

EXCEL

April 5, 2005

Legislative Update

H. 115, the Advance Directive bill is expected to be voted out of the House Judiciary Committee Tuesday, April 5. The bill consolidates and updates current laws on terminal care documents (living wills) and power of attorney for health care decisions. It also adds organ donation and funeral services to the list of items that can be addressed through an advance directive. The section on do-not-resuscitate orders would allow physicians to issue DNR identification such as wallet cards and bracelets. The bill also directs the department of health to establish an electronic registry where patients could file their advance directives. Health care professionals would be required to check the registry for patients who are incapacitated. In the area of pain treatment, the bill would add pain assessment and management to the hospital patients' bill of rights and would require hospitals and nursing homes to inform all patients about the availability of hospice services. Controversial issues in the bill include whether to include a "Ulysses clause" and whether to continue to allow patients without capacity to object to health care requested by their agent or included in their advance directive. The issue of surrogate decision making for patients who do not have advance directives, agents or guardians was

deferred to a study. Physicians and health care professionals continue to follow and testify on the bill.

It seems unlikely that the Vermont legislature will take any formal action on the Death with Dignity bill (H. 168) since the U.S. Supreme Court will be issuing a decision later this year on the constitutionality of the Oregon Physician Assisted Suicide legislation. The week of April 11, however, the House Human Services Committee will have what Ann Pugh, the chair of that committee describes as "a conversation" on the issue of physician assisted suicide and the Death with Dignity bill (H. 168). The committee has scheduled testimony several days that week and a public hearing on Tuesday, April 12 from 7 to 9 pm at the Statehouse in Montpelier to hear from Vermonters interested in this issue. Contact Lynn Hegameyer at Legislative Council 802-828-2231 if you are interested in testifying.

Wendy Morgan (Advanced Care Planning) at (802) 828-5507; or at WMorgan@atg.state.vt.us

Linda Purdy (Pain and Symptom Management) at (802) 241-4442; or at lpurdy@atg.state.vt.us

End of Life Quality of Care Study

Through work by Zail Berry, Sharon McDonnell, and Paul Turner, the End of Life Quality of Care Study will begin surveying individuals during the month of April. The formal reviews for the study were completed by both the Vermont Department of Health Survey Review Committee (SRC) and the Agency of Human Services (AHS) Institutional Review Board (IRB). The study received strong support in January from the SRC and valuable input from the committee was used to refine the final survey. The AHS IRB approved the study for exempt status in February.

Currently the final programming is being completed for the End of Life Survey into the Interactive Voice Response system along with a series of validation audits. A total of 29 items common to the Brown University instruments comprise the survey. Depending on how an individual responds to specific items,

their individual survey may range from 21 to 29 questions. The time estimated to complete the survey is four to five minutes. The death certificates for Vermonters who died from natural causes in the fourth quarter of 2004 (October – December, 2004) forms the basis of the study sample. The survey contacts will begin in April and conclude in the middle of May. Preliminary results will be reported at the June ExCEL meeting.

End-of-Life Care Issues Addressed on New Vermont Advance Directives Form

A new advance directives form available from the Vermont Ethics Network helps Vermonters specify in writing whether or not they wish to be kept alive by a feeding tube, in case they become unable to think or act for themselves.

The Vermont Advance Directive for Health Care, which can be downloaded for free at www.vtethicsnetwork.org, is designed to prevent situations like the Terri Schiavo case in Florida. Schiavo was 26 when her heart stopped beating for a short period. The resulting lack of oxygen left her severely brain damaged. Because she did not complete a written advance directive, her wishes for life-sustaining treatment were in dispute and the subject of a protracted legal battle.

Vermonters who complete the Vermont Advance Directive for Health Care can specify whether they wish physicians to limit treatment or do everything possible to sustain their life, if they become terminally ill or permanently incapacitated. Vermonters whose preference is to limit treatment can specify on the form whether or not they wish food and water to be given to them intravenously or by feeding tube.

“The decision about whether to sustain life through a feeding tube is a deeply personal choice that everyone should put in writing,” said John Campbell, executive director of the Vermont Ethics Network. “The new Vermont Advance Directive for Health Care is an easy-to-understand form that Vermonters can complete without the assistance of an attorney. It is a tool that people can use to discuss medical treatment issues with family, and make sure a person’s wishes are clear.”

The Vermont Ethics Network has also produced a new edition of the guidebook “Taking Steps to Plan for Critical Health Care Decisions.” The booklet contains the Vermont Advance Directive for Health Care form, along with a more detailed discussion of the issues involved with making end-of-life care decisions. The booklet is available for free through Vermont hospitals, home health agencies, nursing homes, area agencies on aging, and some physician offices.

For more information, contact: John Campbell at 828-2909

ExCEL Steering Committee Co-chairs:

***Diana Peirce, RN
Zail Berry, MD, MPH, PLLC
Letha Mills, MD***

Calendar of Events: 2005

****Steering Committee Meetings:
January 3; March 7; May 2;
September 5; November 7
(5:30—7:00 at VMS)***

****Hospice & Palliative Care Council of Vermont (14th Annual Conference):***

***June 9 (Lake Morey Inn)
(for more information contact
Diana Peirce at (802) 223-1878
ExCEL Annual Meeting June 9-10
(Lake Morey Inn)***