

Medical Aid in Dying: State Utilization Reports



January 2021

More than 25 years ago, in November 1994, Oregon passed the nation's first law allowing mentally capable terminally ill adults to have the end-of-life care option of medical aid in dying to peacefully end unbearable suffering.

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 nine states: Oregon (1994, ballot initiative), Washington (2008, ballot initiative), Montana (2009, state Supreme Court decision), Vermont (2013, legislation), California (2015, legislation), Colorado (2016, ballot initiative), Hawaii (2018, legislation), New Jersey (2019, legislation) and Maine (2019, legislation) as well as the District of Columbia (2016, legislation). Because Montana was authorized by a state Supreme Court decision, no medical aid in dying usage data is required to be collected. Therefore, no data from Montana is included in our state utilization reports.

We no longer have to hypothesize about what will happen if this medical practice is authorized. We now have 23 years of experience since the first law was enacted in Oregon, and an additional 40+ years of combined evidence from the laws passed in other jurisdictions on the practice of medical aid in dying, including annual statistical reports from seven jurisdictions.

This report includes a compilation of the annual reports from the authorized states that collect data. These reports clearly demonstrate that concerns of abuse or coercion are unfounded. In decades of experience across all the authorized states, only 4,209 individuals have chosen to use medical aid in dying. We know from other data that while few people use medical aid in dying, many get peace of mind and comfort simply knowing the law exists that makes it accessible to them. Furthermore, medical aid in dying creates a shift within our end-of-life care system from a paternalistic model to one that is resoundingly patient-driven, which contributes to improvements in hospice care and pain and symptom management.

Terminally ill residents don't have the luxury of endless deliberations. They need this option right now. We have the evidence, data and strong public support to authorize medical aid in dying this year.

Sincerely,

A handwritten signature in black ink that reads "Kim Callinan". The signature is written in a cursive, flowing style.

Kim Callinan
President & CEO
Compassion & Choices
Compassion & Choices Action Network

Medical Aid-in-Dying State Usage Reports

Currently, public health departments in nine authorized jurisdictions have issued reports regarding the utilization of medical aid-in-dying laws: Oregon,¹ Washington,² Vermont,³ California,⁴ Colorado,⁵ Hawai'i⁶, the District of Columbia⁷, New Jersey⁸, and Maine⁹.

Based on that data, we know the following:

- > Cumulatively, for the past 20+ years, across all jurisdictions, only 4,209 people have taken a prescription to end their suffering.
- > Slightly more than a third of people (36%) who go through the process and obtain the prescription never take it. However, they derive peace of mind from simply knowing they would have the option if their suffering became too great.
- > Less than 1% of the people who die in each state use the law each year.
- > The vast majority of terminally ill people who use medical aid in dying — more than 85% — received hospice services at the time of their deaths.
- > There is nearly equal utilization of medical aid in dying among men and women.
- > The rate at which people of color access and use prescriptions under medical aid in dying laws appears to be consistently lower than white populations. However, differences in data collection and reporting complicates comparisons across states.
- > 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.
- > Ninety percent of people who use medical aid in dying are able to die at home. According to various studies, most Americans would prefer to die at home.

¹ *Oregon Death with Dignity Act Annual Reports (1998-2019)* Available from: <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>

² *Washington Death with Dignity Data (2009-2018)*. 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 (2016-2019)* 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 (2017-2019)* Available from: <https://www.colorado.gov/pacific/cdphe/medical-aid-dying>

⁶ *Hawai'i Our Care, Our Choice Act Annual Report (2019)* <https://health.hawaii.gov/opppd/files/2020/01/OPPPD-Our-Care-Our-Choice-Act-Annual-Report-2019-1.pdf>

⁷ *District of Columbia Death with Dignity Act Annual Report*. (2017-2018) Available from: <https://dchealth.dc.gov/page/death-dignity-act-2016>

⁸ *New Jersey Medical Aid in Dying for the Terminally Ill Act Data Summary (2019)* Available from: https://www.state.nj.us/health/advancedirective/documents/maid/2019_MAID_DataSummary.pdf

⁹ *Maine Patient Directed Care at End Of Life Annual Report*. (2019) Available from:

<https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Death%20with%20Dignity%20Legislative%20Report%20--%204-2020.pdf>

Authorized Jurisdiction	OR		WA		VT (e)		CA		CO		D.C.		HI		NJ		ME		Cumulative	
Data Period (a)	1997 - 2019		2009 - 2018		2013 - 2019		2016 - 2019		2017 - 2019		2017 - 2018		2019		2019		2019		1998 - 2019	
Summary Data																				
Individuals who received prescriptions (prescriptions written or filled) (b) (c)	2,518		1,668		86		1,985		365		4		30		12		1		6,669	
Individuals who died after ingesting (d)	1,657		1,210		29		1,283		n/a		2		15		12		1		4,209	
Characteristics																				
Gender (h)																				
Female	779	47.0%	766	48.8%	n/a	n/a	603	49.1%	158	48.2%	2	100%	4	26.7%	6	50.0%	n/a	n/a	2,318	48.2%
Male	878	53.0%	804	51.2%	n/a	n/a	616	50.2%	170	51.8%	0	0.0%	11	73.3%	6	50.0%	n/a	n/a	2,485	51.7%
Unknown	0	0.0%	0	0.0%	n/a	n/a	8	0.7%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	n/a	n/a	8	0.2%
Total	1,657	100%	1,570	100%	n/a	n/a	1,227	100%	328	100%	2	100%	15	100%	12	100%	n/a	n/a	4,811	100%
Age Breakdown (Oregon, Washington, Colorado, D.C., and Hawaii) (k)																				
18-54	138	8.3%	128	8.1%	n/a	n/a			33	10.1%	0	0.0%	0	0.0%	n/a	n/a			299	8.4%
55-64	309	18.6%	300	19.0%	n/a	n/a			59	18.0%	0	0.0%	2	13.3%	n/a	n/a			670	18.7%
65-74	498	30.1%	502	31.9%	n/a	n/a			109	33.2%	1	50.0%	6	33.3%	n/a	n/a			1,115	31.2%
75-84	451	27.2%	370	23.5%	n/a	n/a			76	23.2%	1	50.0%	6	46.7%	n/a	n/a			905	25.3%
85+	261	15.8%	275	17.5%	n/a	n/a			51	15.5%	0	0.0%	1	6.7%	n/a	n/a			588	16.4%
Total	1,657	100%	1,575	100%	n/a	n/a			328	100%	2	100%	15	100%	n/a	n/a			3,577	100%

Authorized Jurisdiction	OR	WA	VT (e)	CA	CO	D.C.	HI	NJ	ME	Cumulative										
Age Breakdown (California)																				
Under 60				134	10.9%					134	10.9%									
60-69				271	22.1%					271	22.1%									
70-79				353	28.8%					353	28.8%									
80-89				306	24.9%					306	24.9%									
90+				163	13.3%					163	13.3%									
Total				1,227	100%					1,227	100%									
Age Breakdown (Maine)																				
Under 65									0	0.0%	0	0.0%								
Over 65									1	100%	1	100%								
Total									1	100%	1	100%								
Race/Ethnicity (f)																				
White	1,592	96.1%	1,478	95.6%	n/a	n/a	1,099	88.3%	309	94.2%	2	100%	9	60.0%	11	91.7%	n/a	n/a	4,500	94.3%
Black	1	0.1%	n/a	n/a	n/a	n/a	11	0.9%	n/a	n/a	0	0.0%	0	0.0%	0	0.0%	n/a	n/a	12	0.3%
Asian	23	1.4%	n/a	n/a	n/a	n/a	72	5.8%	n/a	n/a	0	0.0%	3	20.0%	1	8.3%	n/a	n/a	99	2.1%
Indigenous American / Alaskan Native	3	0.2%	n/a	n/a	n/a	n/a	0	0.0%	n/a	n/a	n/a	n/a	0	0.0%	n/a	n/a	n/a	n/a	3	0.1%
Hawaiian / Pacific Islander	1	0.1%	n/a	n/a	n/a	n/a	1	0.1%	n/a	n/a	n/a	n/a	1	6.7%	n/a	n/a	n/a	n/a	3	0.1%
Other / Unknown	10	0.6%	36	2.3%	n/a	n/a	11	0.9%	6	1.8%	0	0.0%	1	6.7%	0	0.0%	n/a	n/a	64	1.3%
Multi Race (Two or more races)	7	0.4%	n/a	n/a	n/a	n/a	4	0.3%	n/a	n/a	0	0.0%	0	0	0	0	n/a	n/a	11	0.2%
Latinx (Hispanic)	20	1.2%	n/a	n/a	n/a	n/a	47	3.8%	13	4.0%	0	0.0%	1	6.7%	0	0.0%	n/a	n/a	81	1.7%
Hispanic and/or non-white (WA)			32	2.1%															32	2.1%
Total	1,657	100%	1,546	100%	n/a	n/a	1,245	100%	328	100%	2	100%	15	100%	12	100%			4,805	100%

Authorized Jurisdiction	OR	WA	VT (e)	CA	CO	D.C.	HI	NJ	ME	Cumulative										
Education (j)																				
High School Diploma or GED or Less	435	26.3%	413	26.7%	n/a	n/a	289	23.6%	80	24.4%	0	0.0%	0	0.0%	2	16.7%	n/a	n/a	1,219	25.5%
Some College	340	20.5%	407	26.3%	n/a	n/a	217	17.7%	51	15.5%	1	50.0%	1	6.7%	1	8.3%	n/a	n/a	1,018	21.3%
Associate's Degree, Bachelor's Degree, Master's Degree, Doctorate or Professional Degree	866	52.3%	713	46.1%	n/a	n/a	706	57.5%	197	60.1%	1	50.0%	7	46.7%	9	75.0%	n/a	n/a	2,499	52.2%
Unknown	16	1.0%	13	0.8%	n/a	n/a	15	1.2%	0	0.0%	0	0.0%	7	46.7%	0	0.0%	n/a	n/a	51	1.1%
Total	1,657	100%	1,546	100%	n/a	n/a	1,227	100%	328	100%	2	100%	15	100%	12	100%	n/a	n/a	4,787	100%
Marital Status																				
Married (Including Registered Domestic Partner)	763	46.0%	728	47.1%	n/a	n/a	n/a	n/a	160	48.8%	n/a	n/a	n/a	n/a	6	50.0%	n/a	n/a	1,657	46.8%
Widowed	358	21.6%	304	19.7%	n/a	n/a	n/a	n/a	51	15.5%	n/a	n/a	n/a	n/a	3	25.0%	n/a	n/a	716	20.2%
Divorced	389	23.5%	395	25.5%	n/a	n/a	n/a	n/a	89	27.1%	n/a	n/a	n/a	n/a	2	16.7%	n/a	n/a	875	24.7%
Never Married, Single, Other, Unknown	147	8.9%	119	7.7%	n/a	n/a	n/a	n/a	28	8.5%	n/a	n/a	n/a	n/a	1	8.3%	n/a	n/a	295	8.3%
Total	1,657	100%	1,546	100%	n/a	n/a	n/a	n/a	328	100%	n/a	n/a	n/a	n/a	12	100%	n/a	n/a	3,543	100%

Authorized Jurisdiction	OR	WA	VT (e)	CA	CO	D.C.	HI	NJ	ME	Cumulative										
Hospice Care																				
Enrolled	1,464	88.4%	1,010	83.1%	n/a	n/a	1,112	86.1%	274	83.5%	n/a	n/a	19	82.6%	n/a	n/a	n/a	n/a	3,879	85.9%
Not Enrolled	159	9.6%	151	12.4%	n/a	n/a	123	9.5%	0	0.0%	n/a	n/a	0	0.0%	n/a	n/a	n/a	n/a	433	9.6%
Unknown	34	2.1%	54	4.4%	n/a	n/a	56	4.3%	0	0.0%	n/a	n/a	4	17.4%	n/a	n/a	n/a	n/a	148	3.3%
Not under hospice care or unknown (Colorado)									54	16.5%									54	1.2%
Total	1,657	100%	1,215	100%	n/a	n/a	1,291	100%	328	100%	n/a	n/a	24	100%	n/a	n/a	n/a	n/a	4,515	100%
Insurance (g)																				
Private	712	43.0%	296	20.4%	n/a	n/a	161	13.1%	n/a	n/a	2	100%	3	20.0%	n/a	n/a	n/a	n/a	1,174	27.0%
Medicare, Medicaid or other governmental	776	46.8%	774	53.2%	n/a	n/a	302	24.6%	n/a	n/a	0	0.0%	3	20.0%	n/a	n/a	n/a	n/a	1,855	42.6%
Medicare with another type of insurance (unspecified) (California)							503	41.0%											503	11.5%
Combination of private and Medicare/Medicaid	n/a	n/a	196	13.5%	n/a	n/a	56	4.6%	n/a	n/a	0	0.0%	8	53.3%	n/a	n/a	n/a	n/a	260	6.0%
None, Other, Unknown	169	10.2%	188	12.9%	n/a	n/a	205	16.7%	n/a	n/a	0	0.0%	1	6.7%	n/a	n/a	n/a	n/a	563	12.9%
Total	1,657	100%	1,454	100%	n/a	n/a	1,227	100%	n/a	n/a	2	100%	15	100%	n/a	n/a	n/a	n/a	4,355	100%

Authorized Jurisdiction	OR		WA		VT (e)		CA		CO		D.C.		HI		NJ		ME		Cumulative	
Underlying Illness																				
Malignant Neoplasms (Cancer)	1,244	75.1%	1,148	75.2%	67	77.9%	828	67.5%	228	62.5%	4	100%	10	66.7%	7	58.3%	1	100%	3,537	72.3%
Neurological Disease	187	11.3%	152	10.0%	14	16.3%	140	11.4%	70	19.2%	0	0.0%	4	26.7%	3	25.0%	0	0.0%	570	11.6%
Respiratory Disease (e.g., COPD)	89	5.4%	95	6.2%	0	0.0%	71	5.8%	26	7.1%	0	0.0%	1	6.7%	1	8.3%	0	0.0%	283	5.8%
Heart/ Circulatory Disease/ Cardiovascular	76	4.6%	83	5.4%	0	0.0%	101	8.2%	29	7.9%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	289	5.9%
Other illnesses	61	3.7%	49	3.2%	5	5.8%	87	7.1%	12	3.3%	0	0.0%	0	0.0%	1	8.3%	0	0.0%	215	4.4%
Total	1,657	100%	1,527	100%	86	100%	1,227	100%	365	100%	4	100%	15	100%	12	100%	1	100%	4,894	100%
Place of Death / Location Where Medication Ingested / Location of Patient																				
Home / Private Home / Residence	1,529	92.3%	1,069	88.0%	n/a	n/a	667	89.9%	271	82.6%	n/a	n/a	n/a	n/a	10	83.3%	n/a	n/a	3,546	89.7%
Assisted-Living Residence / Nursing Home / Long-term Care	95	5.7%	99	8.1%	n/a	n/a	62	8.4%	23	7.0%	n/a	n/a	n/a	n/a	1	8.3%	n/a	n/a	280	7.1%
In-patient Hospice Residence	3	0.2%	0	0.0%	n/a	n/a	10	1.3%	13	4.0%	n/a	n/a	n/a	n/a	0	0.0%	n/a	n/a	26	0.7%
Hospital / Other / Unknown	30	1.8%	47	3.9%	n/a	n/a	3	0.4%	21	6.4%	n/a	n/a	n/a	n/a	1	8.3%	n/a	n/a	102	2.6%
Total	1,657	100%	1,215	100%	n/a	n/a	742	100%	328	100%	n/a	n/a	n/a	n/a	12	100%	n/a	n/a	3,954	100%

Authorized Jurisdiction	OR		WA		VT (e)		CA		CO		D.C.		HI		NJ		ME		Cumulative	
Physician or Trained Healthcare Provider Present at Ingestion																				
Prescribing Physician	257	16.2%	80	6.6%	n/a	n/a	0	0.0%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	337	9.5%
Attending Physician	0	0.0%	0	0.0%	n/a	n/a	243	32.7%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	243	6.9%
Other Physician	0	0.0%	0	0.0%	n/a	n/a	22	3.0%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	22	0.6%
Other Provider / Healthcare Provider	372	23.5%	715	58.8%	n/a	n/a	112	15.1%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	1,199	33.9%
Volunteer	56	3.5%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	56	1.6%
No Provider/Volunteer	130	8.2%	224	18.4%	n/a	n/a	142	19.1%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	496	14.0%
Unknown	770	48.6%	196	16.1%	n/a	n/a	223	30.1%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	1,189	33.6%
Total	1,585	100%	1,215	100%	n/a	n/a	742	100%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	3,542	100%

Table Notes

- (a) California: The first annual report detailed the first 6 months of the law's implementation; for some data points, data is only available from 2018.
- (b) 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 but it is possible that more prescriptions were written.
- (c) 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 this medication, and irrespective of whether their death was caused by ingestion of medication, the underlying terminal illness or condition, or some other cause.
- (d) 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) Racial/Ethnic Demographics: Washington state and Colorado use racial/ethnic categories that do not divide residents into consistent categories. Accordingly, to get an accurate total across all years, we created a new category using WA's terminology - "Hispanic and/or non-white" specifically for Washington. In Colorado, we recorded "white-Hispanic" as "Latinx (Hispanic)."
- (g) California: Because of the way California breaks up insurance metrics, we had to create a new category - "Medicare/Medicaid with another type of unspecified insurance." This could be private or public insurance, there is no way to differentiate.
- (h) Gender: The way that the categories are defined excludes transgender and non-binary individuals. All states that have reportable data do so in categories of only male and female. In order to be more inclusive, the category should be gender identity and there should be more response choices. Our reporting reflects what the state has given.
- (i) Education: Where certain states may have had more specific categories, to remain consistent across all states and all years, we many together into the following two categories: (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, We recorded "high school grad./some college," 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 states and years, we recorded "18-44" under "18-54," "45-65" under "55-65," and "65-84" under "75-84."