

Medical Aid in Dying:

State Utilization Reports



January 2022

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 ten states: Oregon (1994, ballot initiative), Washington (2008, ballot initiative), Montana (2009, state Supreme Court decision), Vermont (2013, legislation), California (2015, legislation, amended in 2021), Colorado (2016, ballot initiative), Hawaii (2018, legislation), New Jersey (2019, legislation), Maine (2019, legislation), New Mexico (2020, 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 report.

We no longer have to hypothesize about what will happen if this medical practice is authorized. We now have close to 25 years of data since Oregon first implemented its law in 1997, and years of experience from the 10 other authorized jurisdictions, including annual statistical reports from seven jurisdictions. In fact, when California lawmakers reviewed the data from the first five years of implementation, they concluded that the law protects vulnerable populations as intended. However, it had too many <u>unnecessary</u> regulatory roadblocks. As a result, California re-authorized its law in 2021 and slightly modified the legislation by reducing the 15-day waiting period to 48 hours so that more eligible dying people would not needlessly suffer trying to access the law.

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 5,171 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,

Kim Callinan

President & CEO

Compassion & Choices

Compassion & Choices Action Network

Kin Callinan

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, Washington, Vermont, California, California, Hawai'i, the District of Columbia, New Jersey, and Maine.

Based on that data, we know the following:

- > Cumulatively, for the past 20+ years, across all jurisdictions, only 5,171 people have taken a prescription to end their suffering.
- > A third of people (33%) who go through the process and obtain the prescription never take it. However, they derive peace of mind simply from 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 majority of terminally ill people who use medical aid in dying more than 86% received hospice services at the time of their deaths, according to annual reports for which hospice data is available.
- > 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.
- > Nearly 90% 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.

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

Maine Patient Directed Care at End of Life Annual Report. (2020) Available from: https://www.maine.gov/dhhs/sites/maine.gov/dhs/sites/main

¹ Oregon Death with Dignity Act Annual Reports (1998-2020) Available from: https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx

 $^{^2\}textit{Washington Death with Dignity Data} \ (2009-2019). \ \textit{Available from: } \underline{\text{https://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData} \\ \\$

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

 $^{^{4} \}textit{ California End of Life Option Act Annual Report} \ (2016-2020) \ Available from: \\ \underline{\text{https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx}}$

⁵ Colorado End of Life Options Act Annual Report (2017-2020) Available from: https://www.colorado.gov/pacific/cdphe/medical-aid-dying

⁶ Hawai'i Our Care, Our Choice Act Annual Report (2019-2020) 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/page/death-dignity-act-2016

⁸ New Jersey Medical Aid in Dying for the Terminally III Act Data Summary (2019-2020) Available from: https://nj.gov/health/advancedirective/maid/

 $^{^{\}rm 9}$ Maine Patient Directed Care at End Of Life Annual Report. (2019) Available from:

Authorized Jurisdiction	OF	R (I)	: (I) WA		VT (e)		CA		СО		D.C.		HI	(0)	NJ (p)		ME (m)		Cumulative	
Data Period (a)	1997 -	- 2020	2009 -	- 2019	2013 - 2020		2016 - 2020		2017 -	2017 - 2020		2017 - 2018		2019-2020		-2020	2019-2020		1998 -	- 2020
Summary Da	ata																			
Individuals who received prescriptions (prescriptions written or filled) (b) (c)	2,895 1,967		115		2,515		55	54	4		67		45		5	1	8,2	213		
Individuals who died after ingesting (d)	1,9	P05	1,4	135	7	4	1,6	662	n	/a	2		47		45		,	l	5,1	71
Characteristi	ics																			
Gender (g)																				
Female	900	47.2%	899	48.2%	n/a	n/a	824	49.6%	254	50%	2	100%	12	30%	18	40.0%	n/a	n/a	2,909	48.3%
Male	1,005	52.8%	968	51.8%	n/a	n/a	830	49.9%	254	50%	0	0.0%	28	70%	27	60.0%	n/a	n/a	3,112	51.6%
Unknown	0	0.0%	0	0.0%	n/a	n/a	8	0.5%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	n/a	n/a	8	0.1%
Total	1,905	100%	1,867	100%	n/a	n/a	1,662	100%	508	100%	2	100%	40	100%	45	100%	n/a	n/a	6,029	100%
Age Breakdov	vn (Ore	egon, \	Nashin	gton, (Colora	do, D.0	C., and	Hawai	i) (k)											
18-54	154	8.1%	141	7.5%	n/a	n/a			44	8.7%	0	0.0%	1	2.5%	n/a	n/a			340	7.9%
55-64	339	17.8%	361	19.3%	n/a	n/a			96	18.9%	0	0.0%	2	5.0%	n/a	n/a			798	18.4%
65-74	582	30.6%		31.9%	n/a	n/a				30.1%	1	50.0%		40.0%	n/a	n/a				31.2%
75-84		27.2%		23.6%	n/a	n/a				27.3%	1	50.0%		42.5%	n/a	n/a				25.6%
85+	312		331	17.7%	n/a	n/a			85	16.7%	0	0.0%	4	10%	n/a	n/a			732	16.9%
Total	1,905	100%	1,872	100%	n/a	n/a			508	100%	2	100%	40	100%	n/a	n/a			4,327	100%

Authorized Jurisdiction	OR	? (1)	V	/A	VT	(e)	С	А	С	0	D.	C.	HI	(0)	NJ	(p)	ME	(m)	Cumu	ulative
Age Breakdov	wn (Ca	lifornia)																	
Under 60							174	10.5%											174	10.5%
60-69							369	22.2%											369	22.2%
70-79							500	30.1%											500	30.1%
80-89							400	24.1%											400	24.1%
90+							219	13.2%											219	13.2%
Total							1,662	100%											1,662	100%
Age Breakdov	wn (Ma	ine)																		
Under 65																	0	0.0%	0	0.0%
Over 65																	1	100%	1	100%
Total																	1	100%	1	100%
Race/Ethnicity	/ (h)																			
White	1,833	96.2%	1,759	95.4%	n/a	n/a	1,479	88.0%	482	94.9%	2	100%	28	70.0%	42	93.3%	n/a	n/a	5,625	94.1%
Black	1	0.1%	n/a	n/a	n/a	n/a	15	0.9%	3	n/a	0	0.0%	0	0.0%	0	0.0%	n/a	n/a	16	0.3%
Asian	26	1.4%	n/a	n/a	n/a	n/a	105	6.3%	8	n/a	0	0.0%	8	20.0%	1	2.2%	n/a	n/a	140	2.3%
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	2	0.1%	n/a	n/a	n/a	n/a	2	5.0%	n/a	n/a	n/a	n/a	5	0.1%
Other / Unknown	11	0.6%	52	2.8%	n/a	n/a	12	0.7%	n/a	n/a	0	0.0%	1	2.5%	2	4.4%	n/a	n/a	78	1.3%
Multi Race (Two or more races)	8	0.4%	n/a	n/a	n/a	n/a	5	0.3%	n/a	n/a	0	0.0%	n/a	n/a	0	0	n/a	n/a	13	0.2%
Latinx (Hispanic)	22	1.2%	n/a	n/a	n/a	n/a	62	3.7%	15	3.0%	0	0.0%	1	2.5%	0	0.0%	n/a	n/a	100	1.7%
Hispanic and/or non-white (WA)			32	1.7%															32	0.5%
Total	1,905	100%	1,843	100%	n/a	n/a	1,680	100%	508	100%	2	100%	40	100%	45	100%			5,980	100%

Authorized Jurisdiction	OR (I) WA		/A	VT (e)		CA		CO		D.C.		HI (o)		NJ (p)		ME (m)		Cumu	ulative	
Education (i) (
High School Diploma or GED or Less	505	26.5%	479	26.0%	n/a	n/a	390	23.5%	131	25.8%	0	0.0%	6	15.0%	8	17.8%	n/a	n/a	1,519	25.3%
Some College	385	20.2%	633	34.3%	n/a	n/a	295	17.7%	76	15%	1	50.0%	5	12.5%	5	11.1%	n/a	n/a	1,400	23.3%
Associate's Degree, Bachelor's Degree, Master's Degree, Doctorate or Professional Degree	999	52.4%	713	38.7%	n/a	n/a	959	57.7%	300	59%	1	50.0%	16	40.0%	32	71.1%	n/a	n/a	3,020	50.3%
Unknown	16	0.8%	18	1.0%	n/a	n/a	18	1.1%	1	0.2%	0	0.0%	13	32.5%	0	0.0%	n/a	n/a	66	1.1%
Total	1,905	100%	1,843	100%	n/a	n/a	1,662	100%	508	100%	2	100%	40	100%	45	100%	n/a	n/a	6,005	100%
Marital Status																				
Married (Including Registered Domestic Partner)		46.0% 21.9%	868 358	47.1% 19.4%	n/a n/a	n/a	n/a n/a	n/a n/a	241 95	47.4% 18.7%	n/a n/a	n/a n/a	n/a n/a	n/a n/a		55.6% 24.4%	n/a n/a	n/a n/a	2,010 882	46.8% 20.5%
						n/a														
Divorced	445	23.4%	468	25.4%	n/a	n/a	n/a	n/a	132	26.0%	n/a	n/a	n/a	n/a	6	13.3%	n/a	n/a	1,051	24.4%
Never Married, Single, Other, Unknown	166	8.7%	147	8.0%	n/a	n/a	n/a	n/a	40	7.0%	n/a	n/a	n/a	n/a	3	7.9%	n/a	n/a	356	8.3%
Total	1,905	100%	1,841	100%	n/a	n/a	n/a	n/a	508	100%	n/a	n/a	n/a	n/a	45	100%	n/a	n/a	4,299	100%

Authorized Jurisdiction	OF	? (1)	V	/A	VT	(e)	С	Α	С	0	D.	C.	HI	(0)	NJ	(p)	ME	(m)	Cumu	ulative
Hospice Care																				
Enrolled	1,699	89.2%	1,010	83.1%	n/a	n/a	1,425	85.7%	425	83.7%	n/a	n/a	19	82.6%	n/a	n/a	n/a	n/a	4,578	86.2%
Not Enrolled	172	9.0%	151	12.4%	n/a	n/a	171	10.3%	n/a	n/a	n/a	n/a	0	0.0%	n/a	n/a	n/a	n/a	494	9.3%
Unknown	34	1.8%	54	4.4%	n/a	n/a	66	4.0%	1	0.2%	n/a	n/a	4	17.4%	n/a	n/a	n/a	n/a	159	3.0%
Not under hospice care or unknown (Colorado)									82	16.1%									82	1.5%
Total	1,905	100%	1,215	100%	n/a	n/a	1,662	100%	508	100%	n/a	n/a	23	100%	n/a	n/a	n/a	n/a	5,313	100%
Insurance (f)																				
Private	763	40.1%	296	17.1%	n/a	n/a	219	13.2%	n/a	n/a	2	100%	5	12.5%	n/a	n/a	n/a	n/a	1,285	24.1%
Medicare, Medicaid or other governmental	927	48.7%	774	44.7%	n/a	n/a	314	18.9%	n/a	n/a	0	0.0%	25	62.5%	n/a	n/a	n/a	n/a	2,040	38.2%
Medicare with another type of insurance (unspecified) (California)							775	46.6%											775	14.5%
Combination of private and Medicare/Med icaid	n/a	n/a	196	11.3%	n/a	n/a	56	3.4%	n/a	n/a	0	0.0%	9	22.5%	n/a	n/a	n/a	n/a	261	4.9%
Insured (unspecified)			246	14.2%															246	4.6%
None, Other, Unknown	215	11.3%	221	12.8%	n/a	n/a	298	17.9%	n/a	n/a	0	0.0%	1	2.5%	n/a	n/a	n/a	n/a	735	13.8%
Total	1,905	100%	1,733	100%	n/a	n/a	1,662	100%	n/a	n/a	2	100%	40	100%	n/a	n/a	n/a	n/a	5,342	100%

Authorized Jurisdiction	OR (1)		WA		VT (e)		CA		СО		D.	C.	HI	(0)	NJ (p)		ME (m)		Cumulativ	
Underlying Illr	ness (n)																		
Malignant Neoplasms (Cancer)	1,410	74.0%	1,336	74.8%	88	76.5%	1,136	68.4%	348	62.8%	4	100%	29	70.7%	31	68.9%	1	100%	4,383	71.7%
Neurological Disease	206	10.8%	179	10.0%	19	16.5%	187	11.3%	98	17.7%	0	0.0%	4	9.8%	8	17.8%	0	0.0%	701	11.5%
Respiratory Disease (e.g., COPD)	104	5.5%	105	5.9%	0	0.0%	105	6.3%	39	7%	0	0.0%	5	12.2%	3	6.7%	0	0.0%	361	5.9%
Heart/ Circulatory Disease/ Cardiovascular	104	5.5%	98	5.5%	0	0.0%	123	7.4%	44	7.9%	0	0.0%	2	4.9%	1	2.2%	0	0.0%	372	6.1%
Other illnesses	81	4.3%	69	3.9%	8	7.0%	111	6.7%	25	4.5%	0	0.0%	1	2.4%	2	4.4%	0	0.0%	297	4.9%
Total	1,905	100%	1,787	100%	86	100%	1,662	100%	554	100%	4	100%	41	100%	45	100%	1	100%	6,114 5	
Place of Death	n / Loc	ation V	Vhere	Medica	ation In	geste	d / Loc	ation o	f Patie	nt										
Home / Private Home / Residence	1,758	92.3%	1,069	88.0%	n/a	n/a	1,067	90.7%	425	83.7%	n/a	n/a	n/a	n/a	40	88.9%	n/a	n/a	4,359	89.9%
Assisted-Living Residence / Nursing Home / Long-term Care	110	5.8%	99	8.1%	n/a	n/a	93	7.9%	34	6.7%	n/a	n/a	n/a	n/a	2	4.4%	n/a	n/a	338	7.0%
In-patient Hospice Residence	3	0.2%	0	0.0%	n/a	n/a	12	1.0%	21	4.1%	n/a	n/a	n/a	n/a	0	0.0%	n/a	n/a	36	0.7%
Hospital / Other / Unknown	34	1.8%	47	3.9%	n/a	n/a	5	0.4%	28	5.5%	n/a	n/a	n/a	n/a	3	6.7%	n/a	n/a	117	2.4%

Total	1,905	100%	1,215	100%	n/a	n/a	1,177	100%	508	100%	n/a	n/a	n/a	n/a	45	100%	n/a	n/a	4,850	100%
Authorized Jurisdiction	OF	R (I)	V	/ A	VT	(e)	С	A	С	0	D.	C.	HI	(0)	NJ	(p)	ME	(m)	Cumu	ılative
Physician or T	rained	Health	care P	rovider	Prese	nt at Ir	ngestio	n												
Prescribing Physician	286	15.0%	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	366	8.5%
Attending Physician	0	0.0%	0	0.0%	n/a	n/a	332	28.2%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	322	7.5%
Other Physician	0	0.0%	0	0.0%	n/a	n/a	40	3.4%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	40	0.9%
Other Provider / Healthcare Provider	432	22.7%	715	58.8%	n/a	n/a	194	16.5%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	1,341	31.2%
Volunteer	98	5.1%	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	98	2.3%
No Provider/Volunteer	164	8.6%	224	18.4%	n/a	n/a	176	15.0%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	564	13.1%
Unknown	925	48.6%	196	16.1%	n/a	n/a	445	37.8%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	1,566	36.4%
Total	1,905	100%	1,215	100%	n/a	n/a	1,177	100%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	4,297	100%

Table Notes

- (a) Data Period 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) 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, but 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 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) 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: 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.
- (g) 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. The data reflects what the state has reported.
- (h) 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 Washinton. In Colorado, we recorded "white-Hispanic" as "Latinx (Hispanic)."
- (i) Education: Where certain states reported more specific categories, to remain consistent across all states and all years, we combined categories into (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."
- (I) 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 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. Accordingly, when the updated information is released, this report will be updated.
- (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 our methods and has been left out.
- (n) Hawaii Underlying Illness: In 2021, one patient in Hawaii 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) Hawaii 2021 Data: For 2021, the state of Hawaii reports that 32 people died from medical aid in dying medication, however, only provides data on 26 of those 32 patients.