-of-Life – With the passage of Act 39 and absent an implementation organization to respond to questions and provide education and training, VEN took on the responsibility for this work. Numerous trainings for health care providers and the public were conducted in 2013. Comprehensive information about the new law was developed and made accessible on the VEN website. In October, VEN hosted a day-long conference for health care professionals, administrators, and policy makers on the topic of aid in dying and end-of-life. Over 150 people attended this educational event.

Ethics Committees - The role of ethics committees and expanding access to ethics expertise and resources has been a focus of VEN's work for the past several years. In the spring of 2012 VEN conducted a short survey to assess the needs of non-hospital health care facilities regarding access to ethics resources and expertise. The results indicated that there was tremendous interest in providing training in ethics and helping communities establish multi-facility ethics committees. In April of 2013, VEN piloted a multi-facility ethics committee training in Southern Vermont which consisted of participants from the area hospital, home health agency, skilled nursing facilities, etc. This training is now being made available to other communities across the state interested in developing multi-facility ethics committees.

Across the Fence Educational Series: In an effort to provide information to the public on issues related to palliative and end-of-life care, VEN taped two presentations on Act 39 that ran back to back in the fall. The first focused on the elements of the new law and the second segment dealt with how to have conversations with patients about end-of-life and respond to questions surrounding

aid in dying. In April of 2014, a third session will be taped on Advance Care Planning to coincide with National Health Care Decisions Day.

C. Fletcher Allen Health Care Approves Adding a Supportive Care Benefit

VNA and Vermont Managed Care collaborated on a newly defined palliative care benefit that will be offered to insured FAHC employees and their families under the age of 65. The purpose of the new benefit will be to provide palliative care services to individuals with serious illness that would not otherwise qualify for hospice or home care services due to homebound status, clinical criteria, or their prognosis. The primary goals will be to improve patient satisfaction, quality of care, and support earlier enrollment in hospice. This benefit will be administered by BCBS of Vermont which will include case management responsibilities and monitoring of outcomes and utilization. The benefit will be provided through VAHHA agencies beginning in January 2014.

D. Pediatric Palliative Care Program (PPCP): See Attachment A

E. Fletcher Allen Health Care Rural Palliative Care Network (RPCN): Activities of the FAHC RPCN include education, mentorship and 24/7 phone consultation support to regional providers of palliative care services. The main activity of the network is a weekly palliative care interdisciplinary telemedicine conference attended by providers on site or remotely through teleconferencing. In 2013 a total of 35 teleconferences were held, 12 rural sites participated with an average attendance of 18 per session. A year-end survey found that for the majority of participants, palliative care practice is a small part of their overall work, with 58% reporting that PC made up 0-24% of their practice. 75% reported feeling less isolated in PC practice and 74% reported they were likely to change their practice as a result of teleconferences.

The FAHC RPCN is furthering efforts now to build specialty level palliative care skills of primary care and specialty care providers. A demonstration project is underway to support regional advanced practice nurse practitioners (APRNs) in becoming certified in Hospice and Palliative Care. Interested APRNs have been recruited and a weekly didactic web-based lecture series is being delivered, along with use of philanthropic funds to pay for certification costs. Certification requires 500 mentored hours in palliative care and passing a certification exam.

F. Fletcher Allen Health Care Palliative Care Service: FAHC, in collaboration with UVM College of Nursing and Health Sciences and VNA Hospice of the Champlain Valley, has developed an APRN Hospice and Palliative Care Fellowship. This is a one year mentored clinical and academic fellowship which will start in March 2014. The aim is to address the palliative care workforce shortage in the region through education and training of independent practitioners who can work in varied health care settings. Candidates with goals of practicing in Vermont are prioritized. Funding for the fellowship was made possible through the efforts of the UVM College of Medicine Dean's Palliative Care Collaborative.

FAHC Palliative care service is well integrated into the FAHC hospital clinical and educational efforts. Further expansion into providing outpatient palliative care in

the Vermont Cancer Center (VCC) has been successful. Dr. McVeigh in collaboration with Janet Ely, APRN have developed a palliative care clinic and have secured philanthropic funds (Buffam Foundation) to hire a palliative care social worker in the VCC. Outcomes from their demonstration project have shown success, with more patients seen by palliative care (PC) receiving hospice care before death (PC % pt received Hospice care = 82%, regional have 46.8%, national 61.3%), longer median length of stay on Hospice (PC 12 days, regional 6.7 days, national 9 days) and lower percentage of patients dying in the hospital (PC 16%, regional 29.8%, national 24.7%)¹.

¹ Quality of End-of-Life Cancer Care for Medicare Beneficiaries. Regional and Hospital-Specific Analyses. Report of the Dartmouth Atlas Project, 2010.

G. Other Educational Initiatives: The Visiting Nurse Association of Chittenden and Grand Isle Counties' Madison-Deane Initiative (MDI) continues to offer educational opportunities to the Burlington community on palliative care. MDI supports UVM first-year medical student leaders in planning and carrying out an annual palliative care week—a week-long series of optional one hour lunchtime presentations focused on providing first-year medical students knowledge of palliative and hospice care.

The 2013 program consisted of local experts including: a four member, multi-specialty physician panel (moderated by Ursula McVeigh, MD), Zail Berry, MD, MPH, Allan Ramsay, MD, and Ginny Fry, MA. The guest speaker was Dr. Timothy Quill, Professor of Medicine, Psychiatry, and Medical Humanities at the University of Rochester School of Medicine and Dentistry and Director of the Center for Ethics, Humanities and Palliative Care. Topics addressed during the week included: integrating palliative care practice into multiple specialties, the perspectives of patients and families, health care reform, helping children understand issues of life and death, and patient pain.

H. Start the Conversation Campaign: The Vermont Assembly of Home Health Agencies (VAHHA) in partnership with the Vermont Ethics Network initiated a campaign in 2012 to increase awareness of hospice services and end-of-life care options through a consumer-targeted initiative. This work is ongoing and will continue into 2014.

IV. ACTIVITIES PLANNED FOR 2014

A. Palliative Care Week at Fletcher Allen Health Care: In January of 2014, the Madison Deane Initiative will support palliative care week at FAHC. There will be two local speakers, two physician panels and one guest speaker. Local expert Ginny Fry will return to present on how to help children understand issues with life and death. Dr. Robert Macauley, pediatric palliative care physician and Director of Clinical Ethics at FAHC, will present on the impact of death on parents and families. Ursula McVeigh, MD, Director of the Palliative Care Service at FAHC

will moderate a multi-specialty physician panel that addresses how different specialties integrate palliative care into their practice. Dr. Jaina Clough, Hospice Medical Director of the VNA and Primary Care Internal Medicine at FAHC, will moderate an interdisciplinary team panel titled, "Hospice: An interdisciplinary approach to end-of-life care." The guest speaker will be journalist, author and advocate, Stephen Kiernan.

- B. Spring Pain Management and Palliative Care Conference:** The Palliative Care and Pain Management Task Force has scheduled a spring conference on April 9, 2014 at the Hilton Hotel and Conference Center in Burlington. The conference, *When Cure is No Longer Possible: Prognosis, Hope and Professional Responsibility* will center around topics of hope, truth-telling and prognostic disclosure.

The event will feature national experts:

- **David E. Weissman, MD, FACP:** Professor Emeritus and founder of the Medical College of Wisconsin Palliative Care Center. He is board certified in Medical Oncology, Hospice and Palliative Medicine. In 1991 he began one of the first academic palliative care programs in the United States. In 2003, the Medical College of Wisconsin's Palliative Care Program was designated as one of six United States Palliative Care Leadership Centers by the Center to Advance Palliative Care (CAPC). Dr. Weissman is Director of the End-of-Life Palliative Education Resource Center (EPERC), and he was the founding editor of the Journal of Palliative Medicine. Currently he directs the Medical School Palliative Care Education Project, serves as a consultant to CAPC and runs a consulting practice, Palliative Care Education, LLC.
- **Chris Feudtner, MD, PhD, MPH:** Assistant professor of pediatrics at the University of Pennsylvania School of Medicine and attending physician, director of research for the Pediatric Advanced Care Team and the Integrated Care Service, and co-scientific director of PolicyLab at The Children's Hospital of Philadelphia. In these roles, Dr. Feudtner both provides care to children with complex chronic conditions and investigates ways to improve the quality of life for these children and their families. In 2008, he assumed the responsibilities of director of the new Department of Medical Ethics at Children's Hospital and holds the Steven D. Handler Endowed Chair of Medical Ethics.

- C. Survey to Identify Palliative Care Providers and Programs Across the State:** The Task Force will be conducting a survey this year to collect information from across the state on the number of palliative care providers and programs that are delivering services to Vermonters. The goal is to establish a baseline and a mechanism for collecting quantitative and qualitative data from across the state on an ongoing basis.

- D. Ongoing Medical-Decision Making, Ethics and End-of-Life Education:** The need for ongoing training about medical decision-making, health care ethics and end-of-life options is critical as our population ages and as our health care resources

become more constrained. Continued efforts to support proactive advance care planning, completion of advance directives, appropriate utilization of DNR/COLST orders, expanded access to ethics expertise and consultative services, increased awareness of hospice and palliative care, and understanding of options available at the end of life will be the focus of professional and community education initiatives throughout the year. More active participation and commitment from state agencies directed at this work is both desired and necessary.

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

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Attachment A



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Agency of Human Services

THE MEDICAID PEDIATRIC PALLIATIVE CARE PROGRAM *Supportive Care for Children Living with Serious Illness*

Program Update December 2013

Background: The Medicaid Pediatric Palliative Care Program (PPCP) provides supportive services for Vermont children living with life limiting or life threatening illness. The PPCP is an Agency of Human Services (AHS) partnership between the Vermont Chronic Care Initiative (VCCI) within state Medicaid and Integrated Family Services (IFS). The PPCP was made possible through an amendment to Vermont's 1115 Demonstration Waiver as approved in December 2011 and informed by a palliative care advisory committee which included consumers, providers, legislators, and AHS partners.

Services: The PPCP offers five supportive services to children who are Vermont Medicaid beneficiaries living with a serious life limiting/life-threatening condition (LL/LTC) and are not likely to live into adulthood (age 21), which include:

1. **Care Coordination** – Development, oversight and implementation of a family-centered care plan that includes telephonic and home visits; and ongoing provider communication.
2. **Family Training** – Training by a nurse to teach family members and caregivers palliative care principals, medical treatment regimen, medical equipment use and how to provide in-home care.
3. **Expressive Therapies** – Therapies provided by certified provider to support the child and family creatively and kinesthetically express their experience and cope with their illness.
4. **Skilled Respite** – Short term relief for caregiver relatives from the demanding responsibilities of caring for a sick child; provided by a skilled nurse, based on medical necessity.
5. **Family Grief Counseling/Bereavement Counseling** – Anticipatory counseling for the child's family by a trained professional intended to address grief and coping both during the child's life and for up to 6 months in the event that the child passes away.

Update: Over the course of the last year, the PPCP has continued to expand and will be available statewide in January 2014 when Orleans and Essex counties begin accepting referrals. Expansion required training of home health and hospice agency staff, networking with local providers, and continued marketing and outreach efforts. Improvements to materials, manuals, and processes have also been ongoing, with input from the PPCP Advisory Committee.

As of December 2013, DVHA had received 40 referrals and the PPCP had provided services to 36 children and families throughout the state. Children enrolled in the program have ranged from 1 week to 19 years of age with a variety of diagnoses such as muscular dystrophy, spinal muscular atrophy, congenital anomalies, and cancer. No two family's needs are alike, and continued collaboration with internal and external state partners such as the Vermont Department of Health's (VDH) Children with Special Health Needs (CSHN), the Department of Children and Families (DCF) Children's Integrated Services (CIS), the Vermont Children's Hospital Pediatric Advanced Care Team (PACT), Vermont Family Network (VFN), and Blueprint for Health community health teams has been essential. Additionally, the DVHA PPCP nurse case manager is now co-located two days per week within the VDH/CSHN unit to increase continuity of care and foster relationships with other state pediatric programs, the result of which has been more efficient communication and improved overall family-centered care.

Challenges: Ongoing challenges include building capacity to deliver the services within the home health and hospice agencies. Not specific to the PPCP, there is a statewide shortage of nurses to provide home health services. This is further exacerbated when requiring agency staff to have pediatric and palliative care experience. In September 2012, DVHA collaborated with VAHHA to organize a statewide pediatric-specific End-of-Life Nursing Education Consortium (ELNEC) training which drew almost 80 attendees, most of which were agency staff. Prior to this, the only other comparable educational program offered in Vermont was a Summit organized by Dr. Robert Macauley in 2008. The nursing shortage has also presented itself as a barrier to delivering any in-home skilled respite care to children who are medically eligible. The DVHA nurse case manager hosts regularly scheduled conference calls with agency leads to discuss ongoing challenges and provide support in adoption and implementation of the program. Additionally, these calls provide opportunities for agency-to-agency sharing of resources, information, and contacts. To address the lack of skilled respite providers, the PPCP works closely with CSHN to connect families with self-directed respite funding so that families are aware of existing state programs to support this need. Capacity to deliver the expressive therapy benefit has also required extensive outreach and networking in order to identify credentialed individuals to provide these services as contracted through the home health and hospice agencies. Currently, five agencies have contracted with providers (nine in total), and five agencies are still in the process of finding and contracting an expressive therapist. This will be on going as the program grows and efforts to identify appropriate providers will endure until all agencies are fully staffed.

Outcome Measures/Evaluation: While focus has largely been around building, training, and implementation, a priority moving forward will include evaluation of key outcome indicators specific to pediatric palliative care. The program will collaborate closely with national organizations and experts in the field to ensure indicators and measures are congruent with best practice. In addition to family satisfaction data, commonly measured outcomes include pain and symptom management, caregiver strain, timely referral to hospice, and preventable utilization of the ER.

While there are many facets of this work that will require ongoing adjustments as previously discussed, additional goals for this upcoming year include:

- Family Satisfaction Surveys – Tremendous thought is being given in developing surveys with input from the VDH Health Surveillance team to measure ongoing satisfaction of enrolled

families as well as bereaved families; family satisfaction being one of the most critical metrics in pediatric palliative care.

- Home Health and Hospice Agency Education – Efforts will be made assess the educational needs of agency staff, recognizing that by providing continued, robust, educational opportunities, the quality of the delivery will improve. These educational efforts will also positively impact the need for increased capacity, expertise, and knowledge as the number of enrolled children and families is likely to increase.
- Outreach – With the program better established in many regions, efforts to identify eligible families who would benefit from the program will continue.
- Quality Improvement – In addition to regular communication already in place with each agency, the DVHA nurse case manager will visit each agency approximately one year from program implementation, to meet with staff, review charts, and obtain feedback on ongoing operations for future improvements.