OREGON HEALTH TRENDS

Center for Health Statistics (503) 731-4354
STATE OF OREGON • **HEALTH DIVISION** • DEPARTMENT OF HUMAN RESOURCES

AMYOTROPHIC LATERAL SCLEROSIS
A Risk to Oregonians?

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Amyotrophic lateral sclerosis, also known as Lou Gehrig's disease, is a fatal disorder often overlooked by the public; nonetheless, during 1997 it killed twice as many Oregonians (78) as did sudden infant death syndrome (36), a more widely known disorder. The age-adjusted death rate[1] for this disease has long been higher for Oregon than for the U.S., and during 1993-1996 ranked second highest nationally.[2,3] Death rates are especially high for Oregon 65- to 74-year-olds (Figure 1). It is unclear why Oregon's ALS death rate rates are higher than the nation's; one possible explanation is that Oregon physicians are more likely to accurately diagnose and report the disorder.

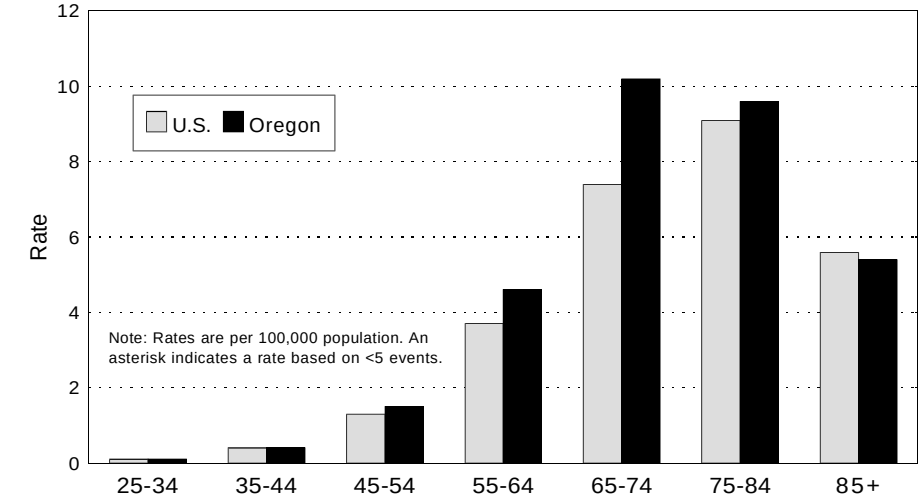
The following briefly describes the nature of amyotrophic lateral sclerosis (ALS) and the demographic characteristics of residents dying from the disease.

WHAT IS ALS?

ALS is a neurological disorder that affects the motor neurons in the brain and spinal cord. It is characterized by neurofilament buildup and diseased nerve fibers that result in a loss of control of an individual's voluntary muscles. As

ALS Death Rates, 1993-96 [2]
Highest (Maine) – 1.5
Oregon – 1.4
U.S. – 1.1
Lowest (D.C.) – 0.5
Age-adjusted per 100,000 population.

Figure 1. Age-specific Amyotrophic Lateral Sclerosis Death Rates, the United States and Oregon, 1993-1996



	25-34	35-44	45-54	55-64	65-74	75-84	85+
U.S.	0.1	0.4	1.3	3.7	7.4	9.1	5.6
Oregon	0.1*	0.4	1.5	4.6	10.2	9.6	5.4

Inside:
Cremation

Who Was Lou Gehrig?

Lou Gehrig, considered a great by baseball aficionados, was the New York Yankee's first baseman who benched himself on May 2,1939, ending a streak of 2,130 consecutive games. For months, his game had been in decline. His reflexes were off. He stumbled, fumbled, and struggled to hit or catch the ball. No one understood why, least of all Gehrig himself. A few weeks after Gehrig benched himself, doctors diagnosed his illness as amyotrophic lateral sclerosis. Two years later, on June 2,1941 Gehrig died at the age of 37. The disease that took his life became known to Americans as Lou Gehrig's disease.

motor neurons die, the muscles weaken and atrophy.

Early symptoms of ALS vary with each individual but may include unusually decreased endurance, stiffness and clumsiness, muscle weakness, slurred speech, and difficulty swallowing. Other manifestations include tripping, decreased grip, abnormal fatigue of the arms and/or legs, muscle cramps and twitches and excessive laughing or crying. As the disease progresses, patients gradually lose the use of their hands, arms, legs, and neck muscles, ultimately becoming paralyzed. Speech or swallowing may be lost or at least difficult. However, thinking ability, bladder, bowel, and sexual function, and the senses (sight, hearing, smell, taste, and touch) are unaffected.[4]

About half of the people with ALS die within three to five years of diagnosis. About 20 percent live five years or more and 10 percent survive for more than ten years. The usual cause of death is failure of the diaphragm muscles that control breathing. Life can be prolonged with the use of a ventilator but death from infections or other complications may ensue.

WHO DOES ALS AFFECT?

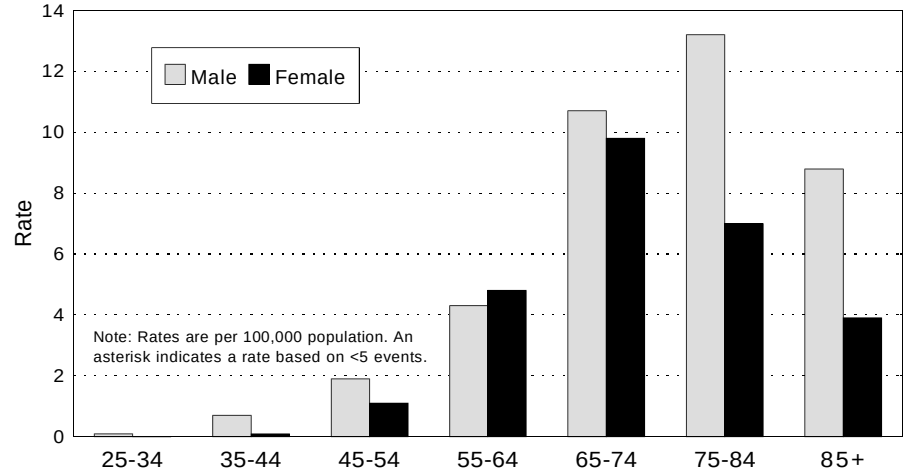
More than 30,000 Americans have ALS, with an additional 3,000-5,000 diagnosed annually. Although ALS can strike at any age, it usually appears between the ages of 40 and 70. Men and women of all ethnic and racial groups are about equally affected. During 1997, more than 4,000 Americans died of ALS. During 1980-1996, the national age-adjusted death rate for this disease increased by 50 percent, rising from 0.8 per 100,000 population to 1.2. The reason for the increase is unknown, but improved diagnosis and reporting on death certificates may be a factor.

WHAT DO THE OREGON DATA SHOW?

Number of deaths. During 1997, a record 78 Oregonians died of ALS, just 15 fewer than the num-

Nearly as many Oregonians died of ALS during 1997 as died of lymphatic leukemia.

Figure 2. Age-specific Amyotrophic Lateral Sclerosis Death Rates by Sex, Oregon Residents, 1993-1996



	25-34	35-44	45-54	55-64	65-74	75-84	85+
Male	0.1*	0.7	1.9	4.3	10.7	13.2	8.8
Female	0*	0.1*	1.1	4.8	9.8	7.0	3.9
Total	0.1*	0.4	1.5	4.6	10.2	9.6	5.4

ber who died from AIDS. During most of the 1990s, 60 or more Oregonians succumbed annually to ALS with the age-adjusted death rate varying between 1.0-1.6 per 100,000 population, but in 1997 the rate increased to 1.8 per 100,000 population, a record high.[5] However unlike the U.S., no clear upward trend has been seen in ALS age-adjusted death rates since at least 1980.

Sex. Nationally, the age-adjusted death rate is half-again as high for men as it is for women (1.2 per 100,000 population vs. 0.8), but the disparity is nowhere near as large among Oregon residents (1.3 vs. 1.1).

Age. The median age at death during 1997 for Oregonians suffering from ALS was 69 years (compared to 77 for all other causes). The highest death rate was recorded among 65- to 74-year-olds. Figure 2 illustrates the death rates by age and sex.

County of residence. During 1986-1996, Oregon's age-adjusted ALS death rate was 1.4 per 100,000 population. Among the counties with at least five deaths during this time period, six recorded a death rate of least 2.0 (Table 1). Rates less than or equal to 1.0 were recorded in four counties; all were located west of the Cascade Mountains (Figure 3).

WHAT CAUSES ALS?

Although first described in 1874, by the French physician J.M. Charcot, the cause of the disease has remained a mystery. A number of hypotheses have been put forth, but in most cases no evidence has been found to support them. Researchers once thought that ALS might be caused by the same virus that causes polio and that exposure to polio would increase the risk of ALS. Another conjecture was that an environmental toxin might cause ALS, but the nearly uniform incidence of ALS worldwide sug-

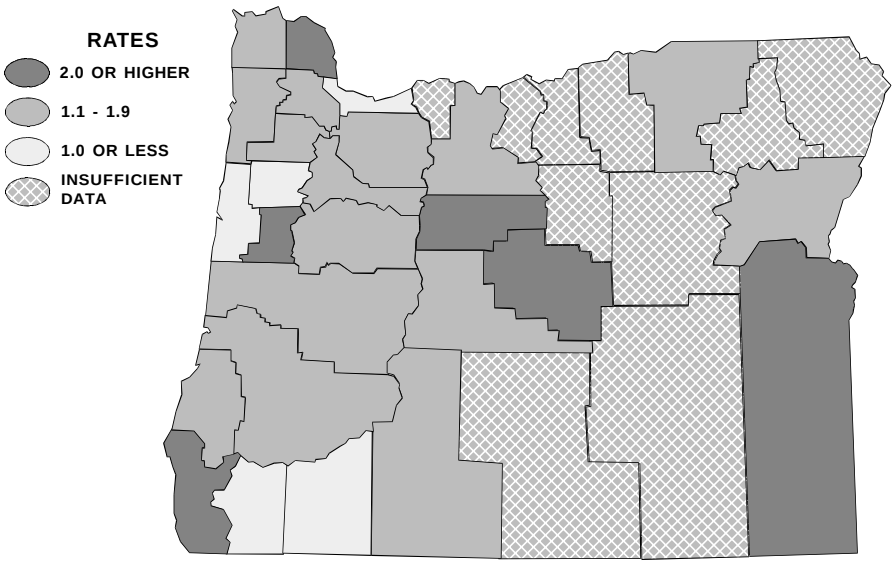
Table 1. Amyotrophic Lateral Sclerosis Death Rates by County of Residence, 1986-1996

County	Number of Deaths	Death Rates[1]	
		Crude	Age-adjusted[2]
Total	633	2.0	1.4
Baker	5	2.9	1.3
Benton	18	2.3	2.2
Clackamas	60	1.9	1.4
Clatsop	12	3.2	1.9
Columbia	13	3.1	2.1
Coos	18	2.7	1.2
Crook	5	3.1	2.9
Curry	6	2.8	2.2
Deschutes	22	2.5	1.5
Douglas	23	2.2	1.4
Gilliam	0	*	*
Grant	1	*	*
Harney	1	*	*
Hood River	4	*	*
Jackson	32	1.9	1.0
Jefferson	5	3.2	2.7
Josephine	13	1.8	0.9
Klamath	14	2.2	1.4
Lake	2	*	*
Lane	62	2.0	1.2
Lincoln	7	1.6	0.8
Linn	18	1.7	1.1
Malheur	8	2.7	2.0
Marion	55	2.1	1.2
Morrow	1	*	*
Multnomah	100	1.5	1.0
Polk	9	1.6	0.8
Sherman	3	*	*
Tillamook	7	2.9	1.4
Umatilla	11	1.6	1.1
Union	3	*	*
Wallowa	2	*	*
Wasco	6	2.5	1.2
Washington	68	1.9	1.4
Wheeler	2	*	*
Yamhill	17	2.3	1.6

1. Rates per 100,00 population. Rates are not calculated for counties with fewer than five deaths.

2. Adjusted to the 1940 U.S. standard million.

Figure 3. Age-adjusted Amyotrophic Lateral Sclerosis Death Rates, by County of Residence, Oregon, 1986-1996



Note: Rates are per 100,000 population.

gests this is not the case.[6] Some physicians have suggested that ALS is an autoimmune disease where antibodies attack and kill the motor neurons. However, aggressive autoimmune therapies have been tried and have failed to alter the course of ALS.

Another hypothesis is that ALS is caused by toxic levels of glutamate in the brain. Glutamate is a protein constituent used by motor neurons to communicate with one another and abnormally high levels of glutamate have been found in the cerebrospinal fluid of some patients with ALS. Treatment with a glutamate-inhibiting drug has shown a modest effect in prolonging life in ALS victims.

About 5-10 of every 100 people who get ALS have an inherited form of the disease. Children of people with familial ALS have a 50-50 chance of developing the disease themselves. In 1993, scientists identified a gene that, when defective, is associated with some cases of familial ALS. However, this genetic mutation is found in only about one-fifth of the people with familial ALS.

HOW IS THE DISEASE DIAGNOSED?

Diagnosis of ALS may be difficult. There is no one test or procedure to establish the diagnosis of ALS, especially in early stages. Only through clinical examination and a series of diagnostic tests to rule out other diseases can a diagnosis be established. There are many diseases that exhibit some of the same symptoms as early ALS — some of which are treatable. The ALS Association recommends that persons diagnosed with ALS seek a second opinion from a neurologist specializing in ALS.

WHAT IS THE TREATMENT FOR ALS?

There is no cure for ALS. The ALS Association has summarized the situation: "Present treatment of ALS is aimed at symptom relief, prevention of complications, and maintenance of maximum optimal function and optimal quality of life. Most of this, in the later stages, requires nursing management of a patient who is alert but functionally quadriplegic with intact sensory function, bedridden and aware he or she is going to die." The cost is not only physical and emotional, but financial; in the advanced stages, care can cost $200,000 a year. One drug has been approved by the Food and Drug Administration (FDA) for the specific treatment of ALS: Rilutek, an anti-glutamate, appears to prolong the life of persons with ALS by at least a few months. However, unless a cure or prevention can be found, it is projected that 300,000 Americans alive today will die of ALS.

Despite the poor current outlook for ALS patients, researchers are pursuing a variety of avenues to better understand and treat ALS. Recent research at the Johns Hopkins Medical Institutions has shown that mutations appear to cause or contribute to more than half of all non-inherited cases of the disease; if a test can be developed to detect the mutations, then diagnosis and treatment could begin much earlier in the course of the disease. Scientists at Columbia-Presbyterian Medical Center have reported finding a human gene

A Remarkable Survivor

Stephen W. Hawking, the author of *A Brief History of Time*, and brilliant British theoretical physicist is one of very few people who have survived for many years with ALS (also known as motor neuron disease in Great Britain). Hawking, now 56, was diagnosed with ALS in 1963 when he was a 21-year-old graduate student at Cambridge University in England. Hawking's life demonstrates that ALS impairs neither intellect nor sexual function. His work on the origin and nature of the universe has been "groundbreaking and revolutionary."[7] Hawking married and subsequently fathered three children after his diagnosis. In 1985, after suffering a windpipe blockage, Hawking had a breathing device surgically implanted in his throat. The surgery resulted in the loss of his voice. He now "speaks" by using a voice synthesizer connected to a computer that he operates by squeezing a switch in his hand.[7]

that may delay the onset of ALS while a team at Massachusetts General Hospital has found evidence that a key programmed cell death gene may play a role, and that inhibiting activity of the gene could slow the progression of ALS. With the expanding sophistication in the fields of molecular biology, genetics, neurology and pharmacology, the prospect of finding a treatment for ALS continues to improve.

Special thanks to Dr. Wendy Johnston for reviewing this article.

1. Age-adjusted death rates control for differences in the age structure of the subsets being compared, for example states and counties; therefore, any differences are due to factors other than age. Death rates are adjusted to the 1940 U.S. standard million population.
2. This is the most recent period for which comparative national data by state are available. Unless otherwise stated, all mortality data reported here are for the period 1993-1996 and are from the Center for Disease Control and Prevention's WONDER system. Other death data are from the Health Division's mortality files. The underlying cause of death is determined by applying a complex set of algorithms to the information provided on a death certificate by the decedent's physician or other certifying physician. For example, if the immediate cause of death of an ALS patient was pneumonia as a consequence of ALS, the underlying cause of death would be coded to ALS -- not pneumonia.
3. Two other states also tied for second: Washington and Kansas.
4. Much of the information (excluding Oregon data) was drawn from the following Internet sites: *http://www.fda.gov/fdac/features/796_als.html*, and *http://www.ALSA.org/*.
5. Because the number of deaths occurring in any one year is not large, rates may vary considerably from year to year due to random statistical variation
6. Rates are elevated in Guam and parts of Japan for unknown reasons. Ingestion of the cycad nut, a traditional food in Guam, contains a substance capable of killing motor neurons, but not at a level capable of causing the degeneration seen in ALS.
7. Michael White and John Gribbin, authors of *Stephen Hawking: A Life in Science*.

RESOURCES

Oregon Health Sciences University
ALS/Neuromuscular/MDA Clinic
503-494-5236 (Portland)
http://www.ohsu.edu/som-als/

ALS Association, National Office
800-782-4747
http://www.alsa.org

Les Turner ALS Foundation
1-888-ALS-1107
http://www.lesturnerals.org

Muscular Dystrophy Association
1-800-572-1717
http://www.mdausa.org

SW Oregon Support Group
541-772-7525 (Medford)

Oregon Self-help Support Systems
503-623-5448 (Dallas Area)

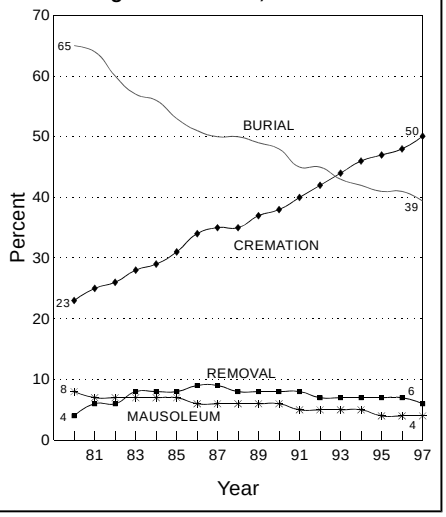
Ashes to Ashes, or the Worm's Lament

It costs me never a stab nor squirm
To tread by chance upon a worm.
"Aha, my little dear," I say,
Your clan will pay me back one day."
Dorothy Parker[1]

Alas, for more and more Oregonians, this is no longer true. We are cheating our vermiform cousins of their rightful due. For the first time, more than half of all Oregonians who died were cremated. During the past several decades, the proportion of decedents who were cremated has increased inexorably. By 1997, and for the first time, just over half of all resident deaths ended in cremation.[2] This article briefly summarizes the demographic characteristics of Oregon residents by type of disposal of remains, information not available from the Center for Health Statistics' *Vital Statistics Annual Report,* but requested by data users with some frequency.

Cremation has been practiced for millennia; European pottery vessels from the Neolithic period have been found filled with human ashes.[3] Cremation was the preferred burial custom in Europe between

Figure 1. Disposal of Remains, Oregon Residents, 1980-97



The first U.S. crematorium was established in Washington, Pennsylvania in 1876.[3]

Table 1. Disposal of Remains by Demographic Characteristics of the Decedent, Oregon Residents, 1997[1]

Characteristic	Percent		No. of deaths[2]
	Cremated	Buried	
Total	50	39	28,750
Sex			
Male	53	38	14,269
Female	47	41	14,481
Age			
0 - 14	37	59	408
15 - 24	41	43	353
25 - 34	53	34	468
35 - 44	62	28	966
45 - 54	65	27	1,696
55 - 64	58	35	2,534
65 - 74	55	37	5,392
75 - 84	50	41	8,914
85+	41	44	8,019
Race/ethnicity[3]			
White	51	39	27,482
African American	31	54	371
American Indian	46	45	235
Hispanic	36	43	368
Japanese	69	24	67
Chinese	27	63	59
Southeast Asian	64	33	36
Other	41	46	132
Years of Education (Ages 25+)			
0	32	56	72
1 - 7	36	52	1,088
8	37	52	3,292
9 - 11	49	40	3,077
12	51	38	11,263
13 - 15	54	36	4,823
16	56	34	2,141
17+	63	28	1,469

1. Remains interred in a mausoleum, removed out-of-state, or donated to medical science are not shown.

2. Total of all methods.

3. All race categories are non-Hispanic; all decedents of Hispanic ethnicity are included in "Hispanic."

1400 B.C. and 200 A.D., but by the Third Century Christianity had become widely accepted and with it the doctrine that forbade cremation (because of the belief that the body could not be resurrected if it were destroyed). Since the late 1800s, however, cremation has become an increasingly popular option. (In other parts of the world, such as India and Japan, there was no gap in the practice of cremation.) Economic and sanitary considerations are the principal reasons for the increased number of cremations in recent years.[3]

TRENDS

In less than a generation, the proportion of Oregon decedents who were cremated more than doubled (Figure 1). In 1980, the first year such data were recorded, 23 percent of Oregonians who died were cremated while 65 percent were buried. By 1997, the figures were 50 percent and 39 percent, respectively. During the same time period, internment in a mausoleum became less common while removal of remains (out-of-state) became more common.

DEMOGRAPHIC CHARACTERISTICS

Gender, age, race/ethnicity, years of education and county of residence are all linked to the method of disposal of remains. Table 1 presents the percentages of persons who were buried or cremated.

Gender. In 1980, males were only marginally (4.5 percent) more likely to be cremated than were females. Over time, however, this difference has continued to widen so that by 1997 males were cremated 13 percent more often than were females.

Age. Cremation is the selected option more often by/for middle-aged Oregonians than by/for their younger or older peers. Nearly two-thirds of 45- to 54-year-olds (65 percent) were cremated after death compared to about two-fifths of children ages 14 or less (37 percent) and elderly ages 85 or older (41 percent).

Race/ethnicity. Race/ethnicity, and its concomitant cultural practices, is strongly linked with the chosen method of disposal of remains. Those least likely to choose cremation were Chinese Oregonians (27 percent) while those most likely to do so were Japanese Oregonians (69 percent).

Education. Strongly correlated with the manner of disposal of remains are the years of education of the decedent -- the greater the number of years of education, the more likely the decedent was to be cremated. Among adults 25 or older, just 32 percent of those with no education were cremated compared to 63 percent of those with a post-baccalaureate education, a twofold difference.

County of residence. A striking geographic pattern is apparent across the state with as much as a nine-fold difference in cremation rates between counties (Table 2). Curry County, the county with the highest cremation rate for residents dying in Oregon (72 percent), is the state's most southwestern county (Figure 2). Trending northeast from Curry County, a pattern of decreasing likelihood of cremation extends along a southwest-northeast axis ending in Wallowa County, the county with the lowest cremation rate (8 percent). The reason for this

pattern is unclear, but the distribution of crematoria may be a factor.

Occupation. In general, white-collar decedents and/or those in analytical/creative occupations were most likely to be cremated while lower education blue-collar workers were least likely. Table 3 lists the occupations in which the decedents were most and least likely to be cremated.[4]

Table 3. Occupations in Which the Decedent Was Most or Least Likely to be Cremated, Oregon Residents, 1996-97

Most Likely		Least Likely	
Occupation	%	Occupation	%
Computer systems analyst	78.4	Housekeeper, etc.	28.6
Management analyst	76.9	Child care provider/worker	28.9
Post-secondary teachers	76.7	Farm/nursery worker	30.3
Architect	75.9	Graders/sorters of agricultural products	33.3
Mechanical engineer	73.8	Dress makers	33.9
Aerospace engineer	73.5	Food batch makers	36.8
Author	72.1	Launderers	37.0
Sculptor, painter, etc.	72.1	Mixing machine op.	37.4
Airplane pilot, navigator	71.4	Misc. hand-working occupations	37.5
Advertising	70.2	Freight/stock handlers	37.6

OREGON VS. THE U.S.

Nationally, 21 percent of all decedents were cremated in 1996, a figure less than half that seen for Oregon.[5] (During 1996, 36 percent of Canadian decedents were cremated, but in British Columbia the figure was 65 percent.) Like Oregon, the U.S., too, shows marked geographic patterns in the proportion of decedents cremated. Rates are highest in the western states and lowest in the southern states (except for Florida). In 1996 (the most recent available data), Oregon's cremation rate (48 percent) tied for fifth highest nationally. The states with the highest proportions of cremations were: Hawaii, 58 percent; Alaska, 55 percent; Nevada, 54 percent; Washington, 49 percent; and Montana, 48 percent. The five states with the lowest proportions of cremations were: Mississippi, 4 percent; Alabama, 6 percent; Kentucky, 6 percent; West Virginia, 6 percent; and Oklahoma, 6 percent.

Figure 2. Percentage of Decedents Cremated, by County of Residence, Oregon, 1997

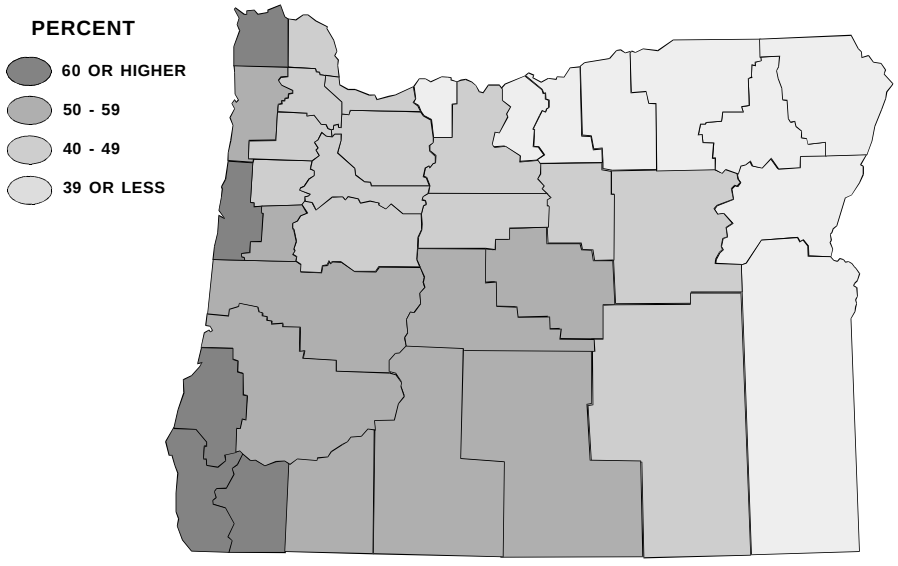


Table 2. Disposal of Remains by County of Residence of the Decedent, Oregon, 1997[1]

County	Percent		No. of Deaths[2]
	Cremated	Buried	
Baker	22	57	203
Benton	58	34	420
Clackamas	49	40	2,398
Clatsop	63	32	337
Columbia	47	46	274
Coos	64	31	792
Crook	54	42	166
Curry	72	25	223
Deschutes	58	34	728
Douglas	57	38	1,114
Gilliam	27	73	15
Grant	41	57	86
Harney	48	48	71
Hood River	37	49	156
Jackson	59	33	1,638
Jefferson	46	48	125
Josephine	64	28	898
Klamath	57	38	626
Lake	57	39	69
Lane	58	35	2,572
Lincoln	68	26	481
Linn	43	50	971
Malheur	15	54	243
Marion	46	45	2,279
Morrow	38	56	71
Multnomah	47	38	5,445
Polk	46	48	462
Sherman	33	61	18
Tillamook	52	41	266
Umatilla	32	56	492
Union	29	62	223
Wallowa	8	48	85
Wasco	44	49	253
Washington	50	39	2,313
Wheeler	45	55	20
Yamhill	43	47	644

1. Remains internned in a mausoleum, removed out-of-state, or donated to medical science are not shown. This table includes residents who died in Oregon.

2. Total of all methods.

ENDNOTES

1. Parker, Dorothy. Thought For A Sunshiny Morning, Scholastic, May 23, 1936.
2. The most recent year available.
3. Infopedia. Funk and Wagnall's New Encyclopedia. SoftKey International Inc. 1996.
4. Based on all Oregon residents who died during 1996-97 and for which more than 25 deaths were recorded by occupation.
5. The most recent available national and Canadian data are for 1996 from the Internet Cremation Society (http://www.cremation.org/stats.htm).

From Cradle to Grave

The Frequency of Vital Events among Oregonians

The Cradle

Every 12 minutes an Oregonian is born.
Every 42 minutes an unmarried woman gives birth.
Every 58 minutes a college graduate gives birth.
Every 60 minutes a woman with less than a high school education gives birth.
Every 1.1 hours a woman who did not receive first trimester prenatal care gives birth.
Every 1.2 hours a substance-using (e.g., nicotine, alcohol, etc.) woman gives birth.
Every 1.2 hours a foreign-born woman living in Oregon gives birth.
Every 1.6 hours a teenager (age 19 or less) gives birth.
Every 3.6 hours an Oregon woman gives birth to a low weight infant.
Every 9.0 hours an Oregon woman 40 or older gives birth.

After the Cradle, Before the Grave

Every 20 minutes a couple is married in Oregon.
Every 35 minutes a couple is divorced in Oregon.

The Grave

Every 18 minutes an Oregonian dies.
Every 1.2 hours an Oregonian dies from heart disease.
Every 1.3 hours an Oregonian dies from cancer.
Every 3.4 hours an Oregonian dies from cerebrovascular disease.
Every 5.3 hours an Oregonian dies from chronic obstructive pulmonary disease.
Every 6.8 hours an Oregonian dies from unintentional injuries.
Every 11 hours an Oregonian dies from diabetes.
Every 12 hours an Oregonian dies from Alzheimer's disease/dementia.
Every 16 hours an Oregonian commits suicide.
Every 3 days an Oregonian is murdered.
Every 4 days an Oregonian dies from AIDS.

OREGON HEALTH DIVISION

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