Report to The Vermont Legislature

Report Concerning Patient Choice at the End of Life

In Accordance with Act 27 (2015), Section 1

Submitted to: House Committees on Human Services and on Health Care; and

Senate Committee on Health and Welfare.

Submitted by: Mark Levine, M.D., Commissioner,

Vermont Department of Health

Prepared by: The Division Health Statistics & Informatics Vermont

Department of Health

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108 Cherry Street PO Box 70 Burlington, VT 05402 **healthvermont.gov**

Introduction

In 2013, the General Assembly passed Act 39 that allowed Vermont physicians to prescribe medication to individuals with a terminal condition with the intent that the medication be self-administered for the purpose of hastening the patient's death. Act 39 (2013) set forth conditions for the patient and the physician for this action to be taken lawfully. Those conditions include an oral and written request by the patient to the physician, a reminder that all steps in the process must be voluntary, that the patient be capable of making such a decision, confirmation of the diagnosis and prognosis by a second Vermont physician, and an attestation by a non-interested witness to these steps. See Appendix A for the complete requirements set forth in 18 V.S.A. § 5283.

Once the prescribing physician fulfills all the statutory requirements, the physician is required to report to the Department of Health that all steps have been taken. The filing of the report confers on health care providers associated with the treatment of the patient for this hastening of the patient's death, immunity from professional, criminal, or civil liability.

In 2015, the General Assembly passed Act 27 (see Appendix A) that requires the Department of Health to adopt rules (see Appendix B) to facilitate the collection of information regarding compliance. Act 27 also requires the Department to generate and make available to the public this report: a biennial statistical overview of the information collected by the Department, as long as releasing the information complies with the federal Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104 - 191.¹

In May 2023, Act 10 (2023) was enacted, removing the requirement that only Vermont residents have access to Patient Choice at the End of Life (Patient Choice).

Summary of Underlying Causes of Death

The following summary is based on cases where the Vermont Department of Health (Department) received all required reporting documents in accordance with state law, at which time the "case" becomes a "reportable event." Due to the timing of the passage of Act 10 (2023), out-of-state residents who used Patient Choice during the reporting period are not accounted for in this report. Future reports will capture the data for out-of-state resident use.

Statistics Since the Passage of Act 39 (2013): May 31, 2013 - June 30, 2023

From May 31, 2013, to June 30, 2023, there were 203 reportable events. The events fell into the following underlying diagnoses groups:

¹ This means that this report will contain no information that could be used to potentially identify any patients or health care providers who have taken steps under the 18 V.S.A Chapter 113.

² Not all Patient Choice deaths are necessarily accounted for in the proceeding figures. The data collected for this report is based on the data submitted to the Department by reporting physicians. It is possible some physicians fail to report all the information that is required in accordance with the law or report incorrect information to the Department.

- 75% were due to cancer (153 cases);
- 13% were due to neurodegenerative conditions (26 cases);
- 3% were due to end-stage lung disease (i.e., COPD, emphysema, idiopathic pulmonary fibrosis) (6 cases);
- 3% were due to multiple conditions (6 cases);³
- 3% were due to other events (6 cases);⁴
- 2% were due to end-stage congestive heart failure (5 cases);
- 0.5% was due to an unknown diagnosis or cause (1 case).

Statistics During the Report Period: July 1, 2021 - June 30, 2023

From July 1, 2021, to June 30, 2023, there were 85 total reportable events to the Department. The events fell into the following underlying diagnoses groups:

- 73% were due to cancer (62 cases);
- 8% were due to neurodegenerative conditions (7 cases);
- 5% were due to end-stage lung disease (i.e., COPD, emphysema, idiopathic pulmonary fibrosis) (5 cases);
- 5% were due to multiple conditions (4 cases);
- 5% were due to other events (4 cases);
- 2% were due to end-stage congestive heart failure (2 cases); and
- 1% was due to unknown diagnosis or cause (1 case).

Eighty-four out of the eighty-five total reportable events have a death certificate on file with the Vermont Vital Records' Office.⁵ All of the available death certificates list the appropriate cause (the underlying disease) and manner of death (natural), per Act 39 (2013) requirements.

The mechanism of death on those 84 death certificates included:

- 72 died by Patient Choice (86%);
- 8 died from the underlying disease (10%);
- 1 died from something "other" (1%); 6 and
- 3 died from unknown mechanisms (4%).⁷

Number of Prescriptions Filled in Vermont

The Department used the Vermont Prescription Monitoring System (VPMS) to identify patients that had filled a prescription in Vermont under the law. The Department positively identified within the VPMS 57 out of the 84 confirmed deceased individuals as having filled a prescription

³ "Multiple conditions" means that more than one disease was listed as an underlying diagnosis. For example, end-stage lung disease and cancer, two or more illnesses otherwise categorized as 'other', or a neurodegenerative condition and end-stage congestive heart failure.

⁴ "Other events" means that the cause of death is known but is not in one of the listed underlying diagnoses groups (i.e., it is not a cancer, neurodegenerative disease, etc.)

⁵ Patients who died out-of-state may not have a birth certificate on file with the Vermont Vital Records Office.

⁶ "Other" means that the prescribing physician indicated the patient died from something other than the Patient Choice prescription, the underlying disease, or the patient was not deceased 60 days after the prescription was written.

⁷ "Unknown" means the patient died but it is unknown to the reporting physician if the patient died from the Patient Choice prescription or from the underlying disease.

in Vermont under the law. There are a variety of reasons that might account for the remainder of the prescriptions not being present in VPMS. 8

⁸ VPMS does not capture medications that are not filled by a patient or prescriptions that are filled out-of-state.

Appendixes

Appendix A: 18 V.S.A. § 5283

https://legislature.vermont.gov/statutes/fullchapter/18/113

Appendix B: Rule Governing Compliance with Patient Choice at the End of Life http://www.healthvermont.gov/sites/default/files/documents/2016/12/REG_patient-choice-at-end-of-life-compliance.pdf

Appendix C: Reporting Forms

Form 1- Patient Request for Medication Form

Form 2- Physician Reporting Form

Form 3- Consulting Physician Reporting Form

Form 4- Prescribing Physician Follow-Up Form