

# Fourth Annual Report on Oregon's Death with Dignity Act



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## Summary

Physician-assisted suicide (PAS) has been legal in Oregon since November 1997, when the Death with Dignity Act was approved by Oregon voters for the second time. In this fourth annual report, we characterize the 21 Oregonians who ingested legally-prescribed lethal medications during 2001, and look at whether the numbers and characteristics of these patients differ from those who used PAS in prior years. Patients choosing PAS were identified through mandated physician and pharmacy reporting. Our information comes from these reports, physician interviews and death certificates. We also compare the demographic characteristics of patients participating during 2001 with other Oregonians who died of similar underlying causes.

In 2001, a total of 44 prescriptions of lethal doses of medication were written by 33 physicians. By comparison, 39 prescriptions were written in 2000, 33 in 1999 and 24 in 1998. Nineteen of the fourth-year prescription recipients died after ingesting the medication; 14 died from their underlying disease and 11 were alive on December 31, 2001. In addition, two patients who received prescriptions during 2000 died in 2001 after ingesting their medication for a total of 21 PAS deaths during 2001. This compares to 27 PAS deaths in 2000, 27 in 1999, and 16 in 1998.

The 21 patients who ingested lethal medications in 2001 represent an estimated 7/10,000 total deaths, compared with 6/10,000 in 1998 and 9/10,000 in both 1999 and 2000. Overall, the 21 patients who took lethal medications were comparable to 6,365 Oregonians dying from similar underlying causes, except that they were slightly more likely to be women, were more likely to have graduated from college, and were more likely to be divorced.

The 21 patients who participated in PAS during 2001 were demographically similar to patients who participated in previous years, except that a slightly higher percentage were women. Cancer was the predominant underlying illness. The three most commonly mentioned end-of-life concerns during 2001 were: loss of autonomy, a decreasing ability to participate in activities that made life enjoyable, and losing control of bodily functions.

The lethal medications ingested during 2001 differed from those used in previous years. During 1998-2000, secobarbital was the lethal medication prescribed for 67 of the 70 patients (96%). In May 2001, Eli Lilly stopped producing secobarbital. During 2001, secobarbital was ingested by 16 (76%) of the patients and pentobarbital by 5 (24%); 4 of these were during the last 3 months of 2001. One patient vomited after ingesting the prescribed medication and died 25 hours later; another patient lived for 37 hours after ingestion. Neither patient regained consciousness, nor were emergency medical services called. One-half of patients became unconscious within three minutes and died within 25 minutes. One physician who wrote a prescription was reported to the Board of Medical Examiners for submitting an incomplete written consent document.

Although the number of prescriptions written for physician-assisted suicide has increased during the past four years, the number of terminally ill patients ingesting lethal medication has remained small with fewer than 1/10 of one percent of Oregonians dying by physician-assisted suicide.

## Introduction

After voters reaffirmed the Death with Dignity Act (DWDA) in 1997, Oregon became the only state allowing legal physician-assisted suicide (PAS) [1]. Although physician-assisted suicide has been legal in Oregon for four years, it remains highly controversial. On November 6, 2001, US Attorney General John Ashcroft issued a new interpretation of the Controlled Substances Act, which would prohibit doctors from prescribing controlled substances for use in physician-assisted suicide. To date, all the medications prescribed under the Act have been barbiturates, which are controlled substances and therefore, would be prohibited by this ruling for use in PAS. In response to a lawsuit filed by the state of Oregon, on November 20, 2001, a US district court issued a temporary restraining order against Ashcroft's ruling pending a new hearing within 5 months. At this time, Oregon's law remains in effect.

Mandated reporting of prescriptions written for lethal medication provides the Oregon Health Services (OHS) with a unique opportunity to describe terminally-ill patients choosing legal PAS. During 1998, 1999 and 2000, 16, 27, and 27 patients, respectively, used PAS [2-4]. Demographically, patients using PAS were better educated than other Oregonians dying of similar diseases. Physician and family members indicated that patient requests for lethal medications stemmed from multiple concerns related to autonomy and control at the end of life [2-4].

This fourth annual report reviews the monitoring and data collection system that was implemented under the law, and summarizes the information collected on patients and physicians who participated in the Act in its fourth year of implementation (January 1, 2001 to December 31, 2001). Using physician reports and interviews, and death certificates, we address the following questions: Are numbers of patients using legal PAS in Oregon increasing? Do patients who participated in 2001 resemble patients using PAS in previous years and other Oregonians dying from similar diseases? Have any changes occurred in the PAS process during the past four years?

## **The Oregon Death with Dignity Act**

The Oregon Death with Dignity Act was a citizen's initiative first passed by Oregon voters in November 1994 with 51% in favor. Implementation was delayed by a legal injunction, but after proceedings that included a petition denied by the United States Supreme Court, the Ninth Circuit Court of Appeals lifted the injunction on October 27, 1997. In November 1997, a measure asking Oregon voters to repeal the Death with Dignity Act was placed on the general election ballot (Measure 51, authorized by Oregon House Bill 2954). Voters rejected this measure by a margin of 60% to 40%, retaining the Death with Dignity Act.

The Death with Dignity Act allows terminally-ill Oregon residents to obtain and use prescriptions from their physicians for self-administered, lethal medications. Under the Act, ending one's life in accordance with the law does not constitute suicide. However, we use the term "physician-assisted suicide" because it is used in the medical literature to describe ending life through the voluntary self-administration of lethal medications prescribed by a physician for that purpose. The Death with Dignity Act legalizes PAS, but specifically prohibits euthanasia, where a physician or other person directly administers a medication to end another's life. [1]

To request a prescription for lethal medications, the Death with Dignity Act requires that a patient must be:

- An adult (18 years of age or older),
- A resident of Oregon,
- Capable (defined as able to make and communicate health care decisions),
- Diagnosed with a terminal illness that will lead to death within six months.

Patients meeting these requirements are eligible to request a prescription for lethal medication from a licensed Oregon physician. To receive a prescription for lethal medication, the following steps must be fulfilled:

- The patient must make two oral requests to their physician, separated by at least 15 days.

- The patient must provide a written request to their physician, signed in the presence of two witnesses.
- The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
- The prescribing physician and a consulting physician must determine whether the patient is capable.
- If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder, the patient must be referred for a psychological examination.
- The prescribing physician must inform the patient of feasible alternatives to assisted suicide including comfort care, hospice care, and pain control.
- The prescribing physician must request, but may not require, the patient to notify their next-of-kin of the prescription request.

To comply with the law, physicians must report to the OHS all prescriptions for lethal medications [5]. Reporting is not required if patients begin the request process but never receive a prescription. In the summer of 1999, the Oregon legislature added a requirement that pharmacists must be informed of the prescribed medication's ultimate use. Physicians and patients who adhere to the requirements of the Act are protected from criminal prosecution, and the choice of legal physician-assisted suicide cannot affect the status of a patient's health or life insurance policies. Physicians and health care systems are under no obligation to participate in the Death with Dignity Act [1].

## **The Reporting System**

The OHS is required by the Act to develop a reporting system for monitoring and collecting information on PAS [1]. To fulfill this mandate, the OHS uses a system involving physician prescription reports, death certificate reviews, and followup interviews [5].

When a prescription for lethal medication is written, the physician must submit to the OHS information that documents compliance with the law. We review all physician reports and contact physicians regarding missing or discrepant data. OHS Vital Records files are searched periodically for death certificates that correspond to physician reports. These death certificates allow us to confirm patients' deaths, and provide patient demographic data (e.g., age, place of residence, level of education).

In addition, using our authority to conduct special studies of morbidity and mortality [6], OHS conducted telephone interviews with prescribing physicians after receipt of the patients' death certificate. Each physician was asked to confirm whether the patient took the lethal medications. If the patient had taken the medications, we asked physicians for information that was not available from physician reports or death certificates--including insurance status and enrollment in hospice. We asked why the patient requested a prescription, specifically exploring concerns about the financial impact of the illness, loss of autonomy, decreasing ability to participate in activities that make life enjoyable, being a burden, loss of control of bodily functions, and uncontrollable pain. We collected information on the time to unconsciousness and death, and asked about any adverse reactions. Because physicians are not legally required to be present when a patient ingests the medication, not all have information about what happened when the patient ingested the medication. If the prescribing physician was not present, we accepted information they had based on discussions with family members, friends or other health professionals who attended the patients' deaths. We do not interview or collect any information from patients prior to their death. Reporting forms and the physician questionnaire are available at [www.ohd.hr.state.or.us/chs/pas/pas.htm](http://www.ohd.hr.state.or.us/chs/pas/pas.htm).

## **Data Collection and Analyses**

We classified patients by year of participation based on when they ingested the legally-prescribed lethal medication. Using demographic information from 2000 Oregon death certificates (the most recent year for which complete data are available), we compared patients who used legal PAS with other Oregonians who died from similar



diseases. The proportion of deaths resulting from legal PAS was estimated for 2001 using total and disease-specific 2000 deaths in the denominator.

## Results

In addition to this electronic report, some results are presented in a letter published in the *New England Journal of Medicine* (<http://www.nejm.org>) [7].

The number of prescriptions written has increased over the four years that PAS has been legal in Oregon, but the number of PAS deaths has not. In 2001, 44 prescriptions for lethal doses of medication were written by 33 physicians. This compares to 39 prescriptions written in 2000, 33 in 1999 and 24 in 1998. Nineteen of the patients who received prescriptions during 2001 died after ingesting the lethal medication; 14 died from their underlying disease; and 11 were alive on December 31, 2001. In addition, two patients who received their prescriptions during 2000 died in 2001 after ingesting lethal medications for a total of 21 PAS deaths during 2001. This compares to 27 deaths in 2000, 27 deaths in 1999, and 16 deaths in 1998.

Based on death certificate data, patients participating in 2001 were similar to those in previous years, although a slightly higher percentage were women (Table 1). Thirty-eight percent of PAS participants were college graduates. Similar to previous years, most patients (86%) choosing PAS had cancer.

During 2000, a total of 29,541 Oregonians died. Thus, patients ingesting lethal medications in 2001 represented an estimated 7/10,000 total Oregon deaths. By comparison, 1998 PAS patients represented 6/10,000 deaths; 1999 and 2000 PAS patients, 9/10,000 deaths. The 21 patients participating in 2000 resembled 6,365 other Oregonians who died from similar underlying causes with respect to age, race, and residence (Table 2). However, patients who participated in PAS were more likely than other Oregonians to be women (62% compared to 48%), college graduates (38% compared to 14%), and divorced (33% compared to 14%).

All patients, except one, died at home; that patient died in an acute-care hospital with the hospital's consent. As in previous years, most (76%) of the patients who used

PAS in 2001 were enrolled in hospice care; the others were offered hospice but declined. All patients had some form of health insurance (Table 3).

Prescribing physicians had been in practice a median of 20 years. Their medical specialties included: internal medicine (50%), oncology (25%), family medicine (19%), and other (6%). One physician was reported to the Oregon Board of Medical Examiners for submitting an incomplete written consent.

The lethal medications ingested during 2001 differed from those used in previous years. During 1998-2000, secobarbital was the lethal medication prescribed for 67 of the 70 patients (96%). In May 2001, Eli Lilly stopped producing secobarbital. During 2001, secobarbital was ingested by 16 (76%) of the patients and pentobarbital by five (24%); four of these were during the last three months of 2001.

Prescribing physicians were present while nine (43%) of the 21 patients ingested the lethal medications. Other health care providers were present while 11 of the remaining patients (52% of the total) ingested the medications. Among the patients for whom we received information about the time of ingestion and death, half of the patients were unconscious within 3 minutes of taking the medication, and half died within 25 minutes (Table 3). One patient vomited immediately after taking the medication, and lived for 25 hours after ingestion. Another patient lived for 37 hours after ingestion. Neither patient regained consciousness after taking the medications. No physician reported activation of the emergency medical system after the medication was taken.

Physicians were asked if, based on discussions with patients, any of six end-of-life concerns might have contributed to the patients' requests for lethal medication (Table 3; information available for 17 of the 21 fourth-year patients). In all cases, physicians reported multiple concerns contributing to the request. The most frequently reported concerns included: losing autonomy (94%), decreasing ability to participate in activities that make life enjoyable (76%), and losing control of bodily functions (53%).

## Comments

Although the number of prescriptions written for physician-assisted suicide has increased during the past four years, the number of terminally-ill patients taking lethal medication has remained small, with fewer than 1/10 of one percent of Oregonians dying by physician-assisted suicide. Each year, the proportion of PAS deaths as a subset of deaths due to terminal illnesses, such as cancers, is of the same magnitude as recently estimated by Emanuel, *et al.* [8], and is consistent with numbers from a survey of Oregon physicians [9]. Overall, smaller numbers of patients appear to use PAS in the U.S. compared to the Netherlands [8-10]. However, as detailed in previous reports [2-4], our numbers are based on a reporting system for terminally-ill patients who legally receive prescriptions for lethal medications, and do not include patients and physicians who may act outside the law.

Overall, the 21 patients who took lethal medications were comparable to 6,365 Oregonians dying from similar underlying causes, except that those who chose PAS were slightly more likely to be women, and were more likely to have graduated from college. That educated patients are more likely to choose PAS is consistent with findings that Oregon patients with at least a college degree are more likely to be knowledgeable about end-of-life choices [11]. Concern about loss of autonomy and participation in activities that make life enjoyable have been consistently important motivating factors in patient requests for lethal medication.

During the course of the year, the primary lethal medication changed from secobarbital to pentobarbital. This happened because Eli Lilly, who manufactured secobarbital, stopped producing it. It is unclear what impact, if any, this will have on the PAS process. This year, one patient vomited the medications and lived for 25 hours after ingestion; another patient lived 37 hours after ingestion. Neither patient regained consciousness. Both of these patients had received prescriptions for secobarbital. These survival times after ingestion indicate that terminally-ill patients have variable responses to the medications.

PAS has become an important element in the national discussion on end-of-life care. In a recent study, changes in end-of-life care since the initial passage of the Death with Dignity Act in 1994 were examined [12]. Oregon physicians reported that they had made efforts to improve their knowledge of the use of pain medications in the terminally-ill, that they sought to improve their recognition of psychiatric disorders, such as depression, and that they were referring patients to hospice more frequently. At the same time, a significant proportion of Oregonians (as represented by outpatients at university-affiliated clinics) appear to misunderstand options in end-of-life care. Fewer than one-fourth (23%) of respondents correctly identified physician-assisted suicide as a legal option for competent terminally-ill adult Oregonians [11].

While the experiences of these few patients and physicians reflect a rarely chosen end-of-life care alternative, they provide an important source of insight to inform the national debate on end-of-life care.

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**Table 1:** Death with Dignity Act participant demographics. Based on death certificate data and physician interviews for 91 patients who died after ingesting a lethal dose of medication – Oregon, 1998-2001.

<b>Characteristics</b>	<b>2001 (N=21)*</b>	<b>1998-2000 (N = 70)*</b>	<b>Total (N=91)*</b>
Age - Median, years (range)	68 (51-87)	70 (25-94)	69 (25-94)
Race			
White, non-Hispanic (%)	20 (95)	68 (97)	88 (97)
Asian (%)	1 (5)	2 (3)	3 (3)
Sex – Male (%)	8 (38)	36 (51)	44 (48)
Marital status			
Married (%)	8 (38)	32 (46)	40 (44)
Widowed (%)	5 (24)	17 (24)	22 (24)
Divorced (%)	7 (33)	16 (23)	23 (25)
Never married (%)	1 (5)	5 (7)	6 (7)
Education			
Less than high school graduate (%)	3 (14)	7 (10)	10 (11)
High school grad./some college (%)	10 (48)	32 (46)	42 (46)
College graduate (%)	7 (33)	20 (29)	27 (30)
Post-baccalaureate education (%)	1 (5)	11 (16)	12 (13)
Residence			
Portland metropolitan area (%)	7 (33)	26 (37)	33 (36)
Other Oregon (%)	14 (67)	44 (63)	58 (64)
Underlying Illness			
Cancer (%)	18 (86)	52 (74)	70 (77)
<i>Lung</i>	2	15	17
<i>Other</i> <sup>+</sup>	16	37	53
Other diseases (%)	3 (14)	18 (26)	21 (23)
<i>Amyotrophic Lateral Sclerosis</i>	1	6	7
<i>Chronic Lower Respiratory Dis.</i> <sup>**</sup>	2	5	7
<i>Other</i> <sup>++</sup>	0	7	7

\* Unknowns are excluded when calculating percentages.

<sup>+</sup> Besides lung cancer, the following cancers were reported five or more times during 1998-2001: breast, 9; pancreas, 7; ovary, 6; prostate, 6; and colon, 5.

<sup>\*\*</sup> Formerly Chronic Obstructive Pulmonary Disease.

<sup>++</sup> Includes acquired immune deficiency syndrome, congestive heart failure, multi-system organ failure, scleroderma, Shy-Drager syndrome, and interstitial pulmonary disease with fibrosis.

Table adapted from "Legalized Physician-Assisted Suicide in Oregon, 2001." N Engl J Med 2002; 346: 450-2. See <http://www.nejm.org>.

**Table 2:** Demographic and disease characteristics of 21 patients who died during 2001 after ingesting a lethal dose of medication compared with 6,365 Oregonians dying of similar causes.

<b>Characteristics</b>	<b>2001 (N=21)*</b>	<b>Oregon deaths, similar diseases (N=6,365)*</b>	<b>DWDA deaths per 10,000 Oregon deaths</b>	<b>Relative Risk Confidence Intervals</b>
<b>Age</b>				
Mean, years	68	73	-	
<b>Race</b>				
White, non-Hispanic (%)	20 (95)	6,138 (96)	33	Ref
Other (%)	1 (5)	227 (4)	44	1.3 (.2-9.9)
<i>Unknown</i>	-	-		
<b>Sex</b>				
Male (%)	8 (38)	3,325 (52)	24	Ref
Female (%)	13 (62)	3,040 (48)	43	1.8 (.7-4.3)
<b>Marital status</b>				
Married (%)	8 (38)	3,249 (51)	25	Ref
Widowed (%)	5 (24)	1,965 (31)	25	1.0 (.3-3.2)
Divorced (%)**	7 (33)	905 (14)	77	3.1 (1.1-8.6)
Never married (%)	1 (5)	238 (4)	42	1.7 (.2-13.6)
<i>Unknown</i>	0	8		
<b>Education</b>				
Less than high school (%)	3 (14)	1,541 (24)	19	Ref
HS grad/some college (%)	10 (48)	3,905 (62)	26	1.3 (.4-4.8)
College graduate (%)**	7 (33)	493 (8)	142	7.3 (1.9-28.1)
Post-baccalaureate (%)	1 (5)	357 (6)	28	1.4 (.2-13.8)
<i>Unknown</i>	-	69		
<b>Residence</b>				
Portland metropolitan (%)	7 (33)	2,274 (36)	31	Ref
Other Oregon (%)	14 (67)	4,091 (64)	34	1.1 (.5-2.8)
<b>Underlying Illness</b>				
Cancer (%)	18 (86)	4,949 (78)	36	
Other diseases (%)	3 (14)	1,416 (22)	21	

\* Unknowns are excluded when calculating percentages.

\*\* Statistically significant.

**Table 3:** Death with Dignity Act participant end of life care and DWDA utilization. Based on physician interviews for 91 patients who died after ingesting a lethal dose of medication – Oregon, 1998-2001.

<b>Characteristics</b>	<b>2001 (N = 21)*</b>	<b>1998-2000 (N= 70)*</b>	<b>Total (N=91)*</b>
<b>End of life care</b>			
Hospice			
Enrolled (%)	16 (76)	55 (81)	71 (80)
Declined by patient (%)	5 (24)	13 (19)	18 (20)
Unknown	-	2	2
Insurance			
Private (%)	15 (71)	42 (63)	57 (65)
Medicare or Medicaid (%)	6 (29)	24 (36)	30 (34)
None (%)	0 -	1 (1)	1 (1)
Unknown	-	3	3
<b>End of life concerns<sup>+</sup> (available for 17 patients in 2001)</b>			
Losing autonomy (%)	16 (94)	58 (83)	74 (85)
Decreasing ability to participate in activities that make life enjoyable (%)	13 (76)	54 (77)	67 (77)
Losing control of bodily functions (%)	9 (53)	46 (66)	55 (63)
Burden on family, friends/caregivers (%)	4 (24)	26 (37)	30 (34)
Inadequate pain control (%)**	1 (6)	17 (24)	18 (20)
Financial implications of treatment (%)	1 (6)	1 (1)	2 (2)
<b>PAS process</b>			
Referred for psychiatric evaluation (%)	3 (14)	20 (29)	23 (25)
Patient died at			
Home (patient, family or friend) (%)	19 (95)	63 (90)	82 (91)
Long term care, assisted living or foster care facility (%)	0 -	7 (10)	7 (8)
Hospital (%)	1 (5)	0 -	1 (1)
Lethal Medication			
Secobarbital (%)	16 (76)	67 (96)	83 (91)
Pentobarbital (%)	5 (24)	2 (3)	7 (8)
Other (%)	-	1 (1)	1 (1)
Health Care Provider Present when Medication Ingested			
Prescribing Physician (%)	9 (43)	38 (54)	47 (52)
Other Provider (%)	11 (52)	++	11 (52)



<b>Characteristics (continued)</b>	<b>2001 (N = 21)</b>	<b>1998-2001 (N = 70)*</b>	<b>Total (N = 91)*</b>
Regurgitation/seizures after medication ingested			
Regurgitated (%)	1 (5)	1 (2)	2 (2)
Seizures (%)	0 -	0 -	0 -
Neither (%)	20 (95)	65 (98)	85 (98)
Unknown	-	4	4
Emergency medical services			
Called after lethal medication ingested (%)	0 -	0 -	0 -
Not called after lethal medication ingested (%)	21 (100)	67 (100)	88 (100)
Unknown	-	3	3
<b>Timing of PAS events</b>			
Duration (weeks) of patient-physician relationship			
Median	14	14	14
Range	0-500	1-851	0-851
Duration (days) between 1 <sup>st</sup> request and death			
Median	54	40	42
Range	15-466	15-377	15-466
Minutes between ingestion and unconsciousness			
Median	3	5	5
Range	1-30	1-38	1-38
Number unknown	-	16	16
Minutes between ingestion and death			
Median	25	30	30
Range	5-37 hrs.	4-26 hrs.	4-37 hrs.
Number unknown	1	10	11

\* Unknowns are excluded when calculating percentages unless otherwise noted.

+ Affirmative answers only ("Don't know" included in negative answers).

\*\* Patients discussing concern about inadequate pain control with their physicians were not necessarily experiencing pain.

++ Physicians were surveyed for the first time in 2001 about the presence of another health care provider if they themselves were not present.

Table adapted from "Legalized Physician-Assisted Suicide in Oregon, 2001." N Engl J Med 2002; 346: 450-2. See <http://www.nejm.org>.