compassion & choices

Care and Choice at the End of Life

Medical Aid-in-Dying Utilization Report

January 2023

Nearly 30 years ago, in November 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 to peacefully end unbearable suffering. The law survived legal challenges as well as 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, either through statute or court decision. This list includes ten states: Oregon (1994, ballot initiative), Washington (2008, ballot initiative), Montana (2009, state Supreme Court decision), 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), 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 now have 25 years of data since Oregon implemented its law in 1997 and years of experience from other authorized jurisdictions, including annual statistical reports from nine jurisdictions. (No Montana data is included in this report since Montana's Supreme Court ruled that no state statute prohibits medical aid in dying, and the court decision did not mandate data collection.) In fact, when California lawmakers reviewed data from the first five years following the End of Life Option Act's implementation, they concluded that the law protects vulnerable populations as intended, but it had too many unnecessary regulatory roadblocks. As a result, California reauthorized and improved its law in 2021. It reduced the 15-day waiting period between the two oral requests for medication to 48 hours so that more eligible dying people would not needlessly suffer, unable to access the law. Based on data from all authorized jurisdictions, New Mexico passed a medical aid-in-dying law in 2021 requiring only one written request for medical aid in dying (no oral requests) and allowing a prescribing clinician to waive the 48-hour waiting period between receiving the written request and filling the medication prescription if the terminally ill person is likely to die during the waiting period. It also followed the standard way medicine is practiced in its jurisdictions and included advanced practice registered nurses (APRNs) and physician assistants as prescribing providers. Finally, Vermont lawmakers updated their law in 2022 to improve access, including eliminating an additional 48-hour waiting period at the end of the request process.

This report is a compilation of annual reports from all of the jurisdictions where medical aid in dying is authorized that collect data. The data clearly demonstrate that concerns of abuse, coercion or misuse are unfounded, and the medical practice provides relief from suffering. Across all the authorized jurisdictions that report data, 6,378 individuals to date have chosen to use medical aid in dying to peacefully end intolerable suffering.

We know that while few people use medical aid in dying, many gain peace of mind and comfort simply knowing the option exists. Further, medical aid in dying creates a shift within our end-of-life care system from a paternalistic model to one that is resoundingly person-driven, which contributes to improvements in hospice, palliative care, and pain and symptom management.

Terminally ill people in jurisdictions that have not 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. The time has come for compassionate lawmakers in their respective states to listen to the wishes of constituents and authorize medical aid in dying this year.

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. 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 2022. Although differences exist in how each jurisdiction collects and reports medical aid-in-dying data, key findings are analyzed below.

[1] *Oregon Death with Dignity Act Annual Reports* (1998-2021) Available from: https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx
[2] *Washington Death with Dignity Data* (2009-2020). Available from: https://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData
[3] *Vermont Report Concerning Patient Choice at the End of Life.* (2017) Available from: https://www.healthvermont.gov/systems/end-of-life-decisions/patient-choice-and-control-end-life
Vermont Report Concerning Patient Choice at the End of Life. (2019) Available from: https://legislature.vermont.gov/assets/Legislative-Reports/2020-Patient-Choice-Legislative-Report-2.0.pdf
[4] *California End of Life Option Act Annual Report* (2016-2021) 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* (2017-2021) Available from: https://www.colorado.gov/pacific/cdphe/medical-aid-dying
[6] *Hawai'i Our Care, Our Choice Act Annual Report* (2019-2021) Available from: https://health.hawaii.gov/opppd/ococ/
[7] *District of Columbia Death with Dignity Act Annual Report. (*2017-2018) Available from:
https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/Death%20With%20Dignity%20Act.FINAL_.pdf
[8] *New Jersey Medical Aid in Dying for the Terminally Ill Act Data Summary* (2019-2021) Available from: https://nj.gov/health/advancedirective/maid/
[9] *Maine Patient Directed Care at End Of Life Annual Report.* (2021) Available from:
https://legislature.maine.gov/doc/8664

Medical Aid-in-Dying Jurisdiction Usage Reports

Based on reported data, the following is known:

- Cumulatively, for the past 20+ years across all jurisdictions, 6,378 people have used a medical aid in dying prescription to end their suffering.
- Just over a third of people (37%) who go through the process and obtain the prescription never take it. However, they derive peace of mind simply from knowing they have the option if their suffering becomes too great. Less than 1% of the people who die in each jurisdiction use the law each year.[10]
- The majority of terminally ill people who use medical aid in dying — more than 87% — received hospice services at the time of their deaths, according to annual reports for which hospice 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 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.
- 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.
- Just over 90% 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.[11]
- Differences in data collection and reporting among jurisdictions do not allow for thorough comparisons of medical aid-in-dying use across the United States.

[10] According to the Center for Disease Control, in 2019 in jurisdictions that authorized medical aid in dying, 427,296 people died in total. In 2019, authorized jurisdictions report 1,027 people died after being provided with a prescription for medical aid in dying – less than 0.002% of total deaths in 2019. Center for Disease Control, *Deaths: Final Data for 2019*, July 26, 2021, available from: https://stacks.cdc.gov/view/cdc/106058/cdc_106058_DS1.pdf

[11] 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	OR (l)		WA		VT (e)		CA		CO		D.C.		HI (o)		NJ (p)		ME (m)		Cumulative	
Data Period (a)	1997 - 2021		2009 - 2020		2013 - 2019		2016 - 2021		2017 - 2021		2017 - 2018		2019-2021		2019-2021		2019-2021		1998 - 2021	
Summary Data																				
People who received prescriptions (prescriptions written or filled) (b) (c)	3,280		2,307		115		3,287		777		4		137		N/A		118		10,025	
People who died after ingesting (d)	2,159		1,687		74		2,208		N/A		2		76		95		77		6,378	
Characteristics																				
Gender (g)																				
Female	1,014	47%	1,049	47.7%			1,087	49.2%	436	50.3%	2	100%	24	34.8%	45	47.4%			3,657	48.1%
Male	1,145	53%	1,151	52.3%			1,113	50.4%	430	49.7%	0	0.0%	44	63.8%	50	52.6%			3,933	51.8%
Unknown	0	0.0%	0	0.0%			8	0.4%	0	0.0%	0	0.0%	1	1.4%	0	0.0%			9	0.1%
Total	2,159	100%	2,200	100%			2,208	100%	866	100%	2	100%	69	100%	95	100%			7,599	100%
Age Breakdown (Oregon, Washington, Colorado, D.C., and Hawaii) (k)																				
18-54	172	8.0%	163	7.4%					65	9%	0	0.0%	2	2.9%					402	7.8%
55-64	370	17.1%	402	18.2%					122	16.9%	0	0.0%	10	14.5%					904	17.5%
65-74	657	30.4%	719	32.6%					226	31.3%	1	50.0%	21	30.4%					1,624	31.5%
75-84	598	27.7%	529	24%					187	25.9%	1	50.0%	27	39.1%					1,342	261%
85+	362	16.8%	392	17.8%					121	16.8%	0	0.0%	9	13%					884	17.1%
Total	2,159	100%	2,205	100%					721	100%	2	100%	69	100%					5,156	100%

Authorized Jurisdiction	OR (l)		WA		VT (e)		CA		CO		D.C.		HI (o)		NJ (p)		ME (m)		Cumulative	
Age Breakdown (California)																				
Under 60							234	10.6%											234	10.6%
60-69							473	21.4%											473	21.4%
70-79							680	30.8%											680	30.8%
80-89							529	24%											529	24%
90+							292	13.2%											292	13.2%
Total							2,208	100%											2,208	100%
Age Breakdown (Maine)																				
Under 65																	10	14.7%	10	14.7%
Over 65																	58	85.3%	58	85.3%
Total																	68	100%	68	100%
Race/Ethnicity (h)																				
Asian	32	1.5%	0	0%			144	6.5%	13	1.8%	0	0.0%	13	18.8%	4	4.2%			206	2.7%
Black	1	0.0%	14	1%			21	0.9%	3	0.4%	0	0.0%	0	0.0%	0	0.0%			39	0.5%
Hawaiian / Pacific Islander	1	0.0%					2	0.1%					5	7.2%					8	0.1%
Hispanic and/or nonwhite (WA)			32	1.5%															32	0.4%
Indigenous American / Alaskan Native	3	0.1%					0	0.0%					0	0.0%					3	0.0%
Latino/a/x (Hispanic)	28	1.3%					89	4%	22	3.1%	0	0.0%	2	2.9%	0	0.0%			141	1.9%
Multi-Race (Two or more races)	8	0.4%					12	0.5%			0	0.0%	3	4.35%	0	0			23	0.3%
Other / Unknown	11	0.5%	62	2.8%			13	0.6%	1	0.1%	0	0.0%	2	2.9%	2	2.1%			91	1.2%
White	2,075	96.1%	2,068	95%			1,945	87.4%	682	94.6%	2	100%	44	63.8%	89	93.7%	49	100.%	6,954	92.8%
Total	2,159	100%	2,176	100%			2,226	100%	721	100%	2	100%	69	100%	95	100%	49	100%	7,497	100%

Authorized Jurisdiction	OR (l)		WA		VT (e)		CA		CO		D.C.		HI (o)		NJ (p)		ME (m)		Cumulative	
Education (i) (j) (q)																				
High School Diploma or GED or Less	575	26.6%	557	25.6%			510	23.1%	174	24.1%	0	0.0%	10	14.5%	19	20%			1,845	24.8%
Some College	435	20.1%	886	40.7%			373	16.9%	98	13.6%	1	50.0%	6	8.7%	9	9.5%			1,808	24.3%
Associate's Degree, Bachelor's Degree, Master's Degree, Doctorate or Professional Degree	1,130	52.3%	713	32.8%			1,301	58.9%	447	62%	1	50.0%	28	40.6%	67	70.5%			3,687	49.6%
Unknown	19	0.9%	20	0.9%			24	1.1%	2	0.3%	0	0.0%	25	36.2%	0	0.0%			90	1.2%
Total	2,159	100%	2,176	100%			2,208	100%	721	100%	2	100%	69	100%	95	100%			7,430	100%
Marital Status																				
Married (Including Registered Domestic Partner)	993	46.0%	1,028	47.3%					333	46.2%					49	51.6%			2,403	46.7%
Widowed	469	21.7%	420	19.3%					138	19.1%					22	23.2%			1,049	20.4%
Divorced	507	23.5%	544	25%					195	27%					14	14.7%			1,260	24.5%
Never Married, Single, Other, Unknown	190	8.8%	182	8.4%					55	7.6%					10	10.5%			437	8.5%
Total	2,159	100%	2,174	100%					721	100%					95	100%			5,149	100%

Authorized Jurisdiction	OR (l)		WA		VT (e)		CA		CO		D.C.		HI (o)		NJ (p)		ME (m)		Cumulative	
Hospice Care																				
Enrolled	1,945	90.1%	1,010	83.1%			1,926	87.2%	612	84.9%			19	82.6%					5,512	87.1%
Not Enrolled	180	8.3%	151	12.4%			214	9.7%					0	0.0%					545	8.6%
Unknown	34	1.6%	54	4.4%			68	3.1%	1	0.1%			4	17.4%					161	2.5%
Not under hospice care or unknown (Colorado)									108	15%									108	1.7%
Total	2,159	100%	1,215	100%			2,208	100%	721	100%			23	100%					6,326	100%
Insurance (f)																				
Private	804	37.2%	296	14.3%			309	14%			2	100%	11	15.9%					1,422	22.5%
Medicare, Medicaid or other governmental	1,076	49.8%	774	37.5%			322	14.6%			0	0.0%	26	37.7%					2,198	34.8%
Medicare with another type of insurance (unspecified) (California)							1,058	47.9%											1,058	16.8%
Combination of private and Medicare/Medicaid			196	9.5%			56	2.5%			0	0.0%	17	24.6%					269	4.3%
Insured (unspecified)			246	11.9%			196	8.9%											246	3.9%
None, Other Unknown	279	12.9%	554	26.8%			267	12.1%			0	0.0%	15	21.7%					1,115	17.7%
Total	2,159	100%	2,066	100%			2,208	91.1%			2	100%	69	100%					6,308	100%

Authorized Jurisdiction	OR (l)		WA		VT (e)		CA		CO		D.C.		HI (o)		NJ (p)		ME (m)		Cumulative	
Underlying Illness (n)																				
Malignant Neoplasms (Cancer)	1,566	72.5%	1,565	74.5%	88	76.5%	1,493	67.6%	491	62.5%	4	100%	51	72.9%	56	69.5%	47	69.1%	5,371	70.6%
Neurological Disease	242	11.2%	199	9.5%	19	16.5%	260	11.8%	139	17.7%	0	0.0%	7	10%	18	18.9%	9	13.2%	893	11.7%
Respiratory Disease (e.g., COPD)	123	5.7%	134	6.4%	0	0.0%	142	6.4%	43	5.5%	0	0.0%	6	8.6%	4	4.2%	4	5.9%	456	6%
Heart/ Circulatory Disease/ Cardiovascular	134	6.2%	115	5.5%	0	0.0%	169	7.7%	56	7.1%	0	0.0%	4	5.7%	3	3.2%	3	4.4%	484	6.4%
Other Illnesses	94	4.4%	88	4.2%	8	7.0%	144	6.5%	57	7.3%	0	0.0%	2	2.9%	4	4.2%	5	7.4%	402	5.3%
Total	2,159	100%	2,101	100%	115	100%	2,208	100%	786	100%	4	100%	70	100%	95	100%	68	100%	7,606	100%
Place of Death / Location Where Medication Ingested / Location of Patient																				
Home / Private Home / Residence	1,999	92.6%	1,069	88.0%			1,575	91.4%	606	85%					88	92.6%			5,337	90.4%
Assisted-Living Residence / Nursing Home / Long-Term Care	122	5.7%	99	8.1%			116	6.7%	56	7.9%					4	4.2%			397	6.7%
Inpatient Hospice Residence	3	0.1%	0	0.0%			23	1.3%	20	2.8%					0	0.0%			46	0.8%
Hospital / Other / Unknown	35	1.6%	47	3.9%			9	0.5%	31	4.3%					3	3.2%			125	2.1%
Total	2,159	100%	1,215	100%			1,723	100%	713	100%					95	100%			5,905	100%

Authorized Jurisdiction	OR (l)		WA		VT (e)		CA		CO		D.C.		HI (o)		NJ (p)		ME (m)		Cumulative	
Physician or Trained Healthcare Provider Present at Ingestion																				
Prescribing Physician	332	15.9%	80	6.6%			0	0.0%											412	8.2%
Attending Physician	0	0.0%	0	0.0%			418	24.3%											418	8.3%
Other Physician	0	0.0%	0	0.0%			58	3.4%											58	1.2%
Other Provider / Healthcare Provider	469	22.5%	715	58.8%			292	16.9%											1,476	29.4%
Volunteer	148	7.1%	*n/a*	*n/a*			*n/a*	*n/a*											148	2.9%
No Provider/Volunteer	198	9.5%	224	18.4%			207	12.0%											629	12.5%
Unknown	940	45%	196	16.1%			748	43.4%											1,884	37.5%
Total	2,087	100%	1,215	100%			1,723	100%											5,025	100%

Table Notes

(a) Data Period - California: The first California annual report detailed the first six months of the law's implementation; for some data points, data is only available from 2018.
(b) Prescriptions - Washington: Washington only reports the number of prescriptions dispensed. To obtain a minimum aggregate count across all jurisdictions, across all years, we assumed that a prescription had to have been written in order to then be dispensed. It is possible that more prescriptions were written.
(c) Death Certificates - Colorado: It is important to note that these statistics reflect all deaths identified among individuals prescribed aid-in-dying medication, whether or not they used the medication, and irrespective of whether their death followed ingestion of medication or was caused by the underlying terminal illness or condition, or some other cause.
(d) Died After Ingestion - California: The cumulative counts reported do not match prior reports (and thus do not match the latter totals shown). 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.
(e) Vermont: Vermont does not report complete data. Data on 34 patients is missing.
(f) Insurance - California: California reports insurance metrics uniquely. "Medicare/Medicaid with another type of unspecified insurance" is used for this aggregate report. "Unspecified insurance" may include private or public insurance; there is no way to differentiate.
(g) Gender: The way that the categories are defined excludes transgender and nonbinary individuals. All jurisdictions that have reportable data do so in categories of only male and female. Data would be more accurate if gender identity were fully included. The data reflects what the jurisdiction has reported.
(h) Racial/Ethnic Demographics: Washington state and Colorado use inconsistent racial/ethnic categories. Accordingly, to accurately aggregate data across all years, Washington's terminology - "Hispanic and/or non-white" is used specifically for Washington. In Colorado, "white-Hispanic" is recorded as "Latinx (Hispanic)."
(i) Education: Where certain jurisdictions reported more specific categories, to remain consistent across all jurisdictions and all years, combined categories include (1) "high school diploma or GED or less" and (2) "Associate's Degree, Bachelor's Degree, Master's Degree, Doctorate or Professional Degree."
(j) Education - Oregon: For Oregon's data from 1998-2002, "high school grad./some college" is included as "high school diploma or GED or less."
(k) Age Breakdown - Oregon: Oregon's data from 2005 uses a different age breakdown than other years. To remain consistent with other jurisdictions and years, "18-44" is reported under "18-54," "45-65" under "55-65," and "65-84" under "75-84."
(l) Incomplete Data: Not all data forms and documentation of death were returned to the state of Oregon and New Jersey prior to the publishing of the 2022 report. Further, some individuals will receive their prescription later in a previous calendar year but not ingest the medication until the next calendar year. Accordingly, when the updated information is released, it will be included in subsequent reports.
(m) Maine: Though Maine released more data than what is contained in this spreadsheet, the way they collected and presented some data was incompatible with aggregating methods and has been left out. Rather than releasing total sums, for the vast majority of categories Maine provided percentages, which cannot be used to accurately discern the total numbers in any given category.
(n) Hawai'i - Underlying Illness: In 2021, one patient in Hawai'i had an underlying illness of both COPD and cancer. Accordingly, that patient is counted twice in this spreadsheet in the category of underlying illness.
(o) Hawai'i 2021 Data: For 2021, the state of Hawai'i reports that 32 people died from medical-aid-in-dying medication; however, the state only provides data on 26 of those 32 patients.
(p) Incomplete Data: Not all data forms and documentation of death were returned to New Jersey prior to the publishing of the 2022 report. Further, some individuals will receive their prescription later in a previous calendar year but not ingest the medication until the next calendar year. Accordingly, when the updated information is released, this report will be updated.
(q) Washington - Education: For 2021, "some college" also includes patients holding collegiate degrees or higher.
(r) N/A vs 0: "N/A" is used to designate categories wherein the jurisdiction does not report on that categorization. "0" is used to show that the jurisdiction does report that category but had nothing to report for that specific year.