



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 committee on health and welfare regarding recommendations, progress and activities related to the work of the Palliative Care and Pain Management Task Force.

II. RECOMMENDATIONS

Members of the Palliative Care and Pain Management Task Force participated in the Department of Health's study committee and proposed rules on *Advance Directives for Health Care and Surrogate Consent for Do-Not-Resuscitate Orders (DNR) and Clinician Orders for Life Sustaining Treatment (COLST)*. As a result of the discussions that occurred during those meetings, the Task Force recommends:

- 1. Legislative action to authorize surrogates to have access to health information relating to the individual for whom they are providing informed consent for a DNR/COLST order.** Currently in 18 V.S.A. § 9711(e) there is specific authorization for an agent or guardian to receive health information relating to the patient/principal. However, the law does not provide for surrogates to have access to health information, which they would need in order to provide informed consent for a DNR/COLST order. We believe it is important that the law be clear so that health care providers understand that it is permissible for them to share relevant health information with surrogates to the same extent that they do for agents and guardians. It is our unanimous recommendation that this section of the statute be amended to include surrogates prior to March 1, 2012 - the effective date of the rule.
- 2. Legislative action to provide immunity for surrogates who provide informed consent for a DNR/COLST order in good faith.** Currently in section 18 V.S.A § 9713 immunity is provided for agents or guardians who are acting in good faith and should also be extended to include surrogates. We unanimously recommend amending this section of the statute as soon as possible and preferably in advance of the March 1, 2012 effective date of the rule.
- 3. Action to correct language in 18 V.S.A § 9708 (f) (3) with respect to access to hospital's internal ethics protocols.** It is unclear what is meant by the phrase "internal ethics protocols". Further, hospital ethics committees do not currently have internal ethics protocols to resolve disputes over who can give informed consent for a DNR/COLST order. Ethics committees make nonbinding recommendations and work to help patients and families understand the health care situation, clarify goals and try to reach consensus about a decision. They function as a facilitator in these discussions and do not serve in the role of arbitrator. There was not unanimous agreement about this recommendation however the vast majority of the task force believes it is important that both the law and the rule accurately reflect what ethics committees can provide.

III. SUMMARY OF 2011 INITIATIVES

A. Spring 2011 Conference on the Interface between Pain Management and

Addiction: On May 23, 2011 the Vermont Ethics Network in partnership with the Palliative Care and Pain Management Task Force hosted a statewide pain conference, *Walking the Tightrope: The Interface Between Pain and Addiction*, at the Capitol Plaza Hotel and Conference Center in Montpelier, VT.

Over 120 health care professionals attended this interdisciplinary educational conference which featured national expert, Steven Passik, PhD. Dr. Passik is a professor of Psychiatry and Anesthesiology at Vanderbilt University Medical Center in Nashville, Tennessee. In addition to Dr. Passik's keynote presentation, breakout sessions included presentations on:

- Pain Contracts
- Assessment, Communication and Setting Realistic Goals
- Treatment of the Addicted Patient
- Multidisciplinary Approaches to Managing Chronic Pain

Given that chronic pain and prescription drug abuse are two of the major public health crises facing us today, this event was timely and well received as evidenced in the post event evaluations.

B. Across the Fence Educational Series:

In an effort to provide information to the public on issues related to palliative and end-of-life care, the Task Force taped three segments that aired on Across the Fence in 2011. The topics covered:

- Palliative Care in Rural Communities (Dr. Diana Barnard and Cindy Bruzzese)
- Shared Decision-Making (Dr. Denise Niemira and Cindy Bruzzese)
- Grief and Bereavement (Angel Means and Virginia Fry)

C. Provider and Community Surveys on Palliative and End-of-Life Care:

To gain a better understanding of community and provider needs and preferences for education in palliative and end-of-life care, the Vermont Ethics Network, in partnership with the Task Force and the Madison-Deane Initiative, developed two surveys. One survey was targeted at health care providers and the other was directed at the community. A summary of each is provided below:

- **Community Survey Results Summary:** An electronic fifteen-question survey was sent to community members across the state with the assistance of local agencies, front porch forums, and other organizations. A total of 390 surveys were completed. Participants self identified as living across the state of Vermont with 46% from Chittenden County. The greatest percentage (49%) of respondents were between 50-64 years of age.

A large percentage of participants had a basic understanding of palliative and hospice care and 80% recognized that hospice is for patients with a life expectancy of less than 6 months. Interestingly, 37% responded that palliative

and hospice care are private services paid for by the patient/family. Sixty-eight percent recognized that palliative care services are available for patients still undergoing disease-modifying therapies. Although 18% felt that hospice services were also granted to patients undergoing disease-modifying therapies. Multiple comments requested clarification on the difference between palliative and hospice care. There seemed to be a basic understanding that these services help with pain and symptom management, care in private homes or hospitals and support for families. Areas for further education include qualifications for these services, access to services and how the costs are covered.

Sixty percent of respondents had completed an Advance Directive and only 9.5% stated that their health care provider helped them to understand/complete the form. Comments support that people seem to understand the need for an advance directive, and know how and where to get the necessary forms; they simply have not taken the time to do it.

The majority of respondents had discussed personal end-of-life issues with family members (77%) followed by friend(s) (30%). Twenty-five percent had discussed their wishes with their primary care provider. Eighteen percent identified that they had not discussed their wishes with anyone. Concerns for end-of-life care were common and spanned a range of aspects of care. Community members stated they were ‘very’ concerned about the following specific areas of their own end-of-life care:

- My comfort (73%)
- My dignity (69%)
- Impact on family/friends (65%)
- The cost of the care (64%)
- The pain I might experience (63%)

A few of the comments supported a sense of control and less concern by having a clear advance directive.

- “I am a healthy adult who has completed Advance Directives and have a Durable POA for Healthcare. I have no concerns in this regard at this time.”
- “As a health care provider I have no concerns with the topics above. They have been addressed in my living will for a very long time.”

When asked about personal concerns for caring for loved ones at the end-of-life, respondents greatest concern was the cost of care (50% were ‘very’ concerned). Combining those that responded ‘very’ and ‘moderately’ concerned the following areas rated high:

- Cost of the care (81.5%)
- Family obligations (62%)
- Work obligations (61%)
- Lack of understanding care needs (57%)

Community members expressed an interest in further education on a wide variety of topics related to end-of-life care. Those listed as topics that would be 'very helpful' included:

- Community resources for end-of-life (53%)
- Palliative Care (49.5%)
- Caring for loved ones at the end-of-life (49%)
- Hospice Care (46.5%)
- Talking to loved ones about end-of-life (41%)

How best to provide this education appears to be via community presentations (85%) or print (mailings, brochures, articles) material (80%). The least popular choice was media (radio, TV, webcast) (61%). These responses support the Vermont Ethics Network's current focus on community presentations across the state as well as clear and concise documents provided to community members, such as the *Taking Steps* booklet.

In conclusion, continued community education in the form of community workshops and printed materials appears to have the most appeal. Topics should include the main differences between palliative and hospice care as well as how to access and pay for these services. Addressing the concerns stated above for personal end-of-life care and caring for loved ones at the end-of-life should also be included.

Many of the final comments were positive and thanked the organizations for current and continued educational opportunities as well as for reaching out to the public for input through the survey.

- "I am pleased with the availability of materials and look forward to being able to assist my clients with questions."
- "I think you are doing a great job and this survey is quite complete. Thank you."
- "Thanks for all of your hard work."
- "Keep up the good work and getting the word out!!!!"
- "I am grateful to live in an area that is asking these questions and is willing to search for answers. Thank you!"
- "Thank you for reaching out in this way!"
- "Extremely worthwhile topic"

- **Provider Survey Results Summary:** An electronic twenty-four-question survey was sent to medical professionals across Vermont with respondents from each county. A total of 105 surveys were started with 58% completing the entire survey. The main demographics of respondents included Medical Doctors (34%), Nurses (26%), Social Workers (9.5%) and self identified as Other (27%). The most common areas of expertise/specialty included Hospice (20%), Palliative Care (20%), Family Medicine (9.6%), Hospitalist (8.7%) and Critical Care (8.7%).

We recognize that this is a limited number of respondents with 20 percent having experience with palliative or hospice care, although it does provide some insight into common barriers and areas for needed education. Based on the responses, there seems to be a solid understanding of palliative and hospice services including when to introduce and refer patients to these programs. Ninety-three percent of respondents also believe that every adult in Vermont with decision-making capacity should have an advance directive.

Barriers to discussing end-of-life care issues and suggested areas for continued education and improvement included:

- Difficulty in predicting a patient's prognosis (47%)
- Concern that patients/families will misinterpret end-of-life discussions (51%)
- Limited time with patients (42%)
- Seventy-Five percent of respondents replied, "I would like more education on managing pain at the end-of-life."
- There was a strong expression for continued and improved education for patients and families on these topics, and providers expressed a need for a place to refer patients/families for further information.

Other suggestions included:

- "A referral system within Vermont with physicians who deal with end of life care issues for whom those physicians who rarely deal with these issues can contact on an informal basis as a resource"
- "Have CME (continuing medical education) opportunities at the VMS (Vermont Medical Society) or local ACP (American College of Physicians) meetings."
- Multiple statements referring to improved communication between medical providers as well as the legal community to provide a clear message to patients and families.

In conclusion the results of this survey were promising to show that respondents had a decent understanding of palliative and hospice care as well as the Vermont Advance Directive for Health Care form. The general consensus was a desire for further education and ways to overcome some of the barriers listed above. The theme of continued provider, patient and family education is in line with the goals of the Palliative Care and Pain Management Task Force and the Vermont Ethics Network.

D. Vermont Ethics Network (VEN) Initiatives: 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 2011.

With the enactment of ACT 60, VEN established a new website, www.colst-vt.org designed to address questions related to the new requirements for out-of-hospital DNR/COLST orders.

In celebration of 25 years of Vermont Ethics Network, VEN hosted a statewide ethics conference *Who Lives, Who Dies, Who Decides and Who Pays?* on October 5, 2011 at the Hilton Hotel in Burlington. The conference featured national speakers Dr. Joanne Lynn and Dr. John Lantos, as well as local experts Dr. Robert Macauley and Anya Wallack Rader. Over 125 people attended this day-long event. It was by all accounts a successful and thought provoking day.

- E. Rural Palliative Care Network (RPCN):** Fletcher Allen's Rural Palliative Care Network allows for the sharing of expertise, as well as the education of clinicians and community hospitals about palliative care.

The network is an expansion of Fletcher Allen's Palliative Care Service – an interdisciplinary, patient and family-centered program designed to deliver excellent pain and symptom management, advanced care planning, and end-of-life care for people with life-threatening illness. The network offers an array of services for hospitals and health care providers in the region, including:

- Telemedicine consultations
- A 24/7 palliative care hotline
- Palliative Care Mentorship Program
- Site visits
- The ability to participate in weekly palliative care case conferences and online discussions

Dr. Ursula McVeigh is the contact person for questions and further information and Dr. Diana Barnard has recently joined the team.

- F. Choices for Care and Hospice Update:** Per Act 60, the department of disabilities, aging and independent living revised its policies to allow people currently enrolled in hospice services to simultaneously enroll in Choices for Care (CFC). In Fiscal Year 2011, the number of individuals in Hospice and CFC under the old policy ranged from 23 – 35 per quarter. Data from the first quarter of Fiscal Year 2012 (July – September) shows an increase in the number of individuals in CFC and Hospice. During the first quarter under the new policy, 56 people were simultaneously enrolled in both programs. This represents 21 more people than in the first quarter of FY11. We will look forward to the year-end report on this program.

- G. Community Education:** The Madison-Deane Initiative continues to offer educational opportunities to the Burlington community on palliative care. In 2011 MDI once again sponsored Palliative Care Week at Fletcher Allen Health Care. In the spring, they brought national expert Diane Meier, MD to Vermont to speak to both health care professionals and the community about palliative care. This event was attended by over 250 people. Finally, in November, they sponsored a local talk on *Navigating Serious Illness: The Role of Palliative Care*, featuring local palliative care specialists Dr. Zail Berry and Dr. Ursula McVeigh.

IV. NEW PROJECTS AND ACTIVITIES FOR 2012

- A. **Spring Palliative Care Summit:** The Palliative Care Task Force is planning a spring conference for health care providers that will focus on topics that were identified through the provider survey. The Task Force will partner with Fletcher Allen's Rural Palliative Care Network to develop the program and identify presenters for this event.
- B. **DNR/COLST Education:** Vermont Ethics Network will be working with the Vermont Program for Quality in Health Care (VPQHC) on a quality improvement project related to DNR/COLST orders.

VEN and VPQHC will work together to provide:

- “train the trainer” education at eight (8) Critical Access Hospitals and three (3) mid-sized hospitals enrolled in the Transitions in Care/Reducing Avoidable Readmissions project
- COLST content and discussion offered via telemedicine or webinar as part of the Transitions in Care/Reducing Avoidable Readmissions project
- Facilitation of a focus group for VT Emergency Department (ED) Directors and Emergency Medical Services (EMS) Directors
- Online DNR/COLST course via the Institute of Healthcare Improvement (IHI) Open School site hosted by VPQHC

- C. **Reducing Hospital Readmissions and Improving Understanding of Hospice, Palliative Care, Advance Directives and DNR/COLST orders.** The Vermont Assembly of Home Health Agencies (VAHHA), the Vermont Health Care Association (VHCA) and the Vermont Ethics Network will be collaborating on a project designed to provide education, training and improved coordination of efforts between hospitals, nursing homes and hospice agencies related to end-of-life care needs and hospice services.
- D. **Across the Fence Community Awareness/Education Segments:** Based on results of the Community Survey, the Task Force plans to tape segments for Across the Fence on palliative and end-of-life care topics as identified in the survey. This will likely include information on the difference between palliative care and hospice, advance directives and DNR/COLST orders, and how hospices services are accessed and paid for.
- E. **Start the Conversation Campaign:** The Vermont Assembly of Home Health Agencies (VAHHA) will be initiating a campaign in 2012 to increase awareness of hospice services and end-of-life care options through a consumer-targeted initiative. Vermont Ethics Network will partner with VAHHA on this effort by providing information, resources and tools on advance care planning and advance directives.

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

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