



ANNUAL REPORT

PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE

JANUARY 2013

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

- 1. Legislative action to grant surrogates access to health information and immunity when providing informed consent for DNR/COLST orders.** Members of the Palliative Care and Pain Management Task Force have been participating in the Department of Health's informal workgroup regarding the pending rules on *Advance Directives for Health Care and Surrogate Consent for Do-Not-Resuscitate Orders (DNR) and Clinician Orders for Life Sustaining Treatment (COLST)*. 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. It is important that the law be clear so that health care providers understand that it is permissible for them to share health information relevant to consent for DNR/COLST with surrogates. In section 18 V.S.A § 9713 immunity is provided for agents or guardians who are acting in good faith. Immunity should also be extended to include surrogates who are consenting for DNR/COLST orders.
- 2. Legislative action to create a subchapter for surrogate consent for DNR/COLST orders within the existing advance directive statute.** 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 the pending rulemaking process.
- 3. 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 left 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 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. Therefore it is the recommendation of the Task Force to amend the current advance directive statute to allow surrogates to consent for admission to palliative care and hospice.
- 4. Legislative action to grant immunity to ethics committees and those members serving on ethics committees.** As we look to expand access to ethics expertise, resources and consult services in the form of multi-facility ethics committees (MFEC), it is recommended that immunity for individuals serving on ethics committees be addressed.

5. **DNR Identification:** Per Act 60, uniform minimum requirements for DNR identification were to be determined by rule by the department of health by no later than March 1, 2012. The rule in which this information is contained is part of the same rule pertaining to surrogate consent for DNR/COLST. Should the legislature see fit to move forward with the recommendation to resolve the surrogate consent needs for DNR/COLST through a statutory remedy, the pending rule will be unnecessary. However the DNR Identification needs will persist, and thus must be addressed.

III. HIGHLIGHTS FROM 2012

- A. **Spring 2012 Palliative Care Conference:** On April 3, 2012 the Vermont Ethics Network in partnership with the Palliative Care and Pain Management Task Force hosted its third statewide palliative care conference, *Navigating Uncertainty: A Palliative Care Road Map*, at the Capitol Plaza Hotel and Conference Center in Montpelier.

Over 150 health care professionals attended this interdisciplinary educational conference which featured local experts: Dr. Allan Ramsay, MD; Marie Bakitas, DNSc, ARPN, FAAN; Robert Macauley, MD; Zail Berry, MD and Urusla McVeigh, MD. Topics included:

- Discussing Prognosis in Life Limiting Disease
- Disease Specific Advance Care Planning for Chronically Ill Non-Cancer Patients
- Responding to Requests for Non-Beneficial Treatment
- Pain Management at the End of Life
- Fostering Palliative Care Collaboration, Mentorship and Education

- B. **Vermont Ethics Network (VEN) Initiatives:**

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 2012.

Ethics Committees - The role of ethics committees and expanding access to ethics expertise and resources has been a focus of the discussions surrounding medical decision-making and surrogate consent for DNR/COLST. What is presently known:

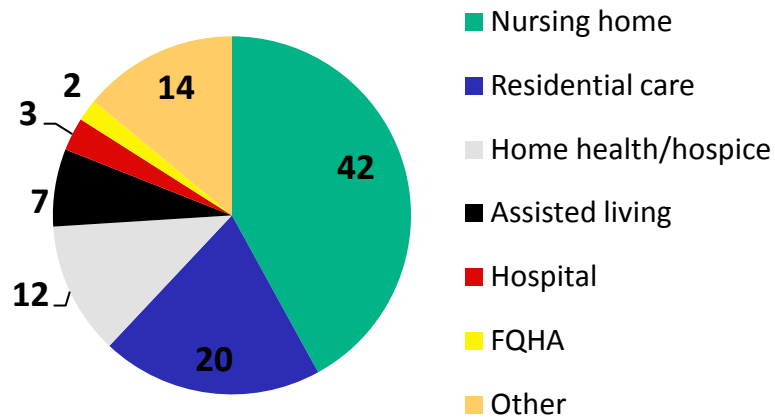
- The concept of having an ethics committee in health care facilities to assist staff and patients with addressing ethical challenges is well established.
- The purpose of an ethics committee is to provide a forum to discuss ethical conflicts with a multidisciplinary group of professionals who have knowledge and skills in applied health care ethics.
- Traditionally, these committees focus on ethics education, policy development, and case consultation.

- Ethics committees are primarily found in larger, urban hospitals. There are many rural hospitals throughout the US, including in VT, that either do not have ethics committees or have ineffective committees.
- There is a broad array of health care facilities, such as nursing homes, assisted living facilities, among others, that do not have ethics committees at all.

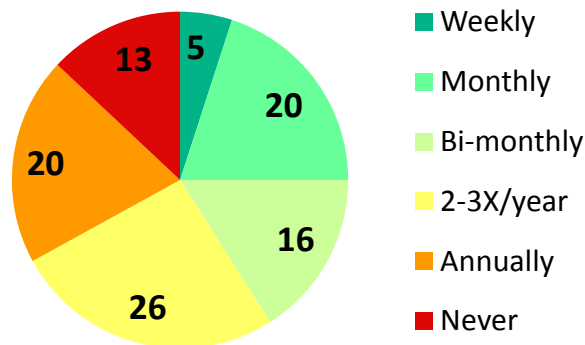
Based on the discussions of the workgroup and the resultant language in the proposed Rule pertaining to Surrogate Consent for DNR/COLST orders, VEN conducted a short survey to assess the needs of non-hospital health care facilities regarding access to ethics resources and expertise in the spring of 2012.

Survey Results (149 surveys were distributed via survey monkey, 65 responses)

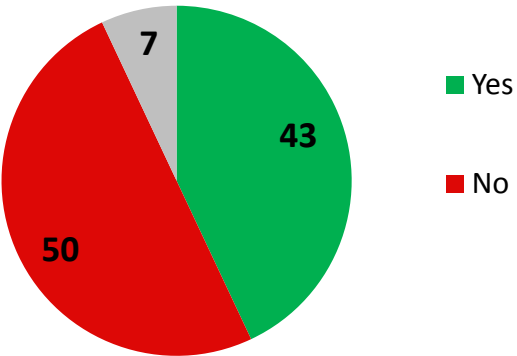
As seen in the figure below, the majority of respondents were nursing homes, followed by residential care facilities and home health/hospice programs.



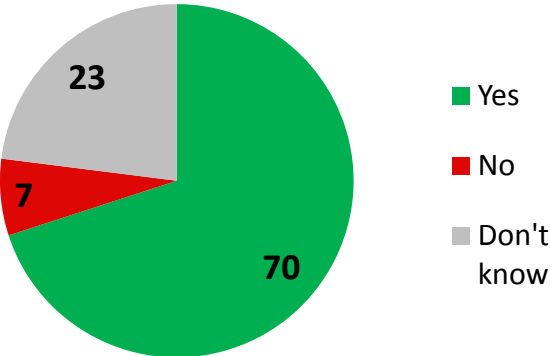
One of the aims of the survey was to assess whether or not non-hospital health care facilities in the state believed they were encountering ethical conflicts. The results revealed that ethical concerns (conflicts, issues) were being encountered on a regular basis – with nearly half of the respondents encountering issues bi-monthly or greater; and a quarter of the respondents acknowledging that they were encountering ethical concerns 2 – 3 times per year.



The survey asked specifically about an ethics mechanism within their organization, such as an ethics committee, to address/resolve ethical conflicts? The responses highlighted that over half of the participants in the survey did not have an ethics mechanism – or weren't sure if they had an ethics mechanism – within their organization, for addressing ethical conflicts.



Finally, the survey indicated that there was interest and a need for access to ethics expertise, whether via a traditional ethics committee or a multi-facility ethics committee (MFEC). Survey participants overwhelmingly responded that a MFEC could be a potential resource for their organization, highlighting not only the need, but also the interest in MFEC resources across the state.



As a follow-up to this survey, VEN hosted a meeting for health care facilities to come together to explore the concept of MFEC(s) in Vermont on November 12, 2012. Over 60 people were in attendance and ongoing work is planned for 2013.

Education - In the fall, VEN hosted a statewide ethics conference: *When Less is Better: Ethical Issues in the Use of Health Care Resources*, at the Lake Morey Resort in Fairlee, VT. The conference featured national speaker Dr. Howard Brody, Director

of the Institute for the Medical Humanities and John P McGovern Centennial Chair in Family Medicine at the University of Texas. Over 100 people attended this day-long event. It was by all accounts a successful and thought provoking day.

C. 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 two segments that aired on Across the Fence in 2012. The topics covered:

- Palliative Care (Dr. Ursula McVeigh and Christina Melvin, RN)
- Health Care Decisions (Dr. Robert Macauley and Cindy Bruzzese)

D. Rural Palliative Care Network (RPCN): The broad aim of Fletcher Allen's Rural Palliative Care Network is to foster educational and clinical collaboration among interdisciplinary clinicians who provide hospice or palliative care services. The network offers an array of opportunities for hospitals and health care providers in the region, including:

- Palliative Care Case Conference: A case based group discussion and educational content, CME credit available. Held each Wednesday noon-1pm. Can be attended in person, via telemedicine (video format) or teleconference (conference call format). Off-site participants frequently listen or watch the conference and have concurrent discussions with people at their site on the topic.
- Palliative Care ListServ: An email distribution list where people can ask their colleagues clinical or practical questions about palliative care: symptom management, home care support, insurance issues, etc.
- RPCN Periodic Meeting: The objectives of the meetings are educational brainstorming, networking and to have a "strategic focus" each year. This year will be advance care planning.

Dr. Ursula McVeigh is the current Director of the program and can be contacted for questions and information. Dr. Diana Barnard joined the team in 2012.

E. Fletcher Allen Preferred Supportive Care Benefit: Vermont Managed Care has been working with the VNA of Chittenden and Grand Isle Counties to draft a proposal for expanded access to supportive care services for patients with serious or life-limiting illness. The goal is to provide care by an interdisciplinary team of skilled palliative care professionals in the home for members who have a serious illness, with a prognosis of greater than six months and who may still be pursuing curative interventions. Members need not be homebound to participate. The benefit may be introduced at the time of diagnosis of serious or life-limiting illness when other appropriate and beneficial medical therapies are initiated. It is designed to address the comfort and emotional needs of this population which will result in an improvement of their symptoms, quality of life, patient satisfaction, reduced caregiver burden and a reduction in the overuse of costly, unproductive therapies in the advanced stages of illness.

F. Community Education: The Visiting Nurse Association of Chittenden and Grand Isle Counties' Madison-Deane Initiative continues to offer educational opportunities to the Burlington community on palliative care. In 2012 MDI once again sponsored Palliative Care Week at Fletcher Allen Health Care. In the fall, they brought national speaker and author Jane Brody. This event was attended by over 300 people.

G. Pediatric Palliative Care Program (PPCP): Over the course of the last year, the Pediatric Palliative Care Program (PPCP) has matured from a concept to early implementation with core pilot efforts underway. In December 2011, CMS authorized DVHA to provide the PPCP under the global commitment for health care waiver. In January 2012, DVHA hired Monica Talbot Ogelby, a Pediatric Nurse Practitioner from Children's Hospital in Boston who has background and experience in Pediatric Palliative Care. Working closely with Eileen Girling, Director of the Chronic Care Initiative, as well as partners at Integrated Family Services, they have developed the required tools, forms and internal operating procedures within DVHA; as well as early outreach and associated training of nurses and physicians to support effective implementation of the program. While there are many facets of this work that will require ongoing adjustments, the program is currently available in eight counties (Chittenden, Washington, Orange, Windsor, Windham, Addison, Bennington, and Rutland) with rollout continuing into 2013. The first children were enrolled in the program in early October and there are currently 10 children participating in the program.

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.

IV. ACTIVITIES PLANNED FOR 2013

A. Spring Pain Management and Palliative Care Conference: The Palliative Care Task Force is planning a spring conference, *A Bridge to Healing: Insights into the Management of Pain and Suffering*, on April 3, 2013 in Burlington.

This event will feature national experts Dr. Janet Abraham, MD, FACP, FAAHPM and Dr. Eric Cassell, MD, MACP. Both Dr. Abraham and Dr. Cassell are pioneers in their respective fields. Dr. Abraham will focus her presentation on the management of pain in the cancer patient and Dr. Cassell on the nature of suffering and healing. In addition to both of their keynote presentations we will have workshops from local experts on:

- Chronic Pain and Opiates
- Integrated Complementary and Alternative Therapies and Chronic Pain
- Symptom Management in the Final Phase of Life
- Building a Statewide Palliative Care Educational Program

- B. Ongoing DNR/COLST Education:** Vermont Ethics Network will be continuing its work with other agencies and organizations, including EMS, on education, training and effective implementation of the new DNR/COLST form. Continued work on establishing expanded access to ethics expertise and resources through a possible multi-facility ethics committee (MFEC) model is underway.
- 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), the Vermont Ethics Network (VEN) and the Vermont Program for Quality in Health Care (VPQHC) will be continuing their collaborative 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, medical decision making and access to hospice services.
- D. Across the Fence Community Awareness/Education Segments:** We will continue to work with Across the Fence to offer topics on end-of-life care issues. We are hoping to schedule 3 segments this year to include: caregiver support, challenges with pain management in the final phase of life and advance care planning.



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

- Madeleine Mongan, Vermont Medical Society
- Angel Means, Hospice and Palliative Care Council of Vermont
- Jackie Majoros, Long Term Care Ombudsman
- Trinka Kerr, State Health Care Ombudsman
- Jill Olson, Vermont Association of Hospitals and Health Systems
- Christina Melvin, UVM Department of Nursing
- Eva Zivitz, Rutland Regional Medical Center
- Patricia Launer, Bi-State Primary Care Association
- Janet Dermody, Vermont Center for Independent Living
- Peg Maffitt, Madsion-Deane Initiative
- Linda McKenna, Foley Cancer Center at Rutland Regional Medical Center
- Beth Stern, Central Vermont Council on Aging
- Laura Pelosi, Vermont Health Care Association
- Avril Cochran, Vermont Program for Quality in Health Care
- Patrice Knapp, Vermont Program for Quality in Health Care
- Ursula McVeigh, Fletcher Allen Health Care - Palliative Care Service
- Kristin Barnum, Bayada Hospice
- Monica Ogelby, Pediatric Palliative Care Program -VT Chronic Care Initiative