compassion & choices

Care and Choice at the End of Life

Medical Aid-in-Dying Utilization Report

2024 Edition

NOTE: The data tables attached to the Utilization Report are continuously updated to include the most recent data as it becomes available. The Utilization Report itself, along with the analyses it contains, undergoes an annual update. As a result, there may be differences between the data presented in the tables and the narrative within the report, since the text reflects the data as it stood at the time of the January 2024 report's publication.

January 2024

Thirty years ago this November, in 1994, Oregon passed the nation's first law giving mentally capable, terminally ill adults the end-of-life care option of medical aid in dying. The law survived legal challenges and a repeal measure referred to the ballot by the Oregon Legislature, with 60% of Oregon voters choosing to retain the law. The law was officially implemented in 1997.

Today, more than one in five people — 22% — live in a jurisdiction where medical aid in dying is authorized. This list includes 10 states: Oregon (1994, ballot initiative), Washington (2008, ballot initiative), Montana (2009, state Supreme Court decision; no Montana data is included in this report, as the court decision did not mandate data collection), Vermont (2013, legislation, amended in 2022), California (2015, legislation, amended in 2021), Colorado (2016, ballot initiative), Hawaii (2018, legislation), New Jersey (2019, legislation), Maine (2019, legislation) and New Mexico (2021, legislation), as well as the District of Columbia (2016, legislation).

We no longer have to hypothesize about what will happen if this medical practice is authorized. We have over 25 years of data since Oregon implemented its law and years of experience from other authorized jurisdictions, including annual statistical reports from nine jurisdictions.

This report is a compilation of annual reports from all of the authorized jurisdictions that collect data. We offer all available 2022 data, making this the most comprehensive utilization report ever published!

Across all the authorized jurisdictions that report data, 9,122 individuals to date have chosen to use medical aid in dying. While few people use the option, many gain peace of mind and comfort simply knowing it exists. Further, medical aid in dying creates a shift within our end-of-life care system to one that is resoundingly person-driven, leading to improvements in hospice, palliative care, and pain and symptom management.

Terminally ill people in jurisdictions that have not yet authorized medical aid in dying need this option now. We have reassuring data, strong public support, and evidence that medical aid in dying is politically viable and desirable. If you have any questions about this report, please contact National Director of Policy Bernadette Nunley at policy@compassionandchoices.org for more information.

Sincerely,

Kim Callinan
President and CEO
Compassion & Choices

Context and Methods

Currently, nine authorized jurisdictions have issued reports regarding the use of medical-aid-in-dying laws: Oregon,[1] Washington,[2] Vermont,[3] California,[4] Colorado,[5] Hawai'i[6], the District of Columbia[7], New Jersey[8] and Maine[9]. In all jurisdictions where medical aid in dying was authorized by legislation or ballot measure, there are statistical reporting requirements for administrative agencies, such as state health departments. However, the reported data is not standardized, and the report formats can change from year to year. In addition, New Mexico has not issued an official report as of this writing, so that data is not included here[10]. Listed below are the data points most useful in demonstrating how medical aid in dying is being used and where there are opportunities to improve access.

- People who received a prescription and people who died after ingestion provide us with two key pieces of information: how many people made it through the entire process to obtain a prescription for medical aid in dying and how many of those individuals decided to take the medication.
- Race, gender and age categories show where disparities exist. Race and ethnicity are not reported universally across jurisdictions, nor are these categories always reflective of the different ways people identify. The inconsistency and limited options for reporting make accurately tracking data among different groups challenging.
- Insurance information illustrates the impacts of cost and healthcare coverage on access to medical aid in dying. Due to the Assisted Suicide Funding Restriction Act (ASFRA), many individuals reliant on federally funded insurance programs cannot use their insurance to cover the costs associated with medical aid in dying.
- Underlying Illness reports the most common illnesses and diagnoses for individuals who request medical aid in dying.

This report aggregates utilization information available in 2023 (2023 reports include data from calendar year 2022), along with 2023 data from Oregon. Although differences exist in how each jurisdiction collects and reports medical aid-in-dying data, we have put all reported data from each jurisdiction in aggregate form in order to provide a picture of medical aid in dying in the United States. Key findings are analyzed below.

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[1] *Oregon Death with Dignity Act Annual Reports* (1998-2022) Available from: https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx
[2] *Washington Death with Dignity Data* (2009-2022). Available from: https://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData
[3] *Vermont Report Concerning Patient Choice at the End of Life.* (2018-2022) Available from: https://www.healthvermont.gov/systems/end-of-life-decisions/patient-choice-and-control-end-life.
[4] *California End of Life Option Act Annual Report* (2016-2022) Available from: https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx
[5] *Colorado End of Life Options Act Annual Report* (2017-2022) Available from: https://www.colorado.gov/pacific/cdphe/medical-aid-dying
[6] *Hawai'i Our Care, Our Choice Act Annual Report* (2019-2022) Available from: https://health.hawaii.gov/opppd/ococ/
[7] *District of Columbia Death with Dignity Act Annual Report. (*2017-2022) Available from: https://dchealth.dc.gov/publication/death-dignity-annual-reports
[8] *New Jersey Medical Aid in Dying for the Terminally Ill Act Data Summary* (2019-2022) Available from: https://nj.gov/health/advancedirective/maid/
[9] *Maine Patient Directed Care at End Of Life Annual Report.* (2019-2022) Available from: https://www.maine.gov/dhhs/data-reports/reports
[10] *Elizabeth Whitefield End-of-Life Options Act.* Available from: https://www.nmhealth.org/about/erd/bvrhs/vrp/maid/

Medical Aid-in-Dying Jurisdiction Usage Reports

Based on reported data, the following is known:

- Cumulatively, for the past 20+ years across all jurisdictions, 9,122 eligible people have used a medical aid-in-dying prescription.
- Less than 1% of the people who die in each jurisdiction use the law each year.[11]
- Only 63% (or just under 2/3) of people with prescriptions ingest the medication and die. Up to 37% of people who go through the process and obtain the prescription may never take it. This group consists of people who die from their underlying illness, another cause of death or an unreported cause of death. In any case, they derive peace of mind simply from knowing they have the option if their suffering becomes too great.
- The majority of terminally ill people who use medical aid in dying (88%) received hospice and/or palliative care services at the time of their deaths, according to annual reports for which hospice and palliative care data is available.
- There is nearly equal use of medical aid in dying among men and women. There is no data on use of medical aid in dying by nonbinary or gender non-conforming people.
- The rate at which Asian, Black, Hawaiian/Pacific Islander, Hispanic, Indigenous American/Alaskan Native, Latino/a/x (Hispanic) and multi-race people access and use prescriptions under medical aid-in-dying laws is consistently lower than with white populations.
- The most recent reports indicate medical aid-in-dying access is improving among people of color. In 2022, California, New Jersey and Washington, D.C., all reported more people of color accessing medical aid in dying. In 2023, Oregon reported more people of color accessing medical aid in dying.
- Terminal cancer accounts for the vast majority of qualifying diagnoses, with neurodegenerative diseases such as ALS or Huntington's disease following as the second-leading diagnosis.
- While cancer remains the most common qualifying diagnosis, some jurisdictions are seeing growing numbers of patients with neurological diseases seeking medical aid in dying.
- Over 75% of people who use medical aid in dying are able to die at home. According to various studies, that is the preference of most Americans.[12]
- Differences in data collection and reporting among jurisdictions do not allow for thorough comparisons of medical aid-in-dying use across the United States.
- Increased access to medical aid in dying is observed in jurisdictions that have expanded their laws by removing residency requirements, shortening waiting periods, and allowing APRNs and other qualified non-physician healthcare providers to participate. While we can only begin to see it in this report, moving forward it will become easier to see the positive impact these changes have had.

[11] According to the Center for Disease Control, in 2020 in jurisdictions that authorized medical aid in dying, 606,525 people died in total. In 2020, authorized jurisdictions report 1,299 people died after being provided with a prescription for medical aid in dying – less than 0.002% of total deaths in 2019. Kochanek, K. D., Murphy, S. L., Xu, J., & Arias, E. (2023). (rep.). *Deaths: Final Data for 2020*. U.S. Department of Health and Human Services. Retrieved December 12, 2023, from https://www.cdc.gov/nchs//data/nvsr/nvsr72/nvsr72-10.pdf.

[12] Kaiser Family Foundation, *Views and Experiences with End-of-Life Medical Care in the U.S.*, April 27, 2017, available from: https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/

Authorized Jurisdiction (a) (b)	Oregon	Washington	Vermont	California	Colorado	Washington, DC	Hawaii	New Jersey	Maine	Cumulative
Date Enacted	October 27, 1997	March 5, 2009	May 20, 2013	6/9/2016	Dec 16, 2016	Feb 18, 2017	Jan 1, 2019	August 1, 2019	June 12, 2019	
Law	Death with Dignity Act	Death with Dignity Act	Patient Choice at the End of Life Act	End of Life Option Act	End-of-Life Options Act	Death With Dignity Act	Our Care, Our Choice Act	Medical Aid in Dying for the Terminally Ill Act	Death With Dignity Act	
Data Period	1997 - 2023	2009 - 2022	2013 - 2022	2016 - 2022	2017 - 2022	2017 - 2022	2019 - 2022	2019 - 2022	2019 - 2022	1997 - 2023
Total Years Effective as of 1/1/2024	26	14	10	7	7	6	5	4	4	27
Summary Data										
Individuals who received prescriptions (written or filled) (c)	4,274	3,159	200	5,168	1,482	31	197	206	252	14,969
Individuals who were dispensed medication (c)		3,159			1,123			206		4,488
Individuals who died after ingesting (a)	2,847	2,341	146	3,349		23	113	186	170	9,175
Individuals who died without having ingested or died from other causes	857	368	45	671		8	8	14	57	2,028
Individuals who ingested medication in a calendar year following their prescription's written date	260			183						443
Individuals whose ingestion status is unknown	606	284	9	885			24	6	11	1,825
Individuals who received prescriptions and for whom a death certificate was subsequently registered (d)		2,639	195		1,297		86		46	4,263
Unique providers who prescribed the medication (e)	146	207		341	248	4	21			967
Prescription rate per provider (f)	2.00	1.70		2.92	2.70	1.60	2.95			2.31
Unique pharmacists who dispensed the medication (e)		68			37					105
Characteristics/Demographics										
Gender (b)										
Female	1,336 46.93%	1,432 47.25%		1,519 49.05%	745 51.66%	13 54.17%	37 34.91%	89 47.85%	27 54.00%	5,198 48.21%
Male	1,511 53.07%	1,599 52.75%		1,570 50.69%	697 48.34%	11 45.83%	68 64.15%	97 52.15%	23 46.00%	5,576 51.71%
Other										
Unknown				8 0.26%			1 0.94%	0 0.00%		9 0.08%
Total	**2,847 100.0%**	**3,031 100.0%**		**3,097 100.0%**	**1,442 100.0%**	**24 100.0%**	**106 100.0%**	**186 100.0%**	**50 100.0%**	**10,783 100.0%**
Age Breakdown										
18-64	656 23.04%	719 23.68%			308 23.75%	9 36.00%	19 17.92%	50 26.88%	25 20.83%	1,786 23.45%
65-74	871 30.59%	982 32.35%			399 30.76%	6 24.00%	34 32.08%	33 17.74%	33 27.50%	2,358 30.96%
75-84	823 28.91%	781 25.72%			340 26.21%	6 24.00%	37 34.91%	59 31.72%	42 35.00%	2,088 27.41%
85+	497 17.46%	554 18.25%			250 19.28%	4 16.00%	16 15.09%	44 23.66%	20 16.67%	1,385 18.18%
Total	**2,847 100.0%**	**3,036 100.0%**			**1,297 100.0%**	**25 100.0%**	**106 100.0%**	**186 100.0%**	**120 100.0%**	**7,617 100.0%**
Age Breakdown (CA)										
Under 60				305 9.85%						305 9.85%
60-69				620 20.02%						620 20.02%
70-79				957 30.90%						957 30.90%
80-89				769 24.83%						769 24.83%
90+				446 14.40%						446 14.40%
Total				**3,097 100.0%**						**3,097 100.0%**

Authorized Jurisdiction (a) (b)	Oregon	Washington	Vermont	California	Colorado	Washington, DC	Hawaii	New Jersey	Maine	Cumulative
Age Median & Range										
Median	73			75	72			72		73
Range	25-102	20 - 101		23-107				32-98	31-98	20-107
Race/Ethnicity (i)										
Asian	44 1.55%	52 1.73%		180 5.78%	18 1.39%		21 19.81%	10 5.38%		325 3.06%
Asian/Native American/Pacific Islander				20 0.64%						20 0.19%
Black	4 0.14%			25 0.80%	6 0.46%	1		2 1.08%		38 0.36%
Hawaiian, Pacific Islander	2 0.07%			2 0.06%			7 6.60%	0 0.00%		11 0.10%
Indigenous American, American Indian, Alaskan Native	8 0.28%			4 0.13%	2 0.15%			0 0.00%		14 0.13%
Latinx, Hispanic	38 1.33%			113 3.63%	38 2.93%	1 4.35%	4 3.77%	1 0.54%		195 1.84%
Multi-race (two or more races)	11 0.39%			17 0.55%			5 4.72%	0 0.00%		33 0.31%
Non-white, Hispanic and/or Non-white		20 0.67%								20 0.19%
Other, Unknown	13 0.46%	97 3.23%		16 0.51%	8 0.62%		3 2.83%	2 1.08%		139 1.31%
White	2,727 95.79%	2,838 94.38%		2,738 87.90%	1,217 93.83%	21 91.30%	66 62.26%	171 91.94%	49 100.0%	9,827 92.52%
Total	**2,847 100.0%**	**3,007 100.0%**		**3,115 100.0%**	**1,297 99.4%**	**23 95.7%**	**106 100.0%**	**186 100.0%**	**49 100.0%**	**10,622 100.0%**
Education (j) (k)										
High School Diploma, GED, or Less	761 26.73%	750 24.94%		711 22.96%	296 22.82%	0 0.00%	18 16.98%	52 27.96%	16 23.88%	2,604 24.49%
Some College	566 19.88%	1,515 50.38%		524 16.92%	171 13.18%	1 4.00%	8 7.55%	10 5.38%	9 13.43%	2,804 26.37%
Associate's, Bachelor's, Master's, Doctorate or Professional Degree	1,499 52.65%	713 23.71%		1,830 59.09%	823 63.45%	22 88.00%	45 42.45%	124 66.67%	43 64.18%	5,099 47.95%
Unknown	21 0.74%	29 0.96%		32 1.03%	7 0.54%	2 8.00%	35 33.02%	0 0.00%	0 0.00%	126 1.18%
Total	**2,847 100.0%**	**3,007 100.0%**		**3,097 100.0%**	**1,297 100.0%**	**25 100.0%**	**106 100.0%**	**186 100.0%**	**67 100.0%**	**10,633 100.0%**
Marital Status										
Married, Domestic Partner	1,305 45.84%	1,421 47.26%			584 45.03%			96 51.61%		3,406 46.42%
Widowed	602 21.15%	583 19.39%			271 20.89%			49 26.34%		1,505 20.51%
Divorced, Separated	702 24.66%	742 24.68%			335 25.83%			27 14.52%		1,806 24.61%
Never Married, Single, Other, Unknown	238 8.36%	261 8.68%			107 8.25%			14 7.53%		620 8.45%
Total	**2,847 100.0%**	**3,007 100.0%**			**1,297 100.0%**			**186 100.0%**		**7,337 100.0%**
End-of-Life Care										
Hospice and/or Palliative Care										
Enrolled	2,559 89.88%	1,010 83.13%		2,772 89.51%	1,084 83.58%		19 82.61%			7,444 87.79%
Not Enrolled	254 8.92%	151 12.43%		257 8.30%						662 7.81%
Unknown	34 1.19%	54 4.44%		68 2.20%	2 0.15%		4 17.39%			162 1.91%
Not under hospice care or unknown					211 16.27%					211 2.49%
Total	**2,847 100.0%**	**1,215 100.0%**		**3,097 100.0%**	**1,297 100.0%**		**23 100.0%**			**8,479 100.0%**

Authorized Jurisdiction (a)(b)	Oregon	Washington	Vermont	California	Colorado	Washington, DC	Hawaii	New Jersey	Maine	Cumulative
Insurance										
Private/Commerical	914 32.10%	296 10.19%		405 13.08%		12 48.00%	14 13.21%			1,641 18.21%
Medicare, Medicaid, and/or Other Governmental	1,477 51.88%	774 26.65%		346 11.17%		10 40.00%	37 34.91%			2,644 29.35%
Combination of Governmental and Private/Commercial		196 6.75%		1,575 50.86%			33 31.13%			1,804 20.02%
Insured (unspecified)		970 33.40%		487 15.72%			37 34.91%			1,494 16.58%
None, Other, Unknown	456 16.02%	668 23.00%		284 9.17%		3 12.00%	16 15.09%			1,427 15.84%
Total	**2,847 100.0%**	**2,904 100.0%**		**3,097 100.0%**		**25 100.0%**	**106 129.2%**			**9,010 100.0%**
Underlying Illness (l)										
Cancer, Malignant Neoplasms	2,014 70.74%	2,149 74.13%	150 75.00%	2,077 67.06%	891 60.04%	20 74.07%	73 67.59%	110 59.14%	127 67.20%	7,611 68.96%
Neurological Disease	310 10.89%	263 9.07%	26 13.00%	336 10.85%	249 16.78%	4 14.81%	16 14.81%	40 21.51%	24 12.70%	1,268 11.49%
Respiratory Disease	183 6.43%	192 6.62%	5 2.50%	200 6.46%	122 8.22%	1 3.70%	8 7.41%	10 5.38%	14 7.41%	735 6.66%
Cardiovascular, Circulatory Disease	206 7.24%	171 5.90%	2 1.00%	279 9.01%	125 8.42%	2 7.41%	8 7.41%	16 8.60%	12 6.35%	821 7.44%
Other illnesses	134 4.71%	124 4.28%	17 8.50%	205 6.62%	97 6.54%	0 0.00%	3 2.78%	10 5.38%	12 6.35%	602 5.45%
Total	**2,847 100.0%**	**2,899 100.0%**	**200 100.0%**	**3,097 100.0%**	**1,484 100.0%**	**27 100.0%**	**108 100.0%**	**186 100.0%**	**189 100.0%**	**11,037 100.0%**
MAID Process										
Place of Death/Where Medication Ingested										
Private Home, Residence	2,614 91.82%	1,069 40.85%		2,362 90.43%	1,063 81.96%			177 95.16%		7,285 76.21%
Hospice Facility	11 0.39%			35 1.34%	53 4.09%			4 2.15%		103 1.08%
Hospital, Acute Care Hospital	8 0.28%	1 0.04%		3 0.11%	14 1.08%					26 0.27%
Long Term Care, Assisted Living, Foster Care Facility	146 5.13%	99 3.78%		185 7.08%						430 4.50%
Nursing Home	22 0.77%			14 0.54%	105 8.10%			5 2.69%		146 1.53%
Other, Unknown	46 1.62%	1,448 55.33%		13 0.50%	62 4.78%					1,569 16.41%
Total	**2,847 100.0%**	**2,617 100.0%**		**2,612 100.0%**	**1,297 100.0%**			**186 100.0%**		**9,559 100.0%**
Patient Informed Family of Decision										
Yes	2,593 91.08%	1,353 42.83%		2,245 85.95%						6,191 71.84%
No, No Family to Inform	254 8.92%			252 9.65%						506 5.87%
Unknown		1,806 57.17%		115 4.40%						1,921 22.29%
Total	**2,847 100.0%**	**3,159 100.0%**		**2,612 100.0%**						**8,618 100.0%**

See endnotes on next page

Endnotes

(a) Incomplete Data: In certain jurisdictions, not all data forms and documentation of death were returned prior to the publishing of the most recent report. Further, some individuals will receive their prescription later in a previous calendar year but not ingest the medication until the next calendar year. Some jurisdictions correct this in later reports, others do not or do not do so in totality. Accordingly, slight variations may occur in numbers from year to year. For further information, please consult the specific jurisdictional reports.

(b) Maine: During the first three years of authorization in ME, data was mostly released in graphs without exact labeled data points. As of 2022, ME has begun labelling the data points. Accordingly, many of the data points from ME's first three years of authorization are not captured here.

(c) Prescriptions & Medication: Some jurisdictions only report the number of prescriptions dispensed. To obtain a minimum aggregate count across all jurisdictions and years, we assumed that a prescription had to have been written in order to be dispensed, and that a prescription had to have been written and dispensed in order to have been ingested. Due to the jurisdictions that only report dispensal and our method of aggregation, the number of prescriptions written, filled, or dispensed is invariably higher than the data shows.

(d) Death Certificates: 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.

(e) Unique Providers/Pharmacists: The only jurisdictions that reports an aggregate total number of unique providers across all years are Oregon & Colorado. Other jurisdictions only report the number of unique providers in a single year. Therefore, to arrive at a minimum aggregate count across all jurisdictions, we used the largest number of unique pharmacists/physicians in a jurisdiction across any single year for the aggregate number of unique physicians/pharmacists where necessary.

(f) Prescription Rate Per Provider: This number is our own calculation and is not reported by any jursidiction: individuals who received prescriptions (written or filled) ÷ unique physicians who prescribed medication = prescription rate per provider. To arrive at an aggregate prescription rate per provider for each jurisdiction, we averaged the prescription rate per provider across all years for each jurisdiction.

(h) Gender: All jurisdictions that report data do so in categories of only "male" and "female," which excludes transgender, non-binary, and gender non-comformative individuals. Though Compassion & Choices does not agree with this approach, our reporting reflects jurisdictional categorization.

(i) Racial/Ethnic Demographics: Though Compassion & Choices does not agree with the way this demographic data is presented, we are not involved in the reporting categorization process in any jurisdiction and must present the data as it is reported.

(j) Education - Oregon: For Oregon's data from 1998-2002, "high school grad./some college" was recorded as "high school diploma or GED or less."

(k) Education - Washington: For 2019-2021, "some college" also includes patients holding collegiate degrees or higher.

(l) Underlying Illness: More than one illness may be reported, and some jurisdictions do not provide information for how illness is reported. Therefore, the number of total illness will vary from the total number of patients utilizing medical aid in dying.

(m) The data tables attached to the Utilization Report are continuously updated to include the most recent data as it becomes available. The Utilization Report itself, along with the analyses it contains, undergoes an annual update. As a result, there may be differences between the data presented in the tables and the narrative within the report, since the text reflects the data as it stood at the time of the January 2024 report's publication.