

Interim Report House Human Services Committee April 9, 2010

Work Related to ACT 25 and the Palliative Care and Pain Management Task Force

Submitted by:

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I. PURPOSE

This interim report is submitted per request of the House Human Services Committee following the March 22, 2010 Statewide Summit on Palliative Care and Pain Management. It describes preliminary findings and recommendations based on information presented and discussed at the Statewide Summit. It also provides a brief summary of the Summit and efforts currently underway that seek to address barriers and gaps in services.

II. PRELIMINARY RECOMMENDATIONS

From a systems standpoint, members of the Palliative Care and Pain Management Task Force recommend the following:

- 1. Legislative action to proceed with a pediatric waiver to allow for concurrent curative and palliative services for pediatric patients. As discussed in OVHA's Report to the Legislature (November 2009), several states are already moving forward with addressing the need for concurrent services via a variety of mechanisms (waiver, direct funding). We strongly recommend that Vermont move forward with meeting its moral obligation to address this issue and take the necessary steps to ensure that children with life-limiting illness (and their families) receive the best care possible to enhance quality of life for both the ill child and their family.
- 2. Legislative action to proceed with expanding simultaneous eligibility for Choices for Care and Hospice Services. As discussed in DAIL's report to the Legislature (January 2010), the issue of simultaneous eligibility is one that has been periodically reviewed. In July of 2005, DAIL revised it policy to allow participants who are already enrolled in Choices for Care, and have a terminal diagnosis, to simultaneously enroll in hospice. However, this current policy is "one-way". That is, people already served by Choices for Care could add hospice, but people already served on hospice could not add Choices for Care. It is our recommendation that this "one-way" policy be amended to function "two-ways", thus ensuring that Vermonters with terminal illness can receive the care that they need while spending their final days at home, regardless of which program was accessed first.
- 3. Legislative action to prioritize within the State's Blueprint for Health, palliative care, advance care planning and pain management so that these areas can be more actively addressed and data collected and analyzed to inform future quality improvement efforts.

III. BRIEF SUMMARY OF THE SUMMIT

On March 22, 2010 the Vermont Ethics Network hosted, *Paving the Way to Real Progress:* A Statewide Summit on Palliative Care and Pain Management. The event drew over 100 professionals, community members and other stakeholders from across the state. It provided a unique opportunity for representatives and providers from Vermont's hospitals, nursing homes, home health and hospice programs to work with policy-

makers, community members, and representatives from state and health related agencies on myriad issues related to palliative care and pain management.

Keynote Address

Robert Macauley, MD, Director of Clinical Ethics and Pediatric Palliative Care at Fletcher Allen Health Care provided the keynote address. He presented a comprehensive overview of the current structure of palliative care and hospice services across Vermont. He provided a basic overview of what palliative care and hospice services provide, discussed trends over time and the evolution of services in Vermont. He reviewed data collected from both the Board of Medical Practice (VBMP) survey and the Vermont Ethics Network (VEN) survey, addressed continuing medical education and pain management, and identified critical issues, including:

- We have a Patient Bill of Rights for Palliative Care and Pain Management but most physicians don't know about it.
- Vermont is doing well with patients NOT dying in the hospital but relatively few dying patients use hospice.
- Vermont has a wide distribution and availability of Home Health Agencies (HHAs), Skilled Nursing Facilities (SNFs) and hospice services for a rural state but the length of stay (LOS) in hospice is below the US average (57 days and 69 days respectively). Confirming the relatively low utilization of hospice in Vermont.
- Vermont physicians are generally confident in their skills (discussing palliative care, managing non-pain symptoms, using opioids to manage pain) according to the VBMP Survey (2009). Yet, the VEN Survey (2009) identified insufficient provider education and training as a barrier and area for improvement.
- Supply and demand issues regarding treatment of pain were identified. Primary Care Providers (PCPs) send pain patients to pain specialists at the tertiary care center because of lack of time, infrastructure and training. Then pain specialists send patients back to PCPs because of lack of time or long-term relationship and the need to focus on acute needs rather than chronic long-term needs. This leaves patients without adequate pain management and support.
- Lack of awareness and utilization of the Clinician Orders for Life Sustaining Treatment (COLST) form.
- Need for concurrent curative and palliative care for pediatric patients.

Pain Panel

Following the keynote address by Dr. Macauley, a panel of speakers provided an overview of issues related to pain management. This panel consisted of:

- A pain specialist from the Center for Pain Management at Fletcher Allen Health Care, working in a tertiary care setting with patients who have acute pain needs.
- A primary care physician and pain specialist providing care in a rural primary care setting.
- A representative from Vermont's Alcohol and Drug Abuse Program (ADAP), addressing issues of addiction, prevention and the prescription monitoring program.

• Two pain patients sharing their experience in obtaining pain management services in Vermont.

The Economic Case

The morning concluded with a presentation by health care journalist Stephen Kiernan, who presented a four-point economic case for better end-of-life care.

- Recent Vermont data indicating that the majority of rising health care costs are due to excessive and inappropriate end-of-life care.
- State demographic trends revealing how these financial pressures are sure to increase, damaging Vermont's economy.
- National research and hospital models that show how benchmarks for palliative care and hospice can lower end-of-life care costs by up to 80 percent.
- Brand new findings for hospitals serving Vermont, upstate New York and New Hampshire that reveal how palliative care patients lower health care costs. One hospital found that palliative care inpatients cost \$700 less per patient per day.

Kiernan's presentation noted that these dramatic savings were not achieved by denying care or using gatekeepers to reduce clinical interventions, but rather by educating patients about the higher quality of care possible through palliation and hospice. He also provided evidence of a major insurer and other for-profit care providers, outside of Vermont, who are embracing these care models purely for the financial advantages.

Afternoon Breakout Sessions

The afternoon portion of the day was broken out into four different sessions and participants chose one session to attend. The sessions were:

- 1. Community Education and Awareness
- 2. Provider Training and Education
- 3. Issues of Access
- 4. Reimbursement, Coordination of Care and Other Systems Issues

Each session focused on what was currently available and working well and where the barriers existed. Highlights of recommendations from each session included:

Community Education and Awareness

- Support for caregivers
- Development of community education tools (ie. Palliate Care Took Kit, etc.) and campaign to improve awareness and debunk common myths and misperceptions
- Support for empowering consumers to be more proactive
- Facilitated conversations with PCPs to support a consistent message about palliative care and to foster earlier discussions
- Clarifying definitions and differences between palliative care and hospice
- Greater saturation about available resources

Provider Training and Education

- Development of "champions" at every facility
- Greater sharing of information (i.e. palliative care symptom orders, etc.) between facilities
- Improved communication between hospital and nursing homes
- Greater coordination between PCPs and specialists
- Improved training in communication skills
- Expansions of mentorship programs
- Incentives

Issues of Access

- Develop a better system for managing the chronic pain patient (i.e. team approach to minimize burnout and bias and share the burden)
- Develop and share standardized tools and approaches
- Increase the number of "Blueprint" sites (rate of rollout) and elevate palliative care, pain management and advance care planning on the list of priorities throughout
- Improve the information about who the appropriate contacts are at each facility for palliative care and pain
- Revisit the "narcotic contract" and how it is utilized
- Find a way to decouple the "homebound status" from the palliative care benefit
- Develop a "checklist" of disease codes for PCPs that would automatically trigger a palliative care consult/referral
- Work with community pharmacies
- Improve website information

Reimbursement and Other Systems Issues

- Hospice to be covered per diem with adjustments for cost increases
- Simultaneous eligibility for Choices for Care and Hospice
- Incorporate home visit model into the Blueprint as a pilot/test
- Reimburse palliative care by home health agency and care planning in the nursing home setting
- Reimburse physicians for non-clinical time related to palliative care and advance care planning
- Discuss importance of advance directives early and often
- Eliminate the six-month prognosis requirement for hospice eligibility

IV. PROJECTS UNDERWAY AND NEXT STEPS

There are several projects already scheduled or in the planning phase that will address issues identified at the Summit.

A. **Hospice Focus Groups** to determine what works now with hospice services in Vermont, what does not work, including to identify barriers for success, and to develop strategies to correct whatever problems exist. The main goal is to assure

that the highest quality of hospice service is available to everyone in need, regardless of location of their home. Five different focus groups, organized geographically, are planned (starting on May 13th and concluding in June of 2010). The first 4 focus groups will meet for 1.5 hours and have representation from physicians, hospitals, home health and hospice and nursing homes. The first half of each session will be devoted to understanding what is working well in each region. The second half of each session will focus on what is not working and strategies to overcome barriers. The 5th focus group will be for advocates and other health related associations to discuss issues from their perspective. Peter Cobb from VAHHA will facilitate each focus group and create a report summarizing what was learned and strategies for overcoming barriers.

- B. Fletcher Allen Palliative Care Network Activities: FAHC Palliative Care Services offers the following:
 - 1. Mentorship Program: Spend a day with the FAHC Palliative Care Service
 - 2. Palliative Care Hotline
 - 3. Telemedicine Palliative Care Consultation in collaboration with the MICU
 - 4. Palliative Care Case Conferences: Interactive via telemedicine, Wednesdays at noon (CME)
 - 5. Site Visits

C. **DMHC Palliative Care Service** has 2 new projects:

- 1. At the end of April, a mailing will go out to the lead pharmacist of every community pharmacy in Vermont and New Hampshire containing *Community Pharmacy Palliative Care Formulary Guidelines*. This will be an 8 page document with information on recommended medications for palliative care. The goal is to survey every pharmacy in one year to see if they have made any changes.
- 2. Beginning in September, DMHC will roll out a Peer Observership Program. This will be a tuition free opportunity for providers to spend 1 2 weeks with the DMHC Palliative Care Service. It will provide one-on-one mentorship for a person working in hospice or palliative care. It is geared mostly toward MD's and RN's but they will encourage other disciplines to attend in the future. They have grant funding to make this a tuition free opportunity for the next 2 years.
- D. Community and Provider Education Opportunity: The Madison-Deane Initiative is bringing Diane E. Meier, MD, FACP to Vermont on October 25, 2010. Dr. Meier is Director of the Center to Advance Palliative Care (CAPC), a national organization devoted to increasing the number and quality of palliative care programs in the United States. Under her leadership the number of palliative care programs in U.S. hospitals has more than doubled in the last 5 years. She is also Director of the Lilian and Benjamin Hertzberg Palliative Care Institute; Professor of Geriatrics and Internal Medicine; and Catherine Gaisman Professor of Medical Ethics at Mount Sinai School of Medicine in New York City.
- E. **Pain Management for Chronic Benign Pain:** Many Summit participants expressed a desire for more information related to managing the chronic pain patient who is not at the end-of-life. Therefore, the Vermont Ethics Network, in partnership with the Palliative Care and Pain Management Task Force, the Vermont

Medical Society, The Center for Pain Medicine at FAHC and others, is currently exploring providing a one day conference for primary care providers on managing the needs of the patient with chronic benign pain.

F. **Reimbursement, Cost Reduction and Improved Quality:** The information presented at the Summit regarding the success of AETNA's Compassionate Care pilot program prompted a desire to explore with private insurers, Medicaid and policy makers the feasibility of creating a similar program here in Vermont. The Vermont Ethics Network will work with the Hospice and Palliative Care Council of Vermont and other interested organizations to convene a meeting with insurance providers and policy makers to discuss willingness to pursue this type of model.

This Report was prepared in consultation with:

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