

COLORADO END-OF-LIFE OPTIONS ACT, YEAR TWO 2018 DATA SUMMARY, WITH UPDATES TO 2017 DATA

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For more information, visit www.colorado.gov/pacific/cdphe/medical-aid-dying

Introduction

In 2016, Colorado voters approved Proposition 106, “Access to Medical Aid In Dying,” which amends Colorado statutes to include the Colorado End-of-Life Options Act, Article 48 of Title 25, Colorado Revised Statutes (C.R.S.). This Act allows an eligible terminally-ill individual with a prognosis of six months or less to live to request and self-administer medical aid-in-dying medication in order to voluntarily end his or her life; authorizes a physician to prescribe medical aid-in-dying medication to a terminally ill individual under certain conditions; and creates criminal penalties for tampering with a person’s request for medical aid-in-dying medication or knowingly coercing a person with a terminal illness to request the medication.

This Act requires prescribing physicians and health care professional dispensing aid-in-dying medication to report to the Colorado Department of Public Health and Environment (CDPHE) specific information outlined by the Act. This information is to be used to ensure documentation requirements outlined in the Act are met, as well as to make available to the public an annual statistical report. Rules for reporting were adopted by the Board of Health in 2017 (6 CCR 1009-4, Reporting and Collecting Medical Aid-in-Dying Medication Information).

This report is the second annual statistical report published per this Act, describing Colorado’s participation in End-of-Life Options activities in 2018, and incorporates updates to previously-published 2017 statistics.

Data collection and statistics

Statistics presented in this report reflect patients for whom prescriptions for aid-in-dying medication were written; and among those, patients to whom aid-in-dying medications were dispensed and deaths among patients subsequent to prescription of aid-in-dying medication. Data used for this report are based on required reporting forms and death certificates received by CDPHE. More information about the reporting process and required forms as well as this this annual report are available at: www.colorado.gov/pacific/cdphe/medical-aid-dying

It is important to note that the Colorado End-of-Life Options Act does not authorize or require the Colorado Department of Public Health and Environment to follow up with physicians who prescribe aid-in-dying medication, patients, or their families to obtain information about use of aid-in-dying medication. Additionally, the Colorado End-of-Life Options Act requires that the cause of death assigned on a patient’s death certificate be the underlying terminal illness. Thus, statistics in this report for deaths are based on all deaths identified among individuals prescribed aid-in-dying medication, whether or not they used this medication, and noting that death may have been caused by ingestion of medication, the underlying terminal illness or condition, or some other cause.

Since the publication of Colorado End-of-Life Options Act, Year One: 2017 Data Summary, additional reporting forms from health care providers concerning 2017 prescriptions were submitted to CDPHE throughout 2018. More death certificates associated with patients who were prescribed aid-in-dying medication in 2017 were also received by CDPHE in 2018. This report incorporates the additional information received about patients participating in End-of-Life Options activities in 2017, in addition to the new data for 2018.

Participation in end-of-life options activities

In 2018, 125 patients received prescriptions for aid-in-dying medications under the provisions of the Colorado End-of-Life Options Act. This represents a 74 percent increase in the number of prescriptions compared to 2017 (during which time there were 72 patients receiving prescriptions). Among those prescribed aid-in-dying medication in 2018, CDPHE has received reports for 86 patients to whom aid-in-dying medication was dispensed. Also among those prescribed aid-in-dying medication, CDPHE has received death certificates for 104 patients through routine vital records registration. Note that not all of these deceased patients were dispensed aid-in-dying medication, and deaths may have been due to ingestion of aid-in-dying medication, the underlying terminal illness or condition, or other causes.

Prescriptions written in 2018 for aid-in-dying medication were provided by 66 unique Colorado physicians. The median age of patients prescribed aid-in-dying medication was 69 (minimum age was in the mid-30's, maximum age was in the upper-90's). Among patients prescribed aid-in-dying medication, the most common illnesses or conditions were malignant neoplasms (cancer), progressive neurodegenerative diseases (including amyotrophic lateral sclerosis/ALS, progressive supranuclear palsy, Parkinson's disease and multiple sclerosis), chronic lower respiratory diseases (including chronic obstructive pulmonary disease, or COPD) and heart diseases (including heart failure) (Table 1).

Table 1. Underlying terminal illnesses/conditions among patients prescribed aid-in-dying medication, 2017-2018.

	2017		2018	
	Number	Percent (%)	Number	Percent (%)
Total number of patients prescribed aid-in-dying medication	72	100	125	100
Malignant neoplasms - Total	47	65.3	75	60.0
Malignant neoplasm - Lung	11	15.3	9	7.2
Malignant neoplasm - Pancreas	8	11.1	9	7.2
Malignant neoplasm - Breast	*	*	6	4.8
Malignant neoplasm - Colon and rectum	4	5.6	6	4.8
Malignant neoplasm - Head and neck	6	8.3	5	4.0
Malignant neoplasm - Central nervous system	*	*	4	3.2
Malignant neoplasm - Esophagus	*	*	4	3.2
Malignant neoplasm - Melanoma	*	*	4	3.2
Malignant neoplasm - Ovary	*	*	4	3.2
Malignant neoplasm - Kidney, bladder and urinary tract	*	*	3	2.4
Malignant neoplasm - Prostate	7	9.7	3	2.4
Other malignant neoplasm	3	4.2	18	14.4
Progressive neurological disorders - Total	12	16.7	26	20.8
Amyotrophic lateral sclerosis	9	12.5	13	10.4
Progressive supranuclear palsy	0	0.0	5	4.0
Parkinson's disease	*	*	4	3.2

	2017		2018	
	Number	Percent (%)	Number	Percent (%)
Other progressive neurodegenerative disorders	*	*	4	3.2
Chronic lower respiratory disease	6	8.3	7	5.6
Heart disease	7	9.7	6	4.8
Other illnesses/conditions	0	0.0	11	8.8

Updated statistics for 2017 presented for same categories as for 2018; however, cells based on one or two events are suppressed as needed to protect confidentiality of patients.

'Other malignant neoplasm' includes cancers of the bile duct, cervix, endometrium, stomach as well as multiple myeloma, leukemia and others.

'Other progressive neurodegenerative disorders' includes multiple sclerosis, corticobasal degeneration and others.

'Other illnesses/conditions' include cerebrovascular disease (stroke), chronic kidney disease, and others.

In 2018, aid-in-dying medications were dispensed by 23 unique pharmacists in Colorado, and included Secobarbital (brand name Seconol) or a combination of diazepam, digoxin, morphine sulfate, and propranolol (prepared as DDMP or DDMP2 combination) (Table 2).

Table 2. Categories of medications dispensed to patients prescribed aid-in-dying medication, 2017-2018.

	2017		2018	
	Number	Percent (%)	Number	Percent (%)
Total number of patients to whom aid-in-dying medication was dispensed	56	100	86	100
Secobarbital	23	41.1	27	31.4
DDMP Compound (diazepam, digoxin, morphine sulfate, propranolol)	32	57.1	59	68.6
Other (morphine sulfate alone, or in some other combination)	1	1.8	0	0.0

Characteristics of patients prescribed aid-in-dying medication who have died

Among patients who died following an aid-in-dying prescription written in 2018, the median duration of time between the date of prescription and date of death was 12 days (minimum of zero days, maximum of nearly eight months). Table 3 presents characteristics of patients who have been prescribed aid-in-dying medication, and for whom a death certificate was subsequently registered with CDPHE. Again, it is important to note that these statistics reflect all deaths identified among individuals prescribed aid-in-dying medication, whether or not they used this medication, and irrespective of whether their death was caused by ingestion of medication, the underlying terminal illness or condition, or some other cause.

Table 3. Summary of patients who died following prescription of aid-in-dying medication, 2017-2018.

	2017		2018	
	Number	Percent (%)	Number	Percent (%)
Total number of decedents prescribed aid-in-dying medication	70	100	104	100
Sex				
Female	32	45.7	50	48.1
Male	38	54.3	54	51.9

	2017		2018	
	Number	Percent (%)	Number	Percent (%)
Age group				
18-44	*	*	3	2.9
45-54	*	*	11	10.6
55-64	10	14.3	18	17.3
65-74	23	32.9	32	30.8
75-84	22	31.4	24	23.1
85+	12	17.1	16	15.4
Race/ethnicity				
White, non-Hispanic	66	94.3	98	94.2
White, Hispanic	3	4.3	5	4.8
Other/unknown	1	1.4	1	1.0
Marital status				
Married	34	48.6	53	51.0
Divorced	19	27.1	20	19.2
Widow/widower	16	22.9	20	19.2
Never been married	1	1.4	11	10.6
Educational attainment				
High school graduate or GED completed or less	19	27.1	25	24.1
Some college credit but no degree	13	18.6	19	18.3
Associate's degree	9	12.9	5	4.8
Bachelor's degree	19	27.1	21	20.2
Master's degree	3	4.3	21	20.2
Doctorate or professional degree	7	10.0	13	12.5
County of residence				
Denver Metro Area (Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, Jefferson)	44	62.9	67	64.4
Other Front Range (El Paso, Larimer, Pueblo, Weld)	17	24.3	20	19.2
Other counties	9	12.9	17	16.3
Place of death				
Residence	58	82.9	90	86.5
Nursing home/long-term care facility	9	12.9	5	4.8
Other/unknown	3	4.3	9	8.7
Hospice enrollment status				
Under hospice care	63	90.0	88	84.6
Not under hospice care	7	10.0	16	15.4

Updated statistics for 2017 presented for same categories as for 2018; however, cells based on one or two events are suppressed as needed to protect confidentiality of patients.

*'Place of death - Other/unknown' includes hospice facilities, inpatient setting, outpatient facilities, or unspecified location.

Monitoring compliance with reporting requirements

To comply with the Colorado End-of-Life Options Act, physicians who prescribe aid-in-dying medication, and those health care providers who dispense such medication, must submit documentation to CDPHE per rules promulgated by the Colorado Board of Health.

Physicians who prescribe aid-in-dying medication must submit:

- Attending/prescribing physician form.
- Patient’s completed written request for medical aid-in-dying medication.
- Written confirmation of mental capacity from a licensed mental health provider (if applicable).
- Consulting physician’s written confirmation of diagnosis and prognosis.

Health care providers who dispense aid-in-dying medication must submit:

- Medication dispensing form.

Table 4 contains a summary of documentation received by CDPHE concerning patients who were prescribed aid-in-dying medication. This information is based on reporting forms and supplemental documentation received by CDPHE as of January 25, 2019.

Table 4. Documentation received for patients participating in the Colorado End-of-Life Options Act, 2017-2018.

	2017	2018
Form/Document	Number	Number
Attending/prescribing physician form	63	109
Patient’s completed written request	50	90
Mental health provider’s confirmation	1	0
Consulting physicians written confirmation	30	84
Medication dispensing form	56	86
Death certificate	70	104

While reporting of the required documentation (including prescribing forms, patients’ written requests, consulting physicians’ written confirmations, and mental health provider confirmation when applicable) may be incomplete, all attending/prescribing forms received contained physicians’ signed attestations that all requirements of the Colorado End-of-Life Options Act have been met, and that required documentation is complete and contained in patients’ records. Efforts continue to educate physicians and other health care providers about reporting requirements.

Additional instructions for reporting, including specific regulations and forms, and past reports are available on the Colorado Medical Aid in Dying website at <https://www.colorado.gov/pacific/cdphe/medical-aid-dying>.

Confidentiality

Colorado’s End-of-Life Options Act states that the information reported to CDPHE is not a public record and is not available for public inspection. To comply with that statutory mandate, CDPHE will not disclose any information that identifies patients, physicians, pharmacists, family members, witnesses or other participants in activities covered by the Colorado End-of-Life Options Act. The information presented in this report is limited to items with sufficient numbers in a reporting field to ensure that confidentiality is preserved.