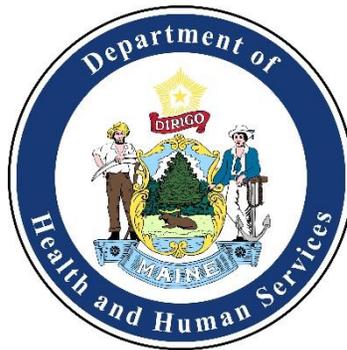

**Report to
The Maine State Legislature**

**PATIENT-DIRECTED CARE
2021 ANNUAL REPORT**



Submitted to: Joint Standing Committee on Health and Human Services

Submitted by: Jeanne M. Lambrew, Commissioner, Department of Health and Human Services

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Report date: Spring 2022

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Executive Summary

In accordance with 22 MRS § 2140(17), the Department of Health and Human Services (Department) shall generate and make available to the public an annual statistical report of information collected under the Maine Death with Dignity Act (Act). The Department is mandated to submit a copy of the report to the Joint Standing Committee of the Legislature having jurisdiction over health matters, annually by March 1. This report is for patients who completed a written request for medication to hasten their death in calendar year 2021. Patients who completed the oral request but not a written request within the calendar year will be included in the subsequent year's report.

This report provides statistics concerning the utilization of patient-directed care under the Maine Death with Dignity Act, 22 MRS chapter 418. Specifically, this report provides information about patients who have reportedly met the requirements of the Act, the underlying causes of qualified patient death, and the number of prescriptions for life-ending medication written or dispensed to qualified patients. In 2021, there were 71 patients who started the process. Three died before they could make their written requests and another made the written request after the end of the year and will be included in next year's report. There were four patients still alive at the time of this report. Patients resided in every county, except Aroostook. Patients were more likely to be older. There was no difference in male or female and cancer was the condition reported most often.

Introduction

In 2019, the 129th Maine Legislature passed Public Law 2019, Ch. 271 known and cited as the Maine Death with Dignity Act (Appendix A). The Act enables physicians to prescribe medication to a Maine resident with a terminal condition with the intent that the medication be self-administered for the purpose of hastening the patient's death. The Act set forth conditions for the patient and the physician for this action to be taken lawfully. Those conditions include, but are not limited to, 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 physician, and an attestation by a qualified witness to these steps.

Once the prescribing physician fulfills all the statutory requirements, the physician is required to attest to compliance with the Act and submit required report forms to the Department. The fact that a health care provider participates in activities under this Act may not be the sole basis for a complaint or report by another health care provider to the appropriate licensing board under Title 32, including, but not limited to, the Board of Licensure in Medicine, the Board of Osteopathic Licensure, and the Maine Board of Pharmacy.

Within six months of the effective date of the Act, the Department was directed to adopt major substantive rules to facilitate the collection of information regarding compliance with the Act. The information collected is confidential, is not a public record, and may not be made available for inspection by the public.

On June 12, 2019, Governor Janet Mills issued executive order number 9 FY19/20, directing the Department to conduct rulemaking on an emergency basis following the enactment of PL 2019 c. 271. Emergency rulemaking was conducted in accordance with 5 MRS §8054, and the Maine

Death with Dignity Act Reporting Rule, 10-146 CMR chapter 15, was in place when the law became effective on September 19, 2019 (Appendix B). The emergency rule provided guidance on reporting requirements for physicians to demonstrate that the individual made an informed decision about their end-of-life care and to ensure compliance with the law. Reporting forms were developed to collect the information required both in law and in the Governor's executive order.

To coincide with expiration of the emergency rule as means to ensuring continuity, the Department submitted for provisional adoption, a major substantive rule in January 2020. In accordance with the Maine Administrative Procedures Act, this major substantive rule was submitted to the Legislature for review and approval for final adoption.

In March 2020, the Legislature approved and the Governor signed LD 2068, *Resolve, Regarding Legislative Review of Portions of Chapter 15: Death with Dignity Act Reporting Rule, a Major Substantive Rule of the Department of Health and Human Services, Maine Center for Disease Control and Prevention*, which finalized the major substantive rules regarding this section.

Currently in effect, the Death with Dignity Act Reporting Rule requires up to five documents for reporting and compliance purposes. The content of reporting forms required by the Department is consistent with the statute. Forms are found on the Data, Research, and Vital Statistics (DRVS) website¹ or by request to the State Registrar and these forms are:

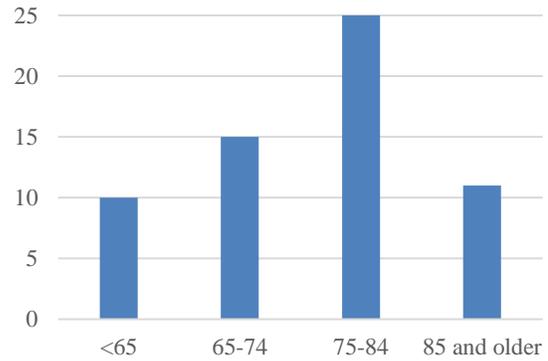
- **Request for Medication to End My Life in a Humane and Dignified Manner Form** that is to be completed and signed by the patient and two witnesses
- **Interpreter Attachment Form**, if applicable
- **Consulting Physician Form** that is to be signed by a physician who has reviewed and confirmed the medical opinion of the attending physician
- **Attending Physician End-of Life Reporting Form** which certifies all the requirements of the Act have been met, including adherence to the waiting periods set forth by the Act
- **End-of-Life Closure Form** to be completed by the attending physician within 30 days of the death of the qualified patient (Appendix C).

¹ Maine CDC Office of Data, Research and Vital Statistics; <https://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/forms/index.shtml>

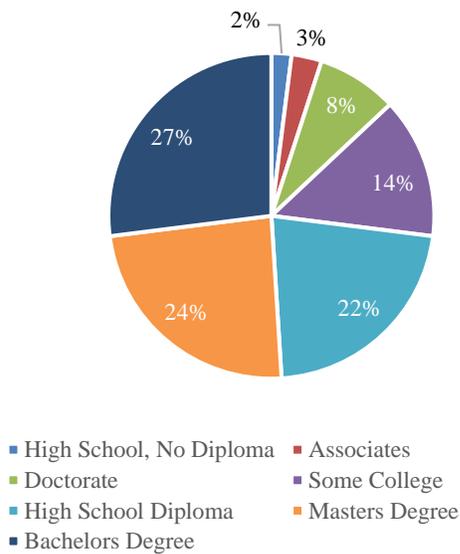
General Statistics

- There were 71 patients who started the process; however, three patients died before making their written request and another made their written request in 2022. The remaining 67 patients met all the requirements of the Act. At the time of this report, there are four for whom a death certificate could not be found. It was confirmed with the attending physician that these patients are still alive.

Number of Patients by Age



Educational Attainment



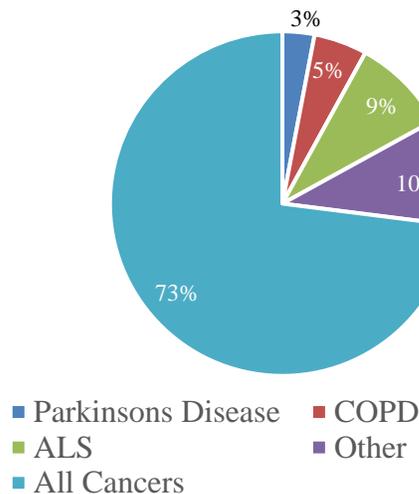
- Ages ranged from the youngest of 52 to the oldest of 97. More than half were 75 years old or older.

- Nearly a quarter of those who died had attained a high school education, while 14% had attended college but did not have a degree and 62% had college degrees.

- Of the 63 patients who died, 46 died by patient choice and 17 from the underlying illness. The average number of days between the time the prescription was written and the date of death for those patients who died from administering the prescription was 20 days.

- Cancer was the terminal condition in 46 of the cases. This represented 73% of the total. Amyotrophic lateral sclerosis (ALS) was indicated in six cases, chronic obstructive pulmonary disease (COPD) in three, Parkinson’s disease in two. The six other conditions were multiple system atrophy, essential hypertension, aortic stenosis, congestive heart failure, pulmonary fibrosis, and multiple sclerosis, with one case each.

Terminal Condition



Appendices

Appendix A

22 MRS chapter 418, available for download at:

<http://legislature.maine.gov/legis/statutes/22/title22sec2140.html>

Appendix B

10-146 CMR chapter 15, available for download at:

<http://www.maine.gov/sos/cec/rules/10/chaps10.htm#146>

Appendix C

Reporting Forms (Attending Physician End-of-Life Reporting Form, Consulting Physician Form, Interpreter Attachment Form, Request for Medication to End My Life in a Humane and Dignified Manner Form, End of Life Closure Form), available for download at:

<http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/forms/index.shtml>

§2140. Patient-directed care at the end of life

1. Short title. This chapter may be known and cited as "the Maine Death with Dignity Act." [PL 2019, c. 271, §4 (NEW).]

2. Definitions. As used in this chapter, unless the context otherwise indicates, the following terms have the following meanings.

A. "Adult" means a person who is 18 years of age or older. [PL 2019, c. 271, §4 (NEW).]

B. "Attending physician" means the physician who has primary responsibility for the care of a patient and the treatment of that patient's terminal disease. [PL 2019, c. 271, §4 (NEW).]

C. "Competent" means that, in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, psychiatrist or psychologist, a patient has the ability to make and communicate an informed decision to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available. [PL 2019, c. 271, §4 (NEW).]

D. "Consulting physician" means a physician who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding a patient's disease. [PL 2019, c. 271, §4 (NEW).]

E. "Counseling" means one or more consultations between a state-licensed psychiatrist, state-licensed psychologist, state-licensed clinical social worker or state-licensed clinical professional counselor and a patient for the purpose of determining that the patient is competent and not suffering from a psychiatric or psychological disorder or depression causing impaired judgment. [PL 2019, c. 271, §4 (NEW).]

F. "Health care provider" means:

(1) A person licensed, certified or otherwise authorized or permitted by law to administer health care services or dispense medication in the ordinary course of business or practice of a profession; or

(2) A health care facility. [PL 2019, c. 271, §4 (NEW).]

G. "Informed decision" means a decision by a qualified patient to request and obtain a prescription for medication that the qualified patient may self-administer to end the qualified patient's life in a humane and dignified manner that is based on an appreciation of the relevant facts and that is made after being fully informed by the attending physician of:

(1) The qualified patient's medical diagnosis;

(2) The qualified patient's prognosis;

(3) The potential risks associated with taking the medication to be prescribed;

(4) The probable result of taking the medication to be prescribed; and

(5) The feasible alternatives to taking the medication to be prescribed, including palliative care and comfort care, hospice care, pain control and disease-directed treatment options. [PL 2019, c. 271, §4 (NEW).]

H. "Medically confirmed" means the medical opinion of an attending physician has been confirmed by a consulting physician who has examined the patient and the patient's relevant medical records. [PL 2019, c. 271, §4 (NEW).]

I. "Patient" means an adult who is under the care of a physician. [PL 2019, c. 271, §4 (NEW).]

J. "Physician" means a doctor of medicine or osteopathy licensed to practice medicine in this State. [PL 2019, c. 271, §4 (NEW).]

STATE OF MAINE
DEATH WITH DIGNITY ACT
REPORTING RULE
10-146 CODE OF MAINE RULES
CHAPTER 15



Department of Health and Human Services
Maine Center for Disease Control and Prevention
11 State House Station
Augusta, Maine 04333-0011

Effective Date: September 19, 2019 (Emergency Major Substantive Rule)

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SECTION 1. PURPOSE AND DEFINITIONS

- A. Purpose.** This rule implements 22 MRS chapter 418, the *Maine Death with Dignity Act*, and specifies the Department's authority to collect and use information related to patient-directed care at the end of life.
- B. Definitions.** As used in this rule, unless the context indicates otherwise, the following terms have the following meanings:
1. **Act** means the *Maine Death with Dignity Act*, 22 MRS Chapter 418.
 2. **Attending physician** means the physician who has primary responsibility for the care of a patient and the treatment of that patient's terminal disease.
 3. **Competent** means that, in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, psychiatrist or psychologist, a patient has the ability to make and communicate an informed decision to health care providers, including communication through persons familiar with the patient's manner of communicating, if those persons are available.
 4. **Consulting physician** means a physician who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding a patient's disease.
 5. **Department** means the Department of Health and Human Services, Maine Center for Disease Control and Prevention.
 6. **Form** means a form prescribed by the Department that the Department requires to be completed for purposes of compliance with this rule. Forms that are missing required signatures, dates or information will not be considered valid or acceptable.
 7. **Life-ending medication** means the medication prescribed or dispensed by a licensed healthcare provider in accordance with the Act to be self-administered by the qualified patient suffering from a terminal disease to end the qualified patient's life in a humane and dignified manner.
 8. **Physician** means a doctor of medicine or osteopathy licensed pursuant to 32 MRS chapter 48 or 36.
 9. **Qualified patient** means a competent adult who is a resident of this State and who has satisfied the requirements of the Act in order to obtain a prescription for medication that the qualified patient may self-administer to end the qualified patient's life in a humane and dignified manner.

SECTION 2. SCOPE

This rule applies to healthcare providers involved in the decisions pursuant to the Act. This rule establishes reporting requirements related to patient-directed care at the end of life and responsibilities of healthcare providers participating in specific conduct under the Act. This rule does not require a healthcare provider to provide life-ending medication to a qualified patient.

SECTION 3. RESPONSIBILITIES OF HEALTHCARE PROVIDERS

- A. Compliance.** The attending physician must verify that all requirements of the Act have been met before prescribing or dispensing life-ending medication. The attending physician is responsible for ensuring that copies of all required forms are received by the Department. The attending physician must ensure that each original, completed form is retained in the qualified patient's medical record. Copies of required forms must be filed within 30 days after the date the prescription for life-ending medication is written, unless otherwise specified.
- B. Request for Medication to End My Life in a Humane and Dignified Manner.** The Request for Medication to End My Life in a Humane and Dignified Manner Form must be used for all written requests for life-ending medication. This form must be completed by the patient and two witnesses no sooner than 15 days following the patient's first verbal request for life-ending medication, in accordance with 22 MRS §§ 2140(5) and 2140(24). A copy of the completed form must be provided to the qualified patient.
1. **Witnesses.** The qualified patient's signature on this form must be witnessed by at least two individuals who, in the presence of the qualified patient, attest that to the best of their knowledge and belief, the patient is competent, is acting voluntarily, and is not being coerced to sign the request. One witness must be a person who is not a relative of the patient by blood, marriage, or adoption; a person who at the time the form is signed would be entitled to any portion of the estate of the patient upon death, under any will or by operation of any law; or an owner, operator or employee of a health care facility where the patient is receiving medical treatment or is a resident.
 - a. **Attending Physician.** The patient's attending physician at the time the written request is signed may not be a witness.
 - b. **Patient in a Long-Term Care Facility.** If the patient resides in a long-term care facility at the time of the patient's written request, one witness must be a licensed healthcare provider designated by the facility. The facility's designee may be an owner, operator or employee of the healthcare facility where the patient resides.
- C. Interpreter Attachment.** The Interpreter Attachment Form is only required if an interpreter is used pursuant to 22 MRS §2140(5)(B), to interpret conversations or consultations between the patient and the patient's attending or consulting physician in a language other than English, regarding the written request for life-ending medication. If an interpreter is used, this form, containing the elements required by 22 MRS §2140 (25), must accompany the Request for Medication to End My Life in a Humane and Dignified Manner Form.
1. **Interpreter Limitations.** The interpreter must not be a person who is a relative of the patient by blood, marriage, or adoption; a person who at the time the written request is signed would be entitled to any portion of the estate of the patient upon death, under any will or by operation of any law; or an owner, operator, or employee of a health care facility where the patient is receiving medical treatment or is a resident.
- D. Consulting Physician End-of-Life Care Form.** The Consulting Physician End-of-Life Care Form, containing the reporting requirements of 22 MRS §§ 2140 (7) and 2140 (14)(D), must be completed by the consulting physician who has examined the patient, has reviewed the patient's medical record, and who has confirmed the medical opinion of the attending

physician that the patient is suffering from a terminal disease and has verified that the patient is competent, is acting voluntarily, and has made an informed decision.

- E. Attending Physician End-of-Life Reporting Form.** The Attending Physician End-of-Life-Reporting Form must be completed by the attending physician to certify that all requirements of the Act have been met, including the attending physician's responsibilities at 22 MRS §2140(6), the documentation requirements at 22 MRS §2140(14), and the waiting periods set forth at 22 MRS §2140(13). A copy of the written prescription record must accompany this form.
- F. End-of-Life Closure Form.** The End-of-Life Closure Form must be completed by the attending physician within 30 days after the qualified patient's death, in accordance with 22 MRS §2140 (17)(B)(1). If six months have passed from the date the attending physician prescribed or dispensed the life-ending medication and the qualified patient's death has not been confirmed, the attending physician must complete this form and provide a copy to the State Registrar within 30 days following the expiration of that six-month period, retaining the original in the patient's medical record.

SECTION 4. REPORTING AND RECORD RETENTION

A. Reporting.

1. Reporting must be in the manner prescribed by the Department, using the forms specified in this rule. Copies of the forms may be accessed at the Department's Data Research and Vital Statistics website at <http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/forms/index.shtml>, or by request to the State Registrar.
2. Copies of completed forms must be mailed to the attention of the State Registrar, Office of Data, Research, and Vital Statistics, 220 Capitol Street, 11 State House Station, Augusta, Maine 04333-0011.
3. All forms must be completed in accordance with the Act and this rule. Unless otherwise specified, all forms must be submitted to the State Registrar no later than 30 days after the date of the prescription for life-ending medication is written. The Department will contact the qualified patient's attending physician when it appears that any required form has not been filed.
4. The Department will collect information from attending physicians who have prescribed or dispensed life-ending medication to ensure compliance with the Act and this rule, and for use in assembling an annual statistical report as required by the Act. Required information will include any information requested on the forms prescribed by the Department and specified in this rule. Additionally, the Department may request from an attending physician any other information reasonably necessary to determine compliance with the Act and this rule.

B. Record Retention.

1. The attending physician prescribing or dispensing life-ending medication to a qualified patient must retain the original of each required form in the patient's medical record.

2. Paper forms submitted to the State Registrar will be retained by the Department to inform the annual report and may be destroyed only after the Department publishes the yearly report required by the Act.
- C. Confidentiality.** Information collected by the Department pursuant to this rule is confidential, is not a public record, and may not be made available for inspection by the public.
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STATUTORY AUTHORITY AND HISTORY

STATUTORY AUTHORITY:

22 MRS Chapter 418 §2140

EFFECTIVE DATE:

September 19, 2019 – filing 2019-170 (*Emergency major substantive*)

APPENDIX C.

Maine CDC Reporting Forms (Attending Physician End-of-Life Reporting Form, Consulting Physician Form, Interpreter Attachment Form, Request for Medication to End My Life in a Humane and Dignified Manner Form, End of Life Closure Form), [available online](#) and linked here:

- [Request for Medication to End My Life in a Humane and Dignified Manner Form](#) (Fillable PDF)
- [Attending Physician Reporting Form](#) (Fillable PDF)
- [Consulting Physician Form](#) (Fillable PDF)
- [Interpreter Attachment Form](#) (Fillable PDF)
- [End of Life Closure Form](#) (Fillable PDF)