



House Human Services Committee: Act 39

April 16, 2015 - Testimony

Cindy Bruzzese, MPA, Executive Director

I. Vermont Ethics Network's Position of Neutrality

Vermont Ethics Network (VEN) has long recognized that Vermonters hold a diversity of views in regard to physician assisted death (PAD). Similarly, among VEN board members some favor legalization of PAD and others oppose it. However, the practice is now another legal end-of-life care option in this state. Consistent with our mission to promote understanding of ethical issues in health care, VEN continues to maintain a neutral stance surrounding the practice of PAD. We view our role as one of education and encouraging thoughtful and respectful discussion and deliberation.

VEN has received criticism from both sides of this issue since the passage of the law. From proponents of Act 39, we have been criticized for being “too neutral” and for pointing out legal specifics (such as the absence of explicit immunity for participating pharmacists) that could present a barrier to utilization of the law. From opponents we have been criticized for not being “neutral enough”, by providing education and serving as a resource for factual information we are promoting and encouraging its utilization. In many respects, to endure criticism from both sides would seem a pretty good definition of “neutrality.” We continue to work to establish and maintain a civil middle ground in the midst of an often heated debate, and to ensure that Vermonters have access to factually accurate information to make informed decisions about the end-of-life care options available to them.

II. Education and Resources

Since the passage of Act 39, and in direct response to inquiries from patients, providers and health care facilities, VEN has focused on providing education and information about the specifics of the law.

- **Summer 2013:** Absent any designated agency or organization to assume responsibility for implementation and education about the law, VEN responded to the high volume of inquiries by creating fact sheets for our website to explain Act 39 and by speaking directly to interested groups upon request. We worked with the Vermont Department of Health and other stakeholders to develop responses to frequently asked questions (FAQ's). This information has been made available on both the VEN and VDH websites.
- **Fall 2013:** VEN invited individuals and organizations both in favor of and opposed to legalization of PAD to participate in and/or sponsor a statewide professional conference on assisted death and Act 39. Approximately 150 people attended this educational event.

- **Ongoing:** In response to direct requests (both in-state and out-of-state) VEN continues to provide information to individuals, health care providers, hospitals, hospice agencies and others about the specifics of the law and ethical questions that have arisen since its passage. This has taken the form of responding to questions via phone and through our website, as well as through requests for direct group presentations.

III. What VEN has Learned

- According to the Vermont Department of Health seven (7) sets of paperwork have been submitted indicating the intent to prescribe.
- Based on the calls VEN continues to receive, questions remain surrounding:

From Patients:

- Who qualifies?
- What constitutes “residency”?
- Where someone can find a prescribing physician?
- What are the options for accessing the law for patients who have dementia or can’t self-administer?
- What is the relationship between advance directives and Act 39?

From Providers/Facilities:

- What are the obligations of health care providers who do not wish to participate?
- Which pharmacies are willing to fill the prescription?
- What is the cost of the medication(s)?
- Which medication(s) is being prescribed/protocol?
- If I am unwilling to prescribe, who can I refer my patient to?
- What are the responsibilities of those who may be involved (i.e. present when a patient ingests the medication, prescriber, etc.)
- What are our obligations if something unexpected happens?
- Who/What agency is the primary resource for questions about the law and for overseeing its implementation?

IV. Health Policy and Ethics

There is an old saying in health care ethics that “good ethics begins with good facts”. With that in mind, from an ethics and health policy perspective, if policies are to be effective, then education about the policy, data collection and measurement are necessary so that you can evaluate performance and improve. Lack reporting and data collection makes it difficult to assess effectiveness and whether or not a policy is accomplishing the goal it was intended to accomplish. It also makes it challenging to evaluate what is working well and where problems may exist that may warrant a corrective course.