# COLORADO END-OF-LIFE OPTIONS ACT, YEAR THREE 2019 DATA SUMMARY, WITH 2017-2019 TRENDS AND TOTALS

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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 professionals 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 third annual statistical report published per this Act, and describes Colorado's participation in End-of-Life Options activities in 2019; incorporates updates to previously-published statistics; and includes summary statistics for the complete three-year period of participation, 2017-2019.

#### Data collection and statistics

Statistics presented in this report reflect patients for whom prescriptions for aid-in-dying medication were written; 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 medical aid-in-dying medication, the underlying terminal illness or condition, or some other cause.

Since the publication of past annual statistical reports, additional or amended reporting forms from health care providers concerning prescriptions in earlier years may have been submitted to CDPHE throughout 2019. More death certificates associated with patients who were prescribed aid-in-dying medication in 2017 and 2018 were also received by CDPHE in 2019. This report incorporates this additional information received about patients participating in End-of-Life Options activities in prior years in addition to the new data for 2019.

## Participation in End-of-Life Options activities

In 2019, 170 patients received prescriptions for aid-in-dying medications under the provisions of the Colorado End-of-Life Options Act. This represents a 38% increase in the number of prescriptions compared to 2018. Among those prescribed aid-in-dying medication in 2019, CDPHE has received reports for 129 patients to whom aid-in-dying medication was dispensed. Also among those prescribed aid-in-dying medication, CDPHE has received death certificates for 139 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 2019 for aid-in-dying medication were provided by **75** unique Colorado physicians. Over the three-year period 2017-2019, prescriptions were provided by **130** unique Colorado physicians. In 2019, the median age of patients prescribed aid-in-dying medication was **72** (minimum age was in the mid-20s, maximum age was in the upper-90s). Among patients prescribed aid-in-dying medication, the most common illnesses or conditions were malignant neoplasms (cancer), progressive neurological disorders (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 major cardiovascular diseases (including heart disease, stroke and vascular diseases). (Table 1)

Table 1. Underlying terminal illnesses/conditions among patients prescribed aid-in-dying medication, 2017-2019.

	2017		20	2018		2019		19 Total
	Number	Percent (%)	Number	Percent (%)	Number	Percent (%)	Number	Percent (%)
Total number of patients prescribed aid-in-dying medication	72	100	123	100	170	100	365	100
Malignant Neoplasm - Total	47	65.3	78	63.4	103	60.6	228	62.5
Lung	11	15.3	9	7.3	14	8.2	34	9.3
Pancreas	8	11.1	9	7.3	14	8.2	31	8.5
Breast	1	1.4	6	4.9	10	5.9	17	4.7
Head and neck	6	8.3	5	4.1	8	4.7	19	5.2
Colon and rectum	4	5.6	5	4.1	8	4.7	17	4.7
Central nervous system	1	1.4	4	3.3	8	4.7	13	3.6
Prostate	7	9.7	4	3.3	5	2.9	16	4.4
Ovary	2	2.8	5	4.1	4	2.4	11	3.0
Endometrium	0	0.0	3	2.4	4	2.4	7	1.9

	2017		20	2018		2019		2017-2019 Total	
	Number	Percent (%)							
Esophagus	2	2.8	4	3.3	3	1.8	9	2.5	
Melanoma	1	1.4	4	3.3	3	1.8	8	2.2	
Kidney, bladder and urinary tract	1	1.4	3	2.4	3	1.8	7	1.9	
Stomach	0	0.0	1	0.8	3	1.8	4	1.1	
Bile duct	1	1.4	2	1.6	2	1.2	5	1.4	
Multiple myeloma	0	0.0	2	1.6	2	1.2	4	1.1	
Leukemia	0	0.0	1	0.8	2	1.2	3	0.8	
Other malignant neoplasm	2	2.8	11	8.9	10	5.9	23	6.3	
Progressive neurological disorders - Total	12	16.7	27	22.0	31	18.2	70	19.2	
Amyotrophic lateral sclerosis	9	12.5	14	11.4	17	10.0	40	11.0	
Parkinson's disease	1	1.4	4	3.3	5	2.9	10	2.7	
Progressive supranuclear palsy	0	0.0	5	4.1	1	0.6	6	1.6	
Multiple sclerosis	0	0.0	2	1.6	1	0.6	3	0.8	
Other progressive neurodegenerative disorders	2	2.8	2	1.6	7	4.1	11	3.0	
Chronic lower respiratory disease	5	6.9	7	5.7	9	5.3	21	5.8	
Cardiovascular disease (including heart disease and stroke)	7	9.7	8	6.5	14	8.2	29	7.9	
Interstitial lung disease	1	1.4	0	0.0	4	2.4	5	1.4	
Other illnesses/conditions	0	0.0	3	2.4	9	5.3	12	3.3	

<sup>&#</sup>x27;Other malignant neoplasm' includes cancers of the bladder, cervix, gallbladder, liver, soft tissue, lymphoma, and others.

In 2019, aid-in-dying medications were dispensed by **33** unique pharmacists in Colorado, and included a combination of diazepam, digoxin, morphine sulfate, propranolol (sometimes amitriptyline), prepared as DDMP or DDMP2 combination. Secobarbitol (brand name Seconol) was no longer prescribed or dispensed in Colorado for medical aid-in-dying in 2019. (Table 2)

Table 2. Categories of medications dispensed to patients prescribed aid-in-dying medication, 2017-2019.

	2017		20	2018		2019		19 Total
	Number	Percent (%)	Number	Percent (%)	Number	Percent (%)	Number	Percent (%)
Total number of patients to whom aid-in-dying medication was dispensed	56	100	85	100	129	100	270	100
Secobarbitol	23	41.1	26	30.6	0	0.0	49	18.1
DDMP/DDMP2 Compound	32	57.1	59	69.4	128	99.2	219	81.1
Other (morphine sulfate alone, or in some other combination)	1	1.8	0	0.0	1	0.8	2	0.7



 $<sup>\</sup>hbox{`Other progressive neurodegenerative disorders' includes corticobasal degeneration and others.}$ 

<sup>&#</sup>x27;Other illnesses/conditions' include chronic kidney and liver disease, autoimmune rheumatic disease and others.

# Characteristics of Patients Prescribed Aid-in-Dying Medication Who Have Died

Among patients who died following an aid-in-dying prescription written in 2019, the median duration of time between the date of prescription and date of death was 17 days (minimum of zero days, maximum of just over one year). 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, 2017-2019.

	20	17	2018		2019		2017-2019 Total	
	Number	Percent (%)	Number	Percent (%)	Number	Percent (%)	Number	Percent (%)
Total number of decedents prescribed aid-in-dying medication	71	100	118	100	139	100	328	100
Sex								
Female	32	45.1	60	50.8	66	47.5	158	48.2
Male	39	54.9	58	49.2	73	52.5	170	51.8
Age group								
18-44	1	1.4	3	2.5	3	2.1	7	2.1
45-54	2	2.8	11	9.3	13	9.4	26	7.9
55-64	10	14.1	21	17.8	28	20.1	29	18.0
65-74	23	32.4	41	34.7	45	32.4	109	33.2
75-84	22	31.0	25	21.2	29	20.9	76	23.2
85+	13	18.3	17	14.4	21	15.1	51	15.5
Race/ethnicity			ı					
White, non-Hispanic	67	94.4	109	92.4	133	95.7	309	94.2
White, Hispanic	3	4.2	7	5.9	3	2.2	13	4.0
Other/unknown	1	1.4	2	1.6	3	2.1	6	1.8
Marital status	1						1	
Married	35	49.3	60	50.8	65	46.8	160	48.8
Divorced	19	26.8	23	19.5	47	33.8	89	27.1
Widow/widower	16	22.5	21	17.8	14	10.1	51	15.5
Never been married	1	1.4	14	11.9	13	9.4	28	8.5
Educational attainment	1						1	
High school graduate or GED completed or less	20	28.2	26	21.9	34	24.4	80	24.4
Some college credit but no degree	13	18.3	21	17.8	17	12.2	51	15.5
Associate's degree	9	12.7	7	5.9	14	10.1	30	9.1
Bachelor's degree	19	26.8	24	20.3	40	28.8	83	25.3
Master's degree	3	4.2	25	21.2	22	15.8	50	15.2
Doctorate or professional degree	7	9.9	15	12.7	12	8.6	34	10.4

	2017		2018		2019		2017-2019 Total	
	Number	Percent (%)	Number	Percent (%)	Number	Percent (%)	Number	Percent (%)
County of residence								
Denver Metro Area (Adams, Arapahoe, Boulder, Broom- field, Denver, Douglas, Jefferson)	45	63.4	79	66.9	84	60.4	208	63.4
Other Front Range (El Paso, Larimer, Pueblo, Weld)	17	23.9	21	17.8	31	22.3	69	21.0
Other Counties	9	12.7	18	15.3	24	17.3	51	15.5
Place of death								
Residence	59	83.1	101	85.6	111	79.9	271	82.6
Nursing home/long-term care facility	9	12.7	6	5.1	8	5.8	23	7.0
Hospice facility	0	0.0	3	2.5	10	7.2	13	4.0
Other/unknown	3	4.2	8	6.7	10	7.2	21	6.4
Hospice enrollment status								
Under hospice care	63	88.7	100	84.7	111	79.9	274	83.5
Not under hospice care or unknown	8	11.3	18	15.3	28	20.1	54	16.4

<sup>&#</sup>x27;Place of death - Other/unknown' includes inpatient settings, outpatient facilities, or unspecified locations.

## 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 27, 2020.

Table 4. Documentation received for patients participating in the Colorado End-of-Life Options Act, 2017-2019.

	2017	2018	2019	2017-2019 Total
Form/Document	Number	Number	Number	Number
Attending/prescribing physician form	63	107	147	317
Patient's completed written request	50	88	130	268
Mental health provider's confirmation	1	0	0	1
Consulting physicians written confirmation	30	82	129	241
Medication dispensing form	56	85	129	270
Death certificate	71	118	139	328

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, 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 such categories within a reporting field to ensure that confidentiality is preserved.