

# CALIFORNIA END OF LIFE OPTION ACT 2018 DATA REPORT

For more information:

<https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx>

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## Executive Summary

California's End of Life Option Act (EOLA) became effective on June 9, 2016. The Act allows terminally ill adults living in California to obtain and self-administer aid-in-dying drugs.<sup>1</sup> The Act requires the California Department of Public Health (CDPH) to provide annual reports under strict privacy requirements. CDPH's reporting requirements are outlined in Health and Safety Code section 443.19 (b), which reads:

*(b) On or before July 1, 2017, and each year thereafter, based on the information collected in the previous year, the department shall create a report with the information collected from the attending physician follow up form and post that report to its Internet Web site. The report shall include, but not be limited to, all of the following based on the information that is provided to the department and on the department's access to vital statistics:*

*(1) The number of people for whom an aid-in-dying prescription was written.*

*(2) The number of known individuals who died each year for whom aid-in-dying prescriptions were written, and the cause of death of those individuals.*

*(3) For the period commencing January 1, 2016, to and including the previous year, cumulatively, the total number of aid-in-dying prescriptions written, the number of people who died due to use of aid-in-dying drugs, and the number of those people who died who were enrolled in hospice or other palliative care programs at the time of death.*

*(4) The number of known deaths in California from using aid-in-dying drugs per 10,000 deaths in California.*

*(5) The number of physicians who wrote prescriptions for aid-in-dying drugs.*

*(6) Of people who died due to using an aid-in-dying drug, demographic percentages organized by the following characteristics:*

*(A) Age at death.*

*(B) Education level.*

*(C) Race.*

*(D) Sex.*

*(E) Type of insurance, including whether or not they had insurance.*

*(F) Underlying illness.*

This report presents data as reported to CDPH from the EOLA-mandated physician reporting forms received between January 1, 2018, and December 31, 2018, and reflects information on individuals who were prescribed aid-in-dying drugs and died in 2018, as well as cumulative counts for the period commencing January 1, 2016. The information collected has been aggregated to protect the privacy of the individuals.

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<sup>1</sup> Assembly Bill x2 15 (Eggman), Chapter 1, Statutes of 2015.

For the year ending December 31, 2018, 452 individuals received prescriptions under the Act. 337 individuals died following their ingestion of the prescribed aid-in-dying drug(s), which includes 23 individuals who received prescriptions prior to 2018. Of the 337 individuals, 88.7 percent were 60 years of age or older, 94.4 percent had health insurance and 88.1 percent were receiving hospice and/or palliative care.

Since the law came into effect June 9, 2016 through December 31, 2018, prescriptions have been written for a total of 1,108 people under the Act and 807 individuals, 72.8 percent, have died from ingesting the medications. Of the 807 individuals who have died under the Act, 700 or 86.7 percent were receiving hospice and/or palliative care. Note that cumulative counts reported above do not match prior reports. These differences arise from a number of factors including the timing of forms received, the registration of deaths, and the inclusion of duplicate records, which have been removed.

## **Introduction**

The EOLA allows an adult diagnosed with a terminal disease, who meets certain qualifications, to request an aid-in-dying drug from a physician. The Act requires physicians to use forms specified in statute for submitting information to CDPH. CDPH is responsible for collecting data from these forms, and preparing an annual report. Data presented in this report are based on the information from physicians' forms and California death certificates for calendar year 2018.

More information on the Act, reporting process, and required forms can be found here:

<https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx>.

## **Participation in the End-of-Life Option Activities**

For the calendar year 2018, 531 individuals started the end-of-life option process, as set forth in the Act, by making two verbal requests to their physicians at least 15 days apart. 180 unique physicians prescribed 452 individuals aid-in-dying drugs. The two most common drug categories prescribed were sedatives at 37.1 percent and a combination of a cardiotoxic, opioid, and sedative at 35.0 percent. Of the 452 individuals who were prescribed such drugs, 314, or 69.5 percent, were reported by their physician to have died following ingestion of aid-in-dying drugs prescribed under EOLA; and 59 individuals, or 13.1 percent, died from the underlying illness or other causes. The ingestion status of the remaining 79 individuals is unknown. Of the remaining individuals, 42, or 9.3 percent, have died, but their ingestion status is unknown because follow up information is not available yet. For the remaining 37 individuals, or 8.2 percent, both death and ingestion status are pending. 23 individuals with prescriptions written in 2017 ingested and died from the drugs during 2018. As a result, the report demographics include the 337 individuals who ingested and subsequently died during the 2018 calendar year from aid-in-dying drugs. A chart illustrating the outcomes is provided on the next page as

Figure 1.

In 2018, 337 individuals<sup>2</sup> died from ingestion of aid-in-dying drugs, a rate of 12.6 per 10,000 deaths based on 268,474<sup>3,4</sup> deaths to California residents in 2018.

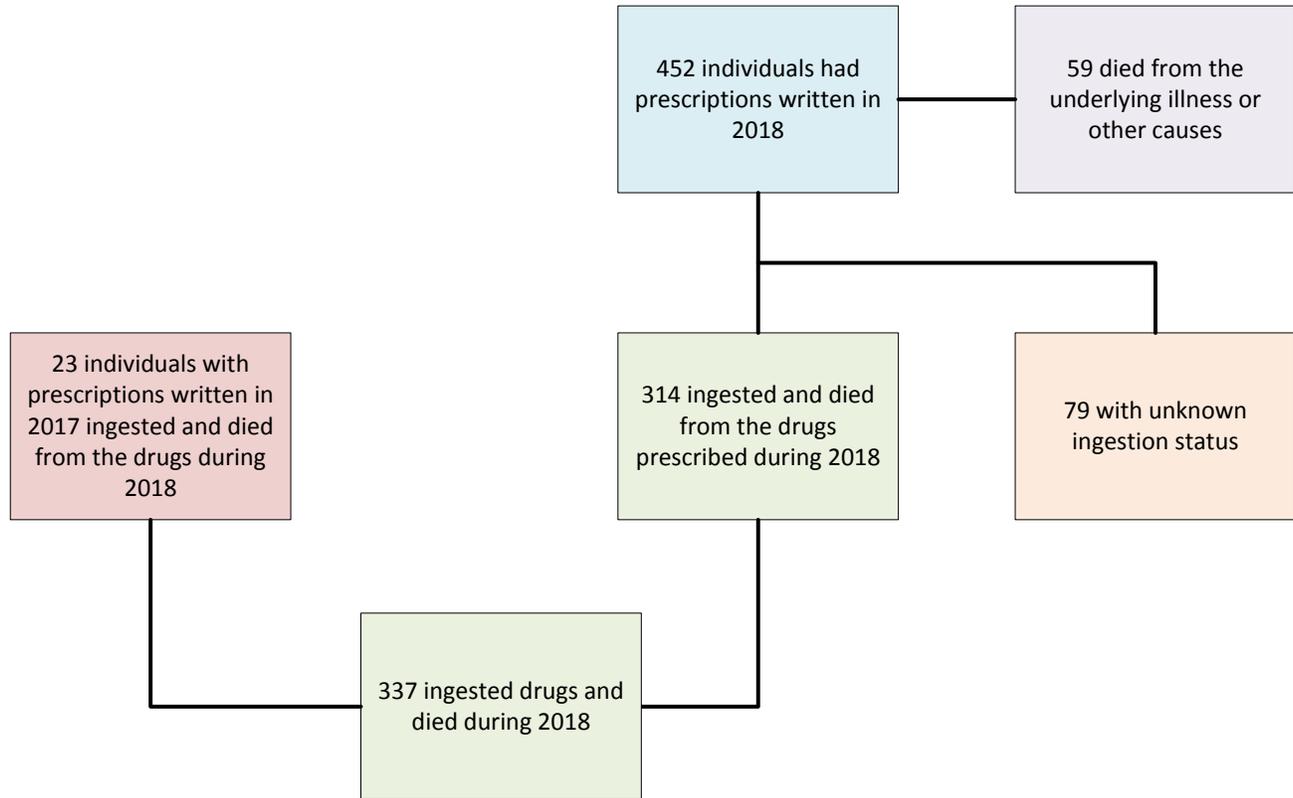
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<sup>2</sup> Total of individuals who received aid-in-dying prescriptions that died in 2018.

<sup>3</sup> California Department of Public Health, Preliminary California Comprehensive Death File, created in April 2019.

<sup>4</sup> Includes 2,667 out-of-state California resident deaths as of March 18, 2019.

**Figure 1: Summary of EOLA Prescriptions Written in 2017 and 2018 and Drugs Ingested in 2018<sup>5</sup>**



**Characteristics of Individuals**

Of the 337 individuals who died pursuant to EOLA during 2018, 11.3 percent were under 60 years of age, 75.9 percent were 60-89 years of age, and 12.8 percent were 90 years of age and older. The median age was 74 years. The decedents were 88.4 percent white, 51.0 percent were female; 88.1 percent were receiving hospice and/or palliative care, and 80.1 percent had at least some level of college education. 87.5 percent informed their family of their decision to participate in EOLA. A summary of this information is set forth in Table 1 and Table 2.

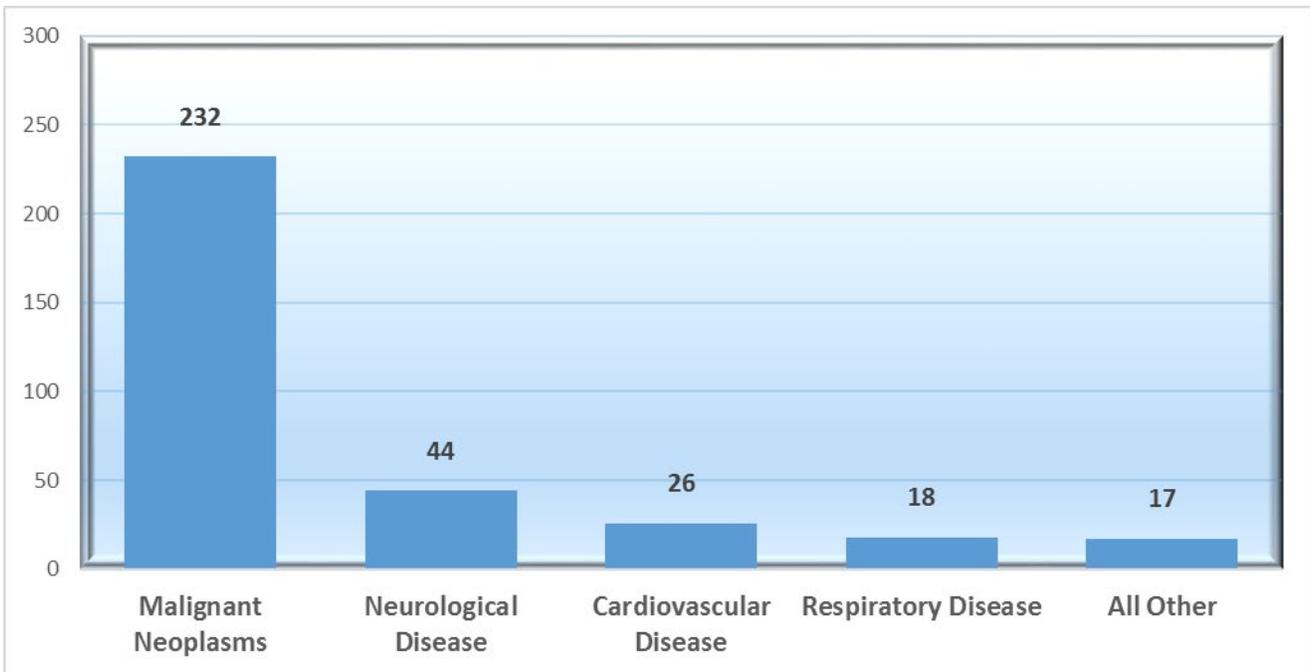
Of the 337 individuals who died pursuant to EOLA during 2018, 68.8 percent were identified as having had malignant neoplasms (cancer). Neurological diseases such as Amyotrophic Lateral Sclerosis and Parkinson’s accounted for the second largest underlying illness grouping, totaling 13.1 percent.

The remaining major categories of underlying illnesses were documented as: cardiovascular diseases (7.7 percent), and respiratory diseases (non-cancer; 5.3 percent). The data are presented in Figure 2.

Certifiers (physicians, coroners, and medical examiners) report the underlying terminal disease as the cause of death on the death certificates. This approach complies with applicable law; best ensures the reliability and usefulness of data collected from the death certificate for state, national, and international surveillance purposes; and effectuates the California Legislature’s intent to maintain the confidentiality of individuals’ participation in the Act.

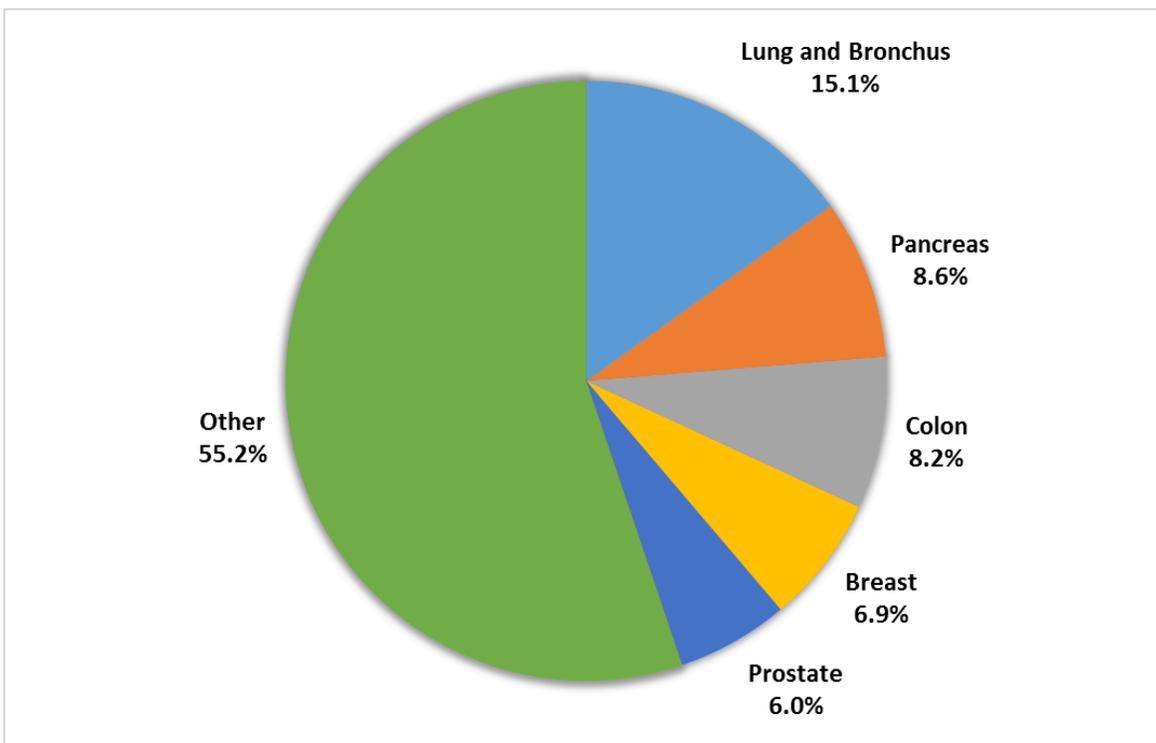
<sup>5</sup> Based on forms received as of March 8, 2019.

**Figure 2: Major Illness Categories for EOLA Individuals in 2018**



Among those with cancer as the underlying terminal disease – the largest group of individuals who utilized the Act – lung cancer accounted for 15.1 percent, pancreatic cancer accounted for 8.6 percent, colon cancer constituted 8.2 percent, breast cancer comprised 6.9 percent, and prostate cancer constituted 6.0 percent. Other malignant neoplasms accounted for the remaining 55.2 percent, as shown in Figure 3. Additional information regarding the other types of malignant neoplasms can be found in Table 1.

**Figure 3: Major Malignant Neoplasm Types for EOLA Individuals in 2018**



In Table 1 on page 8, most (94.4 percent) of the individuals who participated in the Act had some form of health insurance. Medicare or Medicare combined with another type of insurance accounted for 70.3 percent of individuals, individuals who had an unspecified type of insurance at 10.7 percent, and individuals with private insurance at 10.4 percent. Individuals with Medi-Cal comprised 2.7 percent of the Act participants, while individuals with another type of insurance such as Covered California or Veterans Affairs insurance, comprised 0.3 percent of participants. 17 individuals, or 5.0 percent, had undetermined health insurance coverage, while 2 individuals, or 0.6 percent, reported no health insurance coverage.

In Table 2 on page 9, the report shows that 54.3 percent of individuals had a physician or trained healthcare professional present at the time of ingestion of the aid-in-dying drug. Of the individuals who had a physician or trained healthcare professional present at the time of ingestion, the attending physician was present for 70.5 percent of patients. The majority, or 92.0 percent, were in a private home for ingestion.

### **Conclusion**

This Data Report presents data reported to CDPH from EOLA-mandated physician reporting forms and reflects information on all patients who were prescribed aid-in-dying medications in 2018 or prior years, and subsequently died in 2018 of ingesting the prescribed drugs. The information collected by CDPH has been aggregated to protect the privacy of the participants.

**Table 1: Characteristics of the EOLA Individuals who Died Following Ingestion of an Aid-in-Dying Drug**

Characteristics	2018	(N=337)
<b>Age</b>	<b>N</b>	<b>(%)</b>
Under 60	38	(11.3)
60-69	73	(21.6)
70-79	116	(34.4)
80-89	67	(19.9)
90 and Over	43	(12.8)
Median Age (Range)	74	(27-103)
<b>Sex</b>	<b>N</b>	<b>(%)</b>
Female	172	(51.0)
Male	165	(49.0)
<b>Education</b>	<b>N</b>	<b>(%)</b>
No High School Diploma	8	(2.4)
High School Diploma or GED	56	(16.6)
Some College	60	(17.8)
Associate's Degree	29	(8.6)
Bachelor's Degree	90	(26.7)
Master's Degree	53	(15.7)
Doctorate or Professional Degree	38	(11.3)
Unknown	3	(0.9)
<b>Race/Ethnicity</b>	<b>N</b>	<b>(%)</b>
White	298	(88.4)
Black	3	(0.9)
American Indian/Alaskan Native	0	(0.0)
Asian	20	(5.9)
Hawaiian/Pacific Islander	0	(0.0)
Other	1	(0.3)
Multi-Race	2	(0.6)
Hispanic	13	(3.9)
Unknown	0	(0.0)
<b>Hospice and/or Palliative Care</b>	<b>N</b>	<b>(%)</b>
Enrolled	297	(88.1)
Not Enrolled	37	(11.0)
Unknown	3	(0.9)

Characteristics	2018	(N=337)
<b>Insurance</b>	<b>N</b>	<b>(%)</b>
Medicare or Medicare with another type of insurance	237	(70.3)
Private insurance	35	(10.4)
Medi-Cal	9	(2.7)
Other (including VA and Covered California)	1	(0.3)
Has Insurance, but unknown type	36	(10.7)
No Insurance	2	(0.6)
Unknown	17	(5.0)
<b>Underlying Illness</b>	<b>N</b>	<b>(%)</b>
<b>Malignant Neoplasms (Cancer)</b>	<b>232</b>	<b>(68.8)</b>
Lung and Bronchus	35	(15.1)
Pancreas	20	(8.6)
Colon	19	(8.2)
Breast	16	(6.9)
Other Digestive Organs [e.g., stomach, esophagus]	15	(6.5)
Prostate	14	(6.0)
Blood	13	(5.6)
Eye, Brain and Other Parts of Central Nervous System	13	(5.6)
Lip, Oral Cavity and Pharynx	13	(5.6)
Skin	13	(5.6)
Female Genital Organs	12	(5.2)
Ill-defined, Secondary and Unspecified Sites	12	(5.2)
Urinary tract	12	(5.2)
Liver	10	(4.3)
Mesothelial and Soft Tissue	4	(1.7)
Respiratory and Intrathoracic Organs	2	(0.9)
Thyroid and Other Endocrine Glands	1	(0.4)
Other Cancers	8	(3.4)
<b>Neurological Disease</b>	<b>44</b>	<b>(13.1)</b>
Amyotrophic lateral sclerosis	31	(70.4)
Parkinson's Disease	5	(11.4)
Other	8	(18.2)
<b>Cardiovascular Disease</b>	<b>26</b>	<b>(7.7)</b>
<b>Respiratory Disease</b>	<b>18</b>	<b>(5.3)</b>
Chronic Lower Respiratory Disease	16	(88.9)
Other	2	(11.1)
<b>Kidney Disease</b>	<b>4</b>	<b>(1.2)</b>
<b>Cerebrovascular Disease</b>	<b>3</b>	<b>(0.9)</b>
<b>Immune Mediated Disease [e.g., Multiple Sclerosis]</b>	<b>3</b>	<b>(0.9)</b>
<b>Musculoskeletal and Connective Tissue Diseases [e.g., Lupus]</b>	<b>2</b>	<b>(0.6)</b>
<b>Other<sup>6</sup></b>	<b>5</b>	<b>(1.5)</b>

<sup>6</sup> Includes Gastrointestinal Disease; Liver Disease; Endocrine, Nutritional and Metabolic Disease; Infectious and Parasitic Disease

**Table 2: Additional Characteristics of the EOLA Individuals who Died Following Ingestion of Aid-in-Dying Drug**

Characteristics	2018	(N=337)
<b>Patient Informed Family of Decision</b>	<b>N</b>	<b>(%)</b>
Yes	295	(87.5)
No	9	(2.7)
No Family to Inform	6	(1.8)
Unknown	27	(8.0)
<b>Aid-in-Dying Drugs</b>	<b>N</b>	<b>(%)</b>
Sedative	125	(37.1)
Cardiotonic, Opioid, Sedative	118	(35.0)
Other	59	(17.5)
Unknown	35	(10.4)
<b>Physician or Trained Healthcare Provider Present at Ingestion</b>	<b>N</b>	<b>(%)</b>
<b>Yes</b>	<b>183</b>	<b>(54.3)</b>
Attending Physician	129	(70.5)
Other Physician	12	(6.6)
Other Healthcare Provider	42	(22.9)
<b>No</b>	<b>84</b>	<b>(24.9)</b>
<b>Unknown</b>	<b>70</b>	<b>(20.8)</b>
<b>Location Where Aid-in-Dying Drugs Ingested</b>	<b>N</b>	<b>(%)</b>
Private Home	310	(92.0)
Assisted-Living Residence	13	(3.8)
Nursing Home	8	(2.4)
In-patient Hospice Residence	6	(1.8)
Other	0	(0.0)
Unknown	0	(0.0)