

Vermont's New Law on Patient Choice and Control at the End of Life (Act 39)

On May 20, 2013, Vermont became one of four states in the country to permit a terminally ill, capable adult to request and obtain a lethal prescription for medication to self-administer for the purpose of hastening their own death. Life-ending medication has thus become another of the many available options for patients who qualify.

There is no national consensus about this practice, known as Physician Aid in Dying or "PAD" (sometimes also referred to as "Physician Assisted Dying," or "Physician Assisted Suicide.") The US Supreme Court has twice held that the US Constitution does not create a right to PAD. However, the Court left open the possibility that state law could permit the practice, and suggested that the many moral, philosophical and practical issues involved might best be worked out in the "laboratory of the states." Vermont is now part of this experiment.

Vermonters approaching the end of life deserve medical care that maximizes their comfort, respects their values, addresses their fears and concerns and continually seeks to optimize their quality of life. Goals, preference and priorities surrounding care at the end of life often vary from patient to patient. When faced with life-threatening illness, some

patients want aggressive life-prolonging interventions to the very end. Many want comfort measures only. Still others, seeking to control the time and manner of death, find reassurance in having a lethal prescription available, even if they choose not to use it. This divergence of goals and priorities makes it essential that throughout the course of illness, patients receive responsive care based on shared understandings, fully informed choices and repeated assessment of changing needs and concerns. Excellent palliative care (and hospice for those who choose it) remains the standard of care for patients approaching the end of life. Act 39 does not replace this standard.

The Vermont Ethics Network recognizes that while Vermonters hold a diversity of views in regard to PAD, 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 encourages Vermont citizens, health care providers and facilities to thoroughly inform themselves about the new law. To assist in that process, this edition of Health Decisions contains answers to some of the frequently asked questions that have arisen since the passage of Act 39.



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The mission of the Vermont Ethics Network is to promote ethics as a core component of health care and health care decision-making

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FREQUENTLY ASKED QUESTIONS

Act 39: Patient Choice and Control at the End of Life

We recommend reading all of the questions and answers. This information is provided as a courtesy and is not intended as legal advice. Please consult your physician or attorney for further information or clarification.

[GENERAL QUESTIONS]

What is the Patient Choice and Control at End of Life Act?

The Patient Choice and Control at End of Life Act (Act 39), provides eligible Vermont residents with terminal diseases the option to be prescribed a dose of medication that, if taken, will hasten the end of their life. This option requires the participation of a Vermont-licensed physician.

Who is eligible to participate?

Vermont residents who are suffering from an incurable and irreversible disease that would, within reasonable medical judgment, result in death within six months. The patient must be capable of making a voluntary, informed health care decision, and can self-administer the prescribed dose.

How does the law work?

Until July 1, 2016, the Act lays out a step-by-step process for a patient and doctor to follow. It begins with a diagnosis and prognosis of a terminal and incurable illness that will, within medical judgment, take place within six months. Once that determination has been made, a patient may make an oral request of his or her physician to be prescribed a dose of medication that, if taken, would hasten death. The process requires, among other things, both oral and written requests, witnesses, and the second opinion of a physician. Every step must be voluntary by both the patient and the physician. On July 1, 2016, the step-by-step process sunsets, and a new law takes effects that

provides legal protections for patients and physicians choosing to discuss and/or pursue hastening death by means of a prescribed dose of medication.

What makes someone a Vermont resident?

The Act does not specify what qualifies a person as a resident: it is up to the patient's physician to make that determination. Factors demonstrating residency include, but are not limited to 1) Possession of a Vermont driver's license; 2) Registration to vote in Vermont; 3) Evidence that a person leases/owns property in Vermont; or 4) Filing of a Vermont tax return for the most recent tax year.

What does a patient do if he or she chooses not to use the prescribed dose?

Those persons who choose not to ingest a prescribed dose, or those in possession of any portion of the unused dose, must dispose of the dose in a legal manner as determined by the Drug Enforcement Agency. See the website below and consult your pharmacist for more information:

<http://www.fda.gov/forconsumers/consumerupdates/ucm101653.htm>

Do doctors have to tell patients about this option?

Under Act 39 and the Patient's Bill of Rights, a patient has the right to be informed of all options for care and treatment in order to make a fully-informed choice. If a doctor is unwilling to inform a patient, he or she must make a referral or otherwise arrange for the patient to receive all relevant information.

Are all doctors, nurses and pharmacists required to participate in Act 39?

No. Participation by any health care professional is completely voluntary.

How do you know if your doctor will participate in the Act 39?

Make an appointment to talk to your doctor about your end-of-life goals and concerns, including the option available under Act 39.

Who will be providing accountability and oversight for implementation of Act 39?

The legislature did not vest any government Agency with oversight of the Act. The Department of Health is charged with collecting forms provided by participating physicians. Alleged abuses under the law would be investigated by the relevant licensing board, the State's Attorneys Office, and/or the Vermont Attorney General's Office.

How will this impact life insurance policies?

Act 39 prohibits a life insurance company from denying benefits to individuals who act in accordance with Act 39.

Are there immunity and liability protections for physicians who participate?

Yes. A prescribing physician who follows all of the steps required by Act 39 – including documenting them and filing that documentation with the Department of Health – is immune from civil and criminal liability or professional disciplinary action.

What are the reporting requirements and what will be done with the information?

The Act requires only that the prescribing physician provide written report to the Health Department documenting that all the required steps have been taken. This information will be protected under state and federal privacy laws.

Who can prescribe this medication?

Any physician who is licensed to practice medicine in Vermont under 26 V.S.A. chapter 23 or 33. That includes physicians with MD and DO

degrees. Act 39 does not extend to other prescribers such as advanced-practice registered nurses and physician assistants.

Where can I find more information?

The Vermont Department of Health: http://healthvermont.gov/family/end_of_life_care/patient_choice.aspx

The Vermont Ethics Network: <http://www.vtethicsnetwork.org/pad.html> or (802) 828-2909

Patient Choices Vermont: www.patientchoices.org or (802) 985-9473

Compassion & Choices: <http://www.compassionandchoices.org/> or 1-800-247-7421

[PATIENT QUESTIONS]**How do I determine if I am eligible to participate in Act 39 (Vermont's new Patient Choice Law)?**

In order to participate and have a physician legally provide the requested medication, a patient must:

- Be at least 18 years of age
- Have a terminal condition with a life expectancy of 6 months or less
- Be a resident of Vermont
- Be under the care of a physician
- Be capable of making an informed decision
- Make a voluntary request to a physician for medication to be self-administered for the purpose of hastening their own death.

What are the requirements for proof of residency?

The Act does not specify what qualifies a person as a resident: It is up to the patient's physician to make that determination. Factors demonstrating residency include, but are not limited to 1) Possession of a Vermont driver's license; 2) Registration to vote in Vermont; 3) Evidence that a person leases/owns property in Vermont; or 4) Filing of a Vermont tax return for the most recent tax year.

If I live in another state, can I participate while on vacation in Vermont?

No, to participate in Vermont's law a patient must be a resident of Vermont.

What constitutes self-administration? Is some assistance permitted?

Act 39 does not specifically define what constitutes self-administration. Assessment of the ability to self-administer is determined by the physician who is prescribing the medication under the provisions outlined in the law.

If I utilize Act 39, will my death be considered a suicide?

No. According to Act 39, actions taken in accordance with the law will not be construed for any purpose to constitute suicide, assisted suicide, mercy killing or homicide.

Can I change my mind and not ingest the medication?

Yes, a patient can always change his or her mind at ANY TIME during the process, including after obtaining the prescription.

Where can I find a physician who is willing to prescribe under Act 39?

There is no centralized list of participating prescribing physicians. Patients seeking information about Act 39 should consult with their physician. Individuals can also obtain further information about Vermont's law and about aid in dying in general at:

The Vermont Department of Health: http://healthvermont.gov/family/end_of_life_care/patient_choice.aspx

The Vermont Ethics Network: <http://www.vtethicsnetwork.org/pad.html> or (802) 828-2909

Patient Choices Vermont: www.patientchoices.org or (802) 985-9473

Compassion & Choices: <http://www.compassionandchoices.org/> or 1-800-247-7421

If my doctor is from another state, can s/he prescribe for me if I am a Vermont resident?

Under Act 39, the prescribing physician must be licensed to practice in Vermont.

Is there a standard form for the written request?

Yes, the Vermont Department of Health has created a form that patients may, but are not required to use for submitting their written request. (http://www.vtethicsnetwork.org/forms/End_of_Life_Choice_patient_medication_request_form.pdf).

What happens if the medication fails?

The physician and patient should talk in advance about the possibility of an adverse or unexpected event. Ideally patients who are utilizing this option will have executed a Do Not Resuscitate /Clinician Order for Life Sustaining Treatment (DNR/ COLST) Order that directs family and health care professionals, including emergency personnel, about what to do should an unexpected event occur.

Will my pharmacy fill the prescription?

All participation in Vermont's law is voluntary; therefore no pharmacist is under any duty, by law or contract, to provide a lethal dose of medication to a patient. We do not know which pharmacies/pharmacists will be participating.

Should my advance directive include a statement about my wishes related to Act 39?

Advance Directives are not the appropriate tool to specify preferences around aid in dying since those preferences CANNOT be carried out by a health care agent/proxy when a patient is no longer capable of making his or her own decisions. Advance Directives go into effect when a patient is no longer willing or able to make their own health care decisions. Act 39 requires that a patient be capable making an

informed decision about his or her health care at the time that they are seeking the prescription. Therefore a prior declaration through an Advance Directive isn't sufficient to obtain a prescription.

Advance Directives are however an excellent way to think about and document goals, preferences and priorities surrounding care and treatments at the end of life. So, if a patient decides to request a lethal prescription, it would be a good idea to mention that in one's Advance Directive in case the prescription does not lead to the patient's death. It would also be wise to have a COLST form documenting which treatments should be withheld, if death is not successfully hastened.

Will my insurance cover this?

Under federal law, Medicare/Medicaid funds cannot be used for any provider services or medication directly related to physician aid in dying. Medicare and Medicaid both pay for discussions of terminal illness including evaluation and treatment of symptoms and questions related to end of life care. Private insurance companies may vary in terms of coverage so it is best to

inquire in advance to clarify what will and will not be covered.

Who can witness my written request?

The patient must have 2 or more witnesses who are over the age of 18 and can affirm that the patient appeared to understand the nature of the document and was free from duress or undue influence at the time that the request was signed. The witnesses CANNOT be:

- The patient's physician;
- A patient's relative by blood, civil marriage, civil union or adoption;
- A person who knows that s/he would be entitled, upon the patient's death, to any portion of the estate, or assets of the patient under any will or trust, by operation of law, or by contract; or
- An owner, operator, or employee of a health care facility, nursing home, or residential care facility where the patient is receiving medical treatment or is a resident.

The written request does not need to be witnessed in the presence of the prescribing physician.

Health Care Planning is for Everyone

*It's always too soon...until it's too late –
Start the Conversation Today!*

- TALK to others about your values and future health care wishes.
- GO to www.vtethicsnetwork.org for the Vermont Advance Directive Form and for comprehensive information about Advance Care Planning and Advance Directives.
- COMPLETE your Advance Directive.
- REGISTER your Advance Directive with the Vermont Advance Directive Registry—an easy and secure way to give your health care providers immediate access to your wishes about health care decisions.

For more information about the Vermont Ethics Network, or to order the Taking Steps Booklet, contact us by phone at 802.828.2909 or via e-mail at ven@vtethicsnetwork.org.

VEN FALL CONFERENCE

Vermont's New Normal

End-of-Life Care & Physician Aid in Dying (ACT 39)

Lake Morey Resort & Conference Center | Fairlee, VT | October 29, 2013 | 9:00 – 4:00

TOPICS & PRESENTERS

Vermont's Act 39: Ethical Issues for physicians, hospice workers & institutions caring for persons near the end of life

Nancy Berlinger, PhD, Deputy Director and Research Scholar, The Hastings Center

Nancy Berlinger, a research scholar, focuses on ethical challenges in health care work and on related areas of professional education and health policy in the United States and internationally. Special interests include treatment decision-making and care near the end of life; ethical issues in the management of chronic illnesses, including cancer; and access to health care for undocumented immigrants and migrant workers. She directed the research project that produced a revised and expanded edition of *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life* (2013) and is the first author of the new Guidelines. She is also the author of *After Harm: Medical Error and the Ethics of Forgiveness* (2005). She teaches health care ethics at Yale University School of Nursing.

Oregon & the Death With Dignity Law: Finding our Way

Peter Reagan, MD, Regional Medical Director, Compassion & Choices of Oregon

Dr. Reagan is a retired family physician and was involved in the election campaigns for Oregon's Death with Dignity (DWD) law in 1993 and in 1997. In response to a request from a colleague, he wrote Oregon's first prescription under the DWD law. Dr. Reagan wrote about ten prescriptions during his practice and attended three deaths. Currently, Dr. Reagan serves as a regional medical director for Compassion & Choices of Oregon focusing on helping Oregonians who qualify for the process find the resources and information they need to proceed.

Legal & Reimbursement Considerations with Act 39

Linda Cohen, JD, Health Care Attorney, Dinse, Knapp & McAndrew

Linda J. Cohen focuses her practice on health care regulatory compliance, reimbursement and transactions. She serves as outside general counsel for home health agencies and skilled nursing facilities and has substantial experience in reimbursement issues involving both governmental and commercial payors, having litigated many disputes to conclusion.

Clinical Practice Guidelines for Aid in Dying

Judith Neall Epstein, ND, Medical Director, Compassion and Choices

Dr. Judy Neall Epstein is the national Medical Director for the End-of-Life Consultation Program with Compassion & Choices. Her background is as a family practice naturopathic physician in private practice for twelve years and a hospice volunteer. Dr. Epstein is motivated by the belief that we all are entitled to live the most meaningful life we choose, and to have a peaceful death as part of that life. She graduated from Oregon State University with a major in Public Health and minor in Nutrition Science. She received her doctorate from National College of Natural Medicine in Portland, Oregon.

Hastening Death without PAD: An ethical analysis focusing on the right to refuse life-sustaining treatment, high dose opioids to control pain and voluntarily stopping eating & drinking

Robert Macauley, MD, FAAP, FAAHPM, Medical Director of Clinical Ethics, Fletcher Allen Health Care

Robert Macauley is Medical Director of Clinical Ethics at Fletcher Allen Health Care, and Professor of Pediatrics at the University of Vermont College of Medicine. He presently serves on the ethics committees of

both the American Academy of Hospice and Palliative Medicine, as well as the American Academy of Pediatrics, and is currently at work on a textbook on ethics of end-of-life care.

Honoring Choice: Effective Communication about Death & Dying

Diana Barnard, MD, Palliative Care Specialist, Fletcher Allen Health Care

Diana Barnard is a Family Practice Physician who has worked in a variety of care settings including 15 years in a Private Family Practice Office in Middlebury, VT. From 2009-2011 she and a partner ran a home based practice in Addison County for those facing serious illness. Since then she has worked as a Palliative Care Attending at Fletcher Allen Health Care and is an Assistant Professor at the University of Vermont. Dr. Barnard is Board Certified in Family Medicine with certification in Hospice and Palliative Medicine.

Dartmouth Atlas End-of-Life Quality Report: Where do we go from here?

William Nelson, PhD, Associate Professor, The Dartmouth Institute for Health Policy & Clinical Practice and the Geisel School of Medicine

William A. Nelson, PhD, is Associate Professor at the Dartmouth Institute for Health Policy and Clinical Practice, Geisel School of Medicine at Dartmouth in Hanover, NH. Nelson is considered a pioneer in the area of healthcare organization ethics and has made many ground-breaking scholarly and education contributions to the field. He is the principal investigator on several federal- and state-funded research projects to foster an evidence-based approach to ethics and the linkage between ethics and quality healthcare. In addition to his current post, he serves as adjunct associate professor of Health Administration, Robert F. Wagner Graduate School of Public Service at New York University.



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VEN NEWS & UPDATES

GEORGE K. BELCHER JOINS THE VEN BOARD OF DIRECTORS

George Belcher graduated from Kansas University ('71) and Vermont Law School ('77). He was an officer in the U.S. Navy for three years. After graduating from law school he practiced general law in central Vermont until 1990 when he was elected as the Washington County Probate Judge, a position he held until retirement in 2012. He is a past president of the probate judges' association and has been active in various committees and programs concerning end-of-life, electro-convulsive therapy, surrogate decision making, and medical-legal issues surrounding guardianships.

George lives in Montpelier with his wife, Suzanne, who is a MSW social worker with the University of Vermont training partnership.

NEW ONLINE COURSE

CLINICAL ETHICS FOR ETHICS COMMITTEE MEMBERS

Office Of Staff Development
Loma Linda, California
(909) 558-3500 • Fax (909) 558-3541

Instructor: Robert D. Orr, M.D.

Dr. Orr received his M.D., C.M. from McGill University in 1966, did residency training in family medicine, and practiced in Vermont for 18 years. Since completing a fellowship in clinical ethics at the University of Chicago, he has taught clinical ethics at Loma Linda University School of Medicine (CA), the University of Vermont College of Medicine, the Graduate College at Union University (NY),

and Trinity International University (IL). He is currently Professor of Medical Ethics and Consultant in Clinical Ethics at Loma Linda University in southern California. He lectures widely and has co-authored or co-edited 6 books, 11 book chapters, and over 150 articles on ethics, ethics consultation, and end-of-life care. His awards include the Vermont Family Doctor of the Year (1989), the Isaac Hayes and John Bell Award for Leadership in Medical Ethics and Professionalism (AMA, 1999), Scholar in Residence at the Kilns (CS Lewis Foundation, 2006) and the Servant of Christ Award (Christian Medical and Dental Associations, 2009). His most recent book is *Medical Ethics and the Faith Factor* (Wm.B. Eerdmans, 2009).

Course Description:

Hospital Ethics Committees generally have 3 functions: (1) education, (2) policy review, and (3) case consultation. This course is designed to address that 3rd function, case consultation. We will discuss some of the more common issues that lead to requests for consultation in clinical ethics and offer some procedural assistance in providing consultations.

Course Objectives:

By completing this course, participants should be able to:

1. articulate several basic concepts and principles of clinical ethics,
2. apply these concepts and principles to specific cases,
3. describe the basic steps in clinical ethics consultation, and
4. construct a case report with case analysis suitable for inclusion in the patient's medical record.

CE credit hours are available. No charge for ethics committee members. If you have any questions please feel free to contact us at staffdevelopment@llu.edu.