



CALIFORNIA
HEALTHCARE
FOUNDATION

SNAPSHOT

Death and Dying in California

2006

Introduction

In the past 100 years, the way we die and the way we deal with death has changed radically. As medicines that combat bacterial and viral infections allow us to live longer, infectious diseases have given way to chronic ailments as the main cause of death in California. The health care system is adapting to this new reality, developing hospice care for the terminally ill and palliative care programs in hospitals to provide comfort and support when medical intervention is no longer curative.

The cost of care at the end of life has also come under scrutiny. The national price tag for health care continues to grow at an unsustainable rate, with end-of-life care accounting for a major share of the cost. This snapshot on death and dying in California reports on all these trends, and includes results of a survey on residents' attitudes. Some of the findings reveal that:

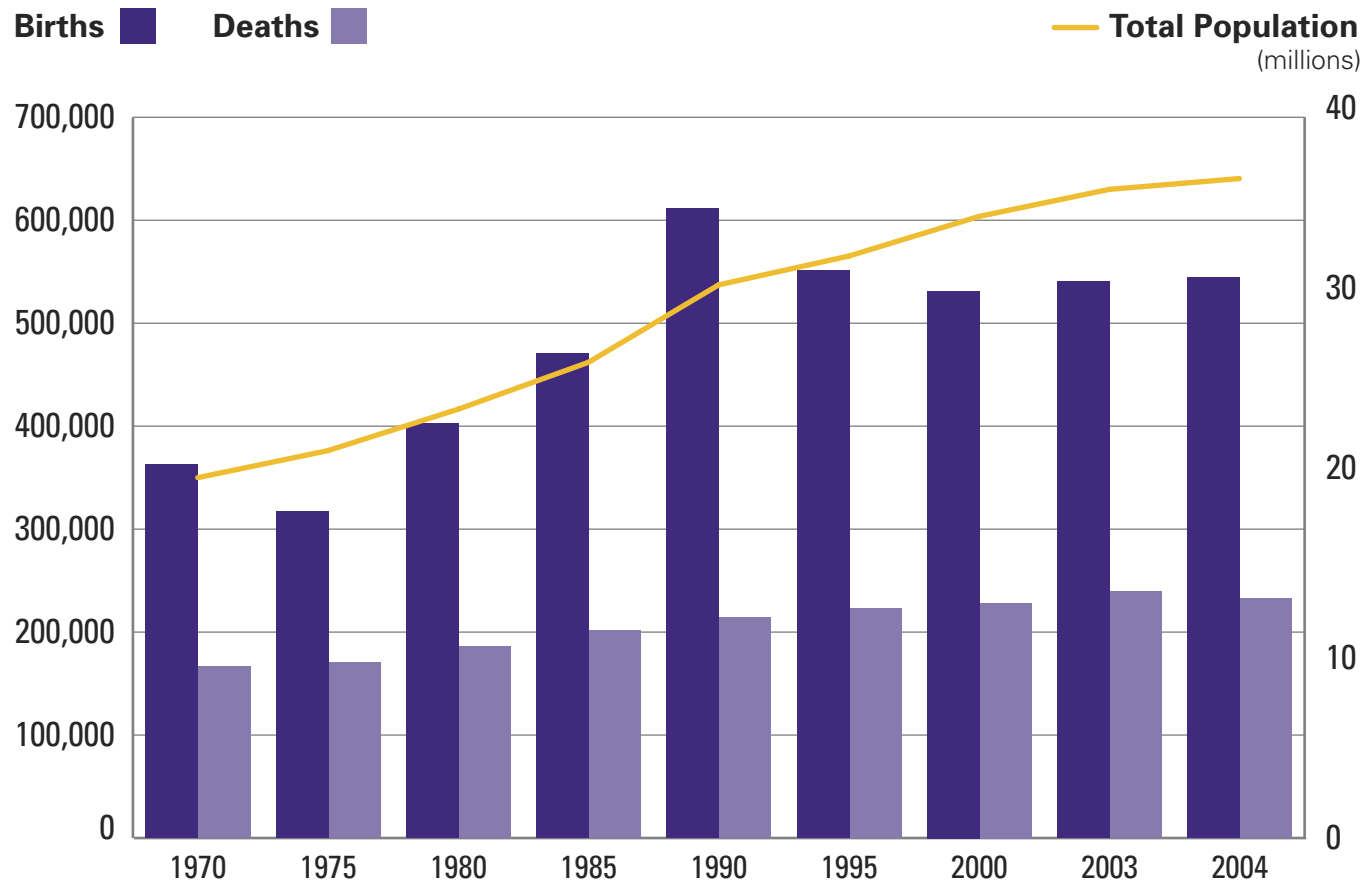
- Nearly seven out of ten Californians die in hospitals and nursing homes, even though surveys show they want to die at home.
- Pain tops the list of concerns people face when they think about dying, but 62 percent of state residents also worry that they won't be able to get or pay for needed care.
- The vast majority of adults—83 percent—believe it's "somewhat" or "very" important to write down their end-of-life wishes, but only 36 percent have done so.
- Non-white Californians are more likely than Whites to give the state's healthcare system fair to poor marks in caring for those who are dying.

Death and Dying

Introduction

Nearly seven out of ten Californians die in hospitals and nursing homes, even though surveys show they want to die at home.

Population, Births, and Deaths, 1970 to 2004 by selected years



Sources: California Department of Health Services, Birth, Death, and Fetal Death Records; California Department of Finance, 1970–1989 Population; 1970–1996 Population Estimates with Age, Sex, and Race/Ethnic Detail, January 1998; 1990–2000 Population: Intercensal Estimates of the Population of California: State and Counties 1990–2000, Report I 1990–2000 July, May 2001. Population Estimates for California Counties, Report E-2, July 1, 1990 through July 1, 2003, February 2004.

Death and Dying Trend

The rapid growth of California's population, and resulting increases in deaths, means that issues around care at the end of life will become ever more important for clinicians and policymakers.

Leading Causes of Death, United States, 1900 vs. 2002

TOP THREE CAUSES OF DEATH

1900	2002
<ul style="list-style-type: none">• Pneumonia and Influenza• Tuberculosis• Diarrhea and Enteritis	<ul style="list-style-type: none">• Heart Disease• Cancer• Stroke

Death and Dying Causes

In the early 1900s, people most often died of infectious diseases. As advances in public health and modern medicine greatly reduced deaths due to these diseases, more people now die of chronic conditions that tend to develop as people age.

Sources: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Leading Causes of Death 1900–1998, Table of Deaths and Death Rates for Leading Causes of Death: Death Registration States, 1900–1940 (http://www.cdc.gov/nchs/data/statab/lead1900_98.pdf and www.cdc.gov/nchs/fastats/lcod.htm).

Leading Causes of Death, by Ethnicity, 2003

TOTAL DEATHS	NO. 1 CAUSE	NO. 2 CAUSE	NO. 3 CAUSE
Asian N = 15,857	Cancer N = 4,250	Heart Disease N = 4,201	Stroke N = 1,566
African-American N = 18,557	Heart Disease N = 5,372	Cancer N = 4,067	Stroke N = 1,357
Latino N = 33,416	Heart Disease N = 7,705	Cancer N = 6,666	Accidents N = 2,692
White N = 168,678	Heart Disease N = 51,028	Cancer N = 38,764	Stroke N = 12,550

Death and Dying Causes

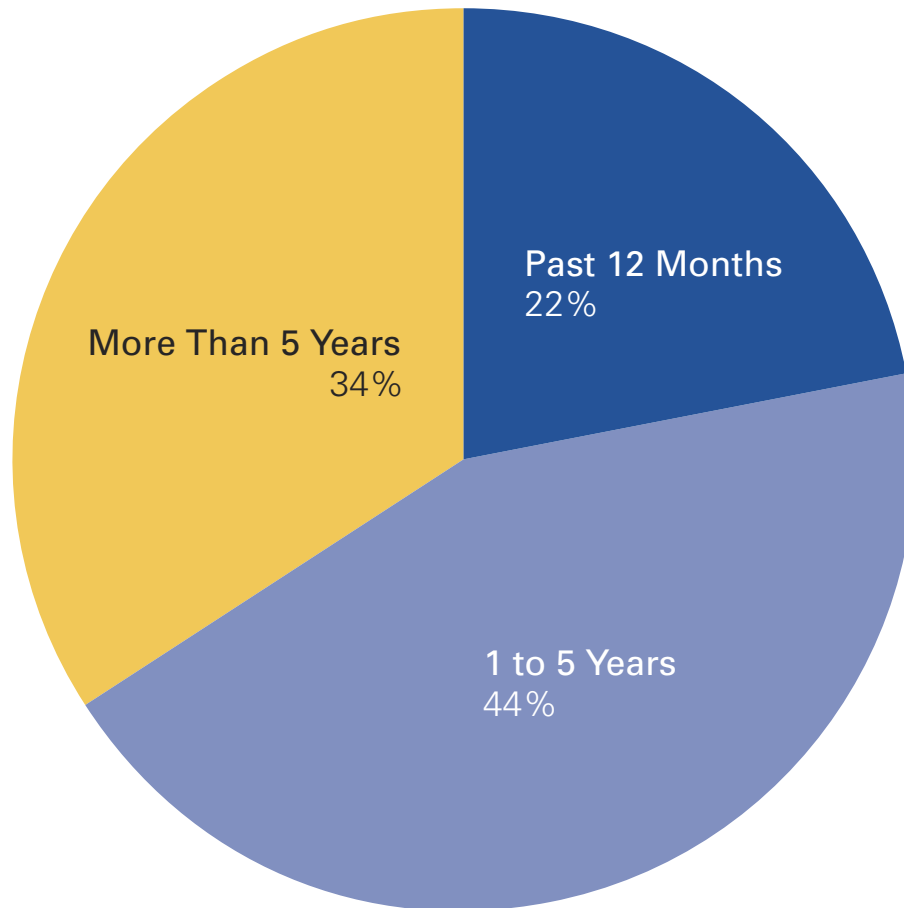
While heart disease is the number one cause of death for Whites, Latinos, and African-Americans, Asians are most likely to die of cancer. Stroke is the third most likely cause of death for all but Latinos, who die more frequently from accidents, the majority of which are motor vehicle-related.

Source: Centers for Disease Control and Prevention, National Center for Injury Control and Prevention, Web-based Injury Statistics Query And Reporting System, Unintentional Injuries for Latinos in California, All Ages, All Races, Both Sexes, 2003

Source: California Department of Health Services, Center for Health Statistics, Vital Statistics of California 2003, Table 5-8 Thirteen Leading Causes of Death by Race/Ethnicity Group and Sex, California, 2003.

Most Recent Loss of a Loved One, 2006

“Have you experienced the loss of a loved one? within the past five years... 12 months?”



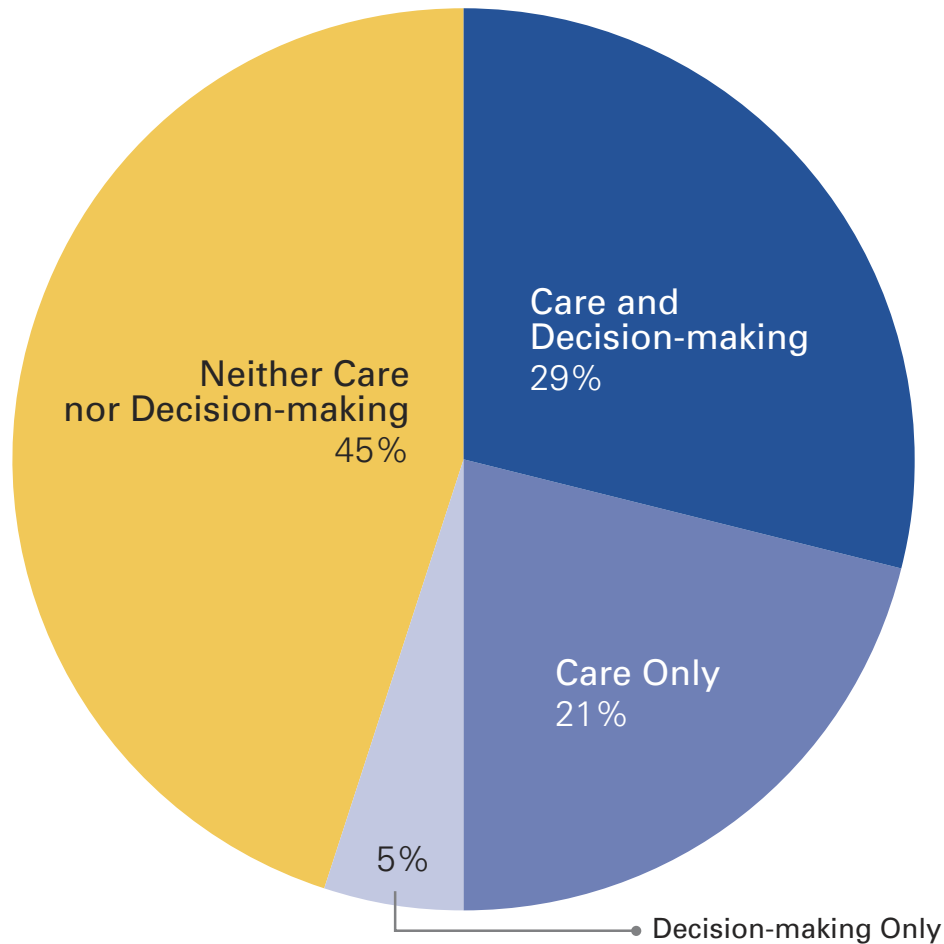
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Perspective

Two-thirds of Californians lost a loved one within the past five years—nearly a quarter of those within the past 12 months.

Role in End-of-Life Care, 2006

“Did you help care for or were you involved in medical decision-making for your loved one?”

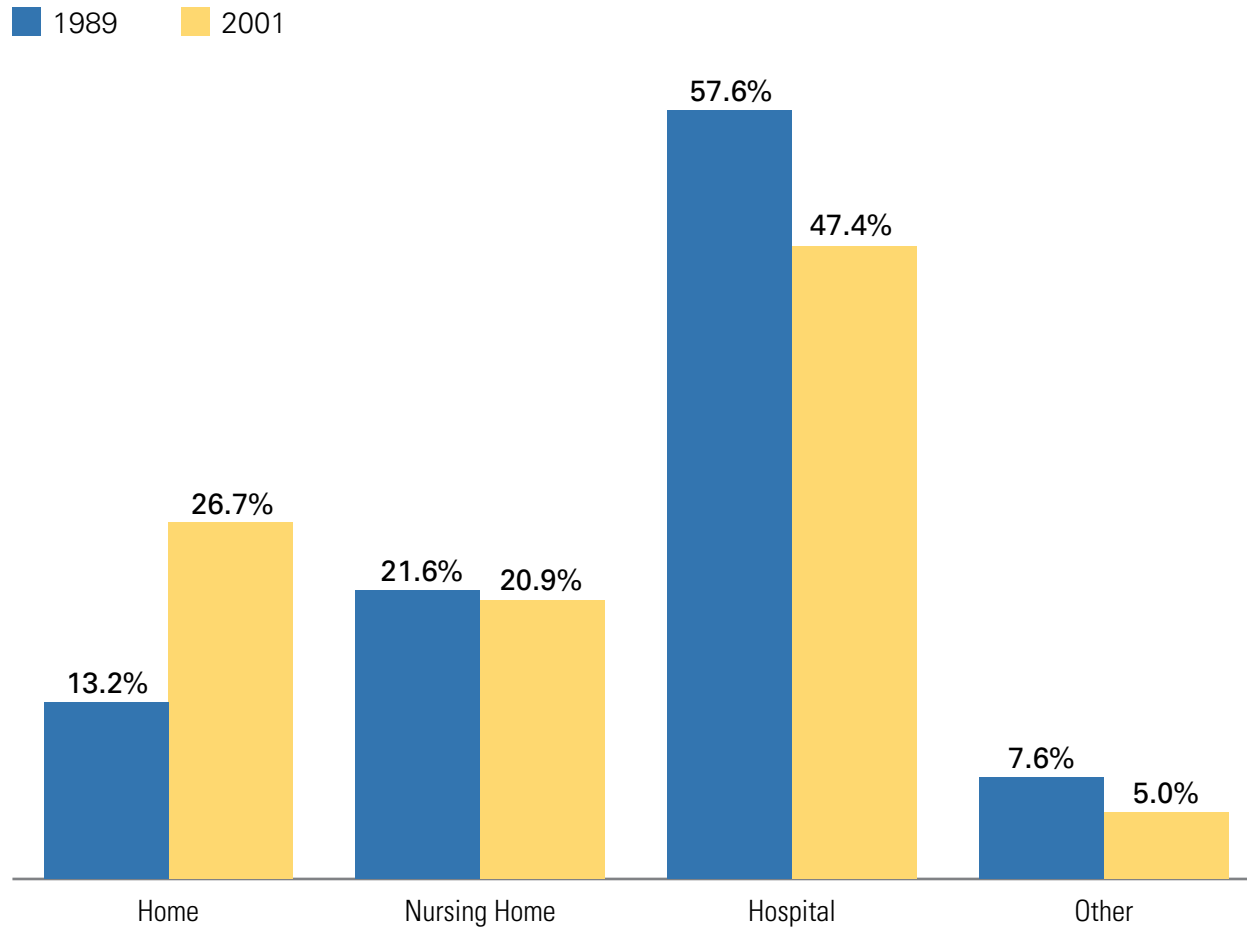


Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Perspective

More than half of Californians who recently lost a loved one were involved in the care or medical decision-making for their loved ones. These results underscore the need for making one's end-of-life wishes known in advance.

Place of Death, 1989 vs. 2001



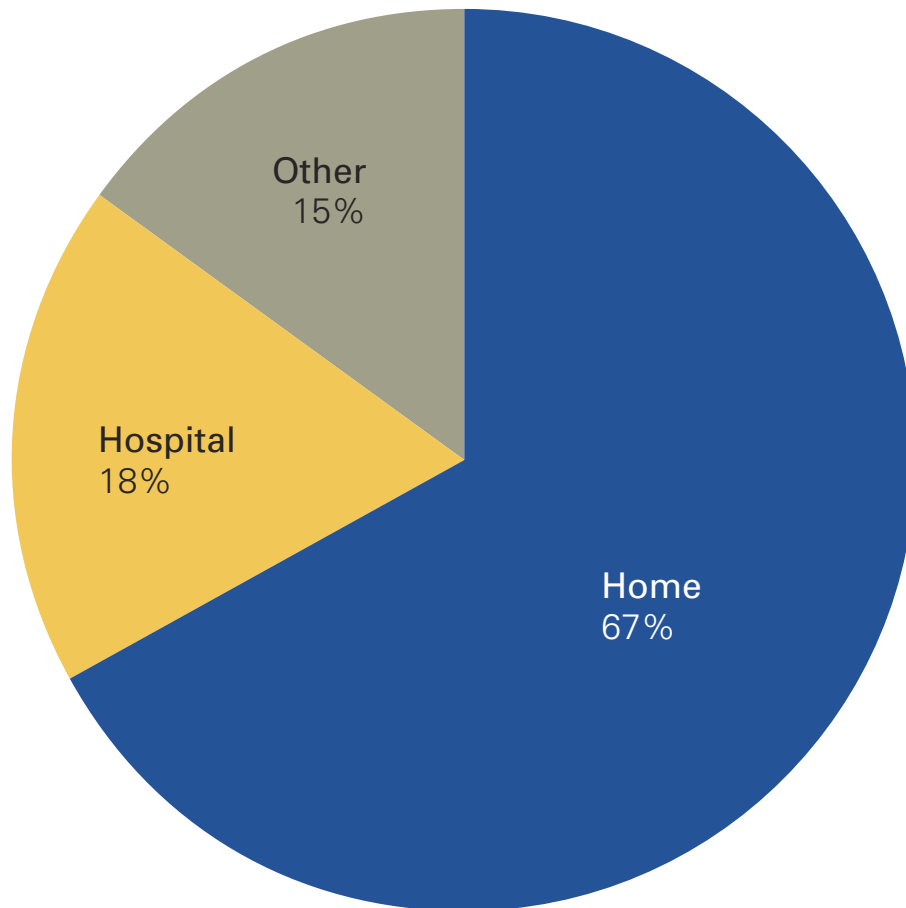
Death and Dying Perspective

Place of death for Californians changed considerably from 1989 to 2001. Twice as many people now die at home, and less than 50 percent now die in hospitals.

Source: Center for Gerontology and Health Care Research at Brown Medical School, Brown University. Brown Atlas of Dying. Evaluation of Mortality Files compiled by the National Center for Health Statistics, by Joan Teno, MD, MS (<http://www.chcr.brown.edu/dying/castats.htm>).

Preferred Place of Death, 2006

“Where would your loved one have preferred to die?”



Note: Charted results reflect respondents who knew loved one's preference.

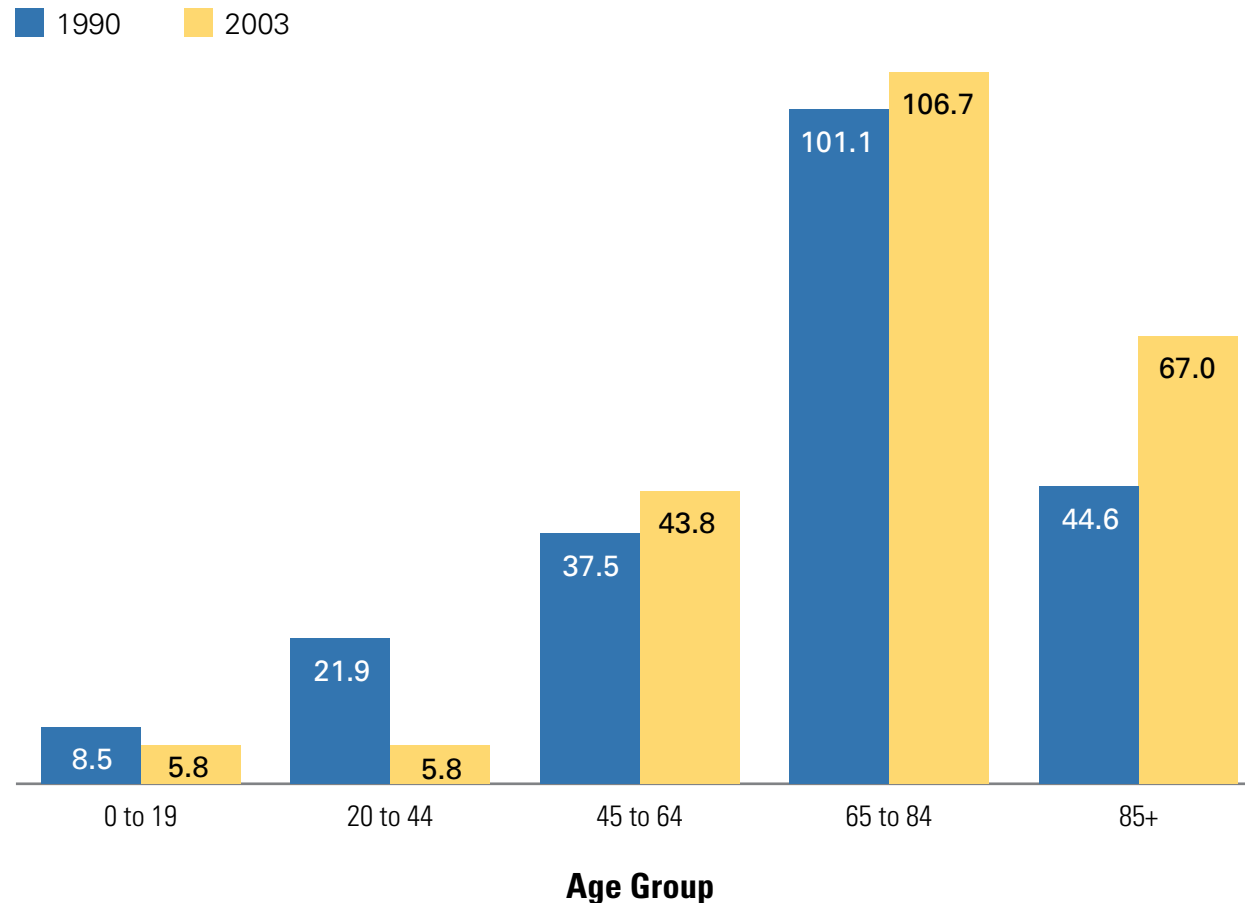
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Perspective

In contrast to where people are most likely to die, in the hospital or nursing home, the vast majority would prefer to die at home. This holds true across all racial groups.

Number of Deaths, by Age Group, 1990 vs. 2003

Number of Deaths (in thousands)



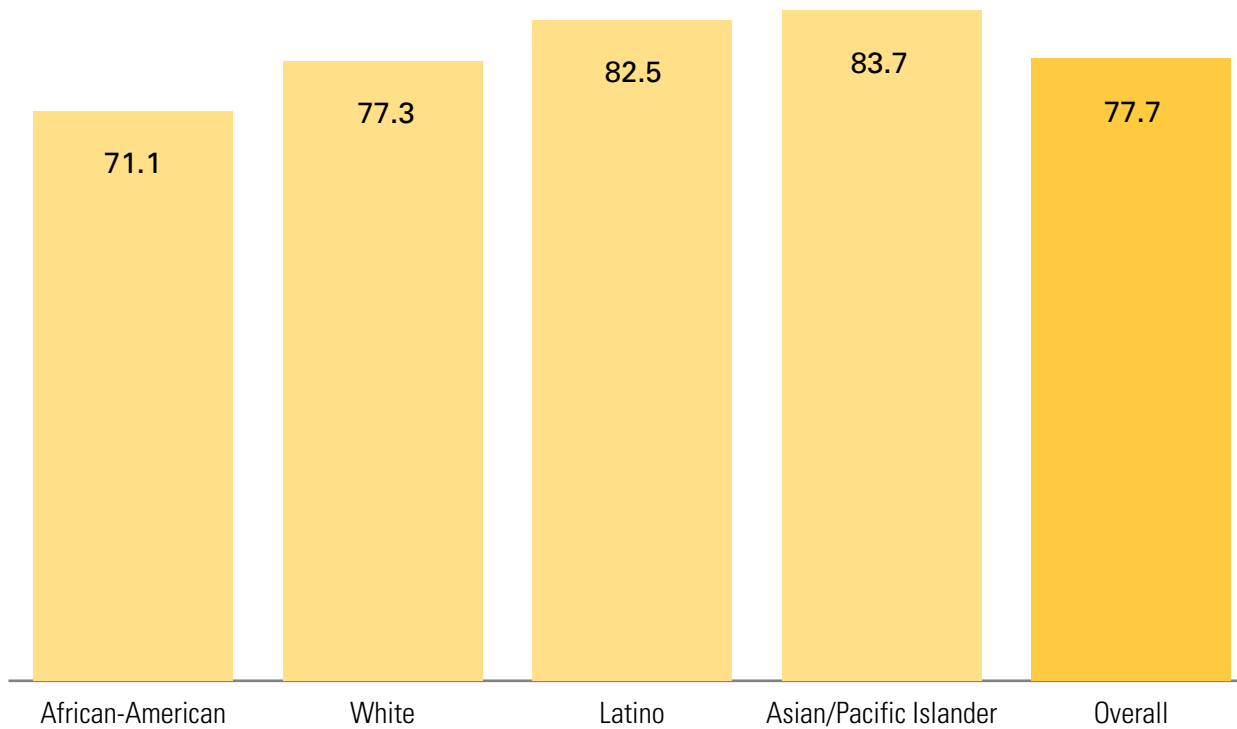
Source: California Department of Health Services, Center for Health Statistics, Vital Statistics of California 2003, Table 5-2 Deaths By Age, and Age-specific Death Rates, 1990–2003, California.

Death and Dying Demographics

Californians are living longer. Fewer people are now dying before the age of 45, shifting a greater number of deaths into older age groups. The greatest increase is seen in people who are living to age 85 and beyond.

Life Expectancy, by Ethnicity, 1995–1997

Average Years of Age



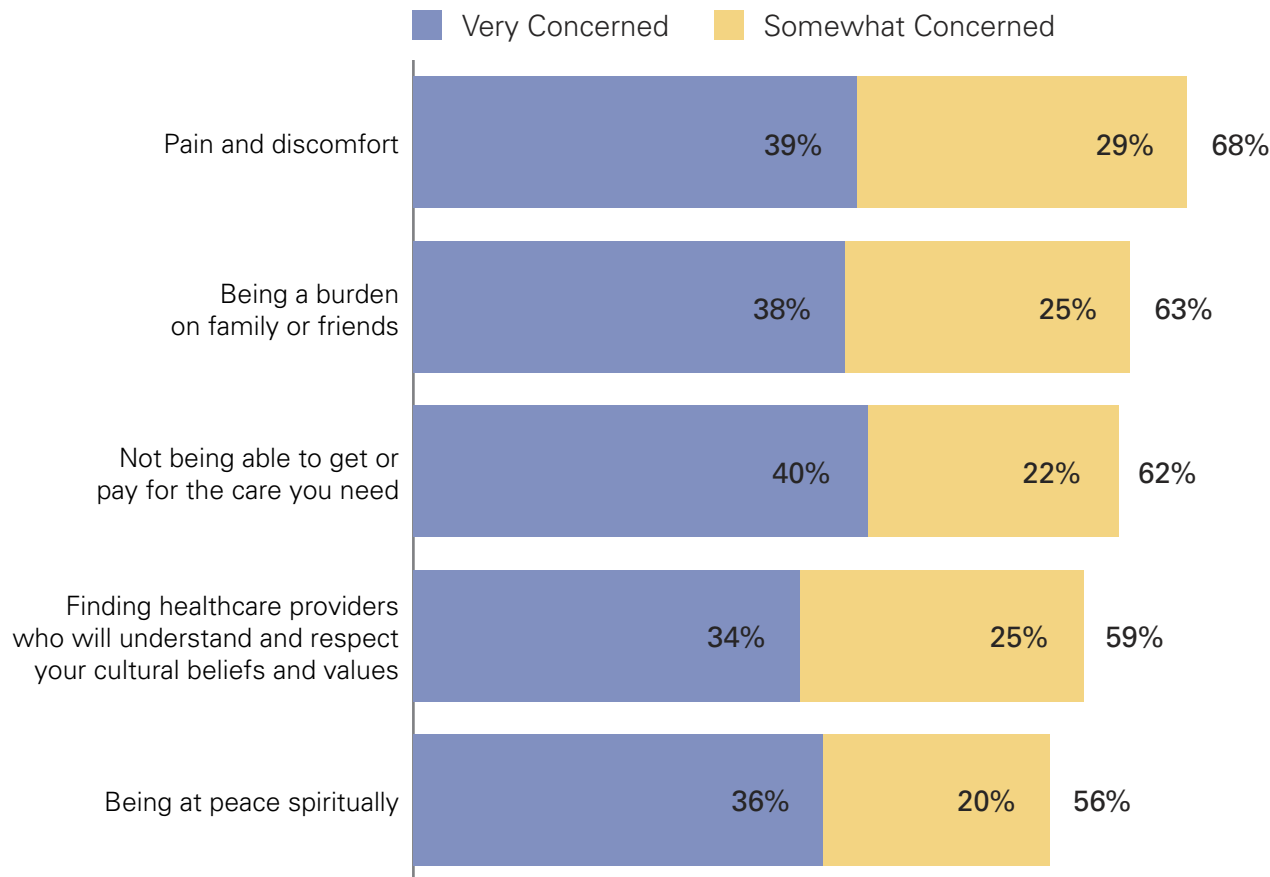
Death and Dying Demographics

On average, Asian/Pacific Islanders have the longest life expectancy, followed by Latinos, Whites, and African-Americans.

Source: California Department of Health Services, Center for Health Statistics. *Data Matters*, Report Register No. DM99–10000 (October 1999) re: California Life Expectancy: Abridged Life Tables by Race/Ethnicity for California 1995–97, Table 1 Life Expectancy at Birth (in Years) By Sex and Race/Ethnicity, California.

Concerns About Death and Dying, 2006

“When you think about death and dying, how concerned are you about...”



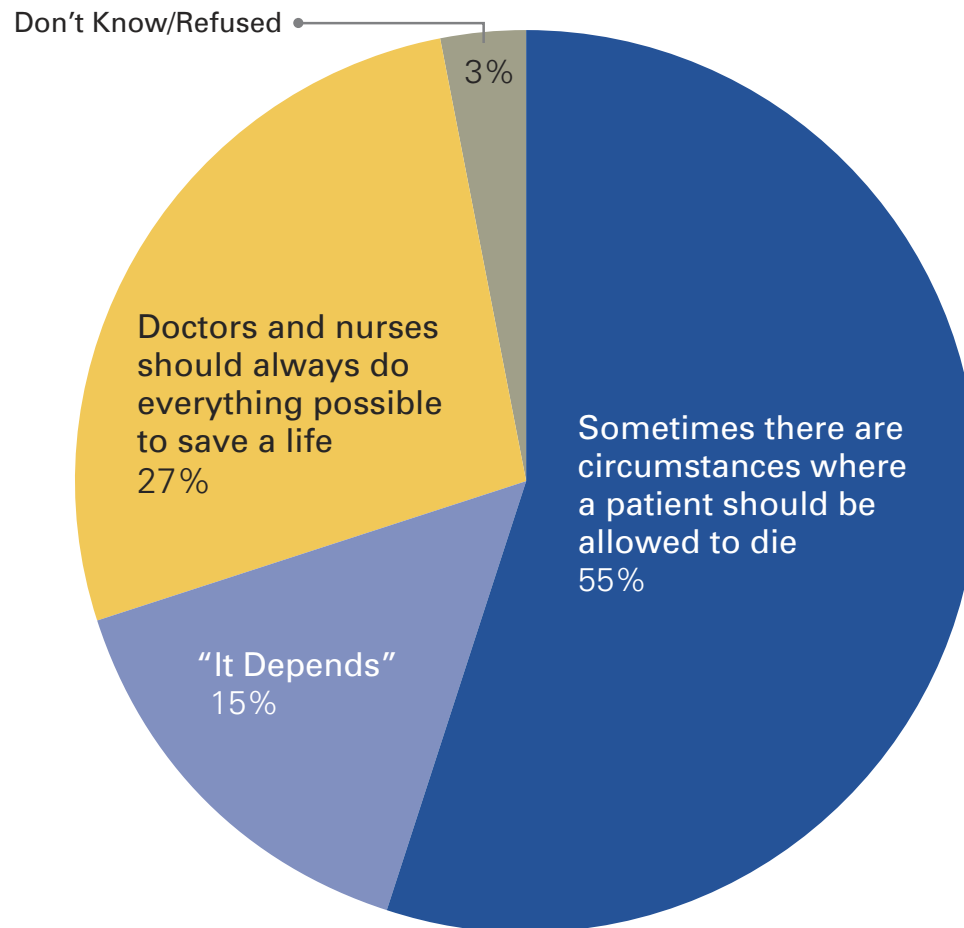
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Attitudes Toward

Survey participants were asked to rank five concerns about death and dying on a 4-step scale, ranging from “not concerned at all” to “very concerned.” Although the majority of Californians are concerned about all aspects of death and dying, pain and discomfort tops the list for those who are somewhat or very concerned.

Attitudes About a Patient's Right to Die, 2006

"Which statement comes closer to your view?"



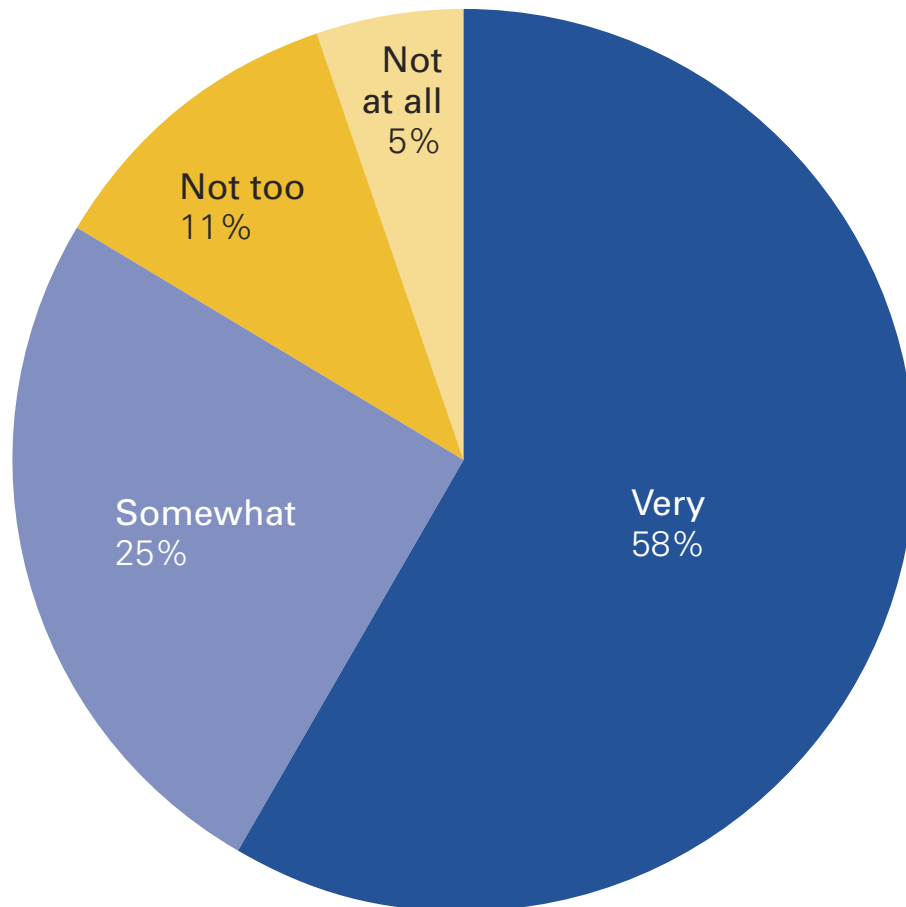
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Attitudes Toward

The majority of Californians believe there are circumstances in which a patient should be allowed to die. Over half agreed outright with this statement, and an additional 15 percent of those who agreed qualified their agreement by first responding "it depends."

Importance of Having End-of-Life Wishes in Writing, 2006

“How important is it for you at this stage of your life to have your end-of-life wishes in writing?”



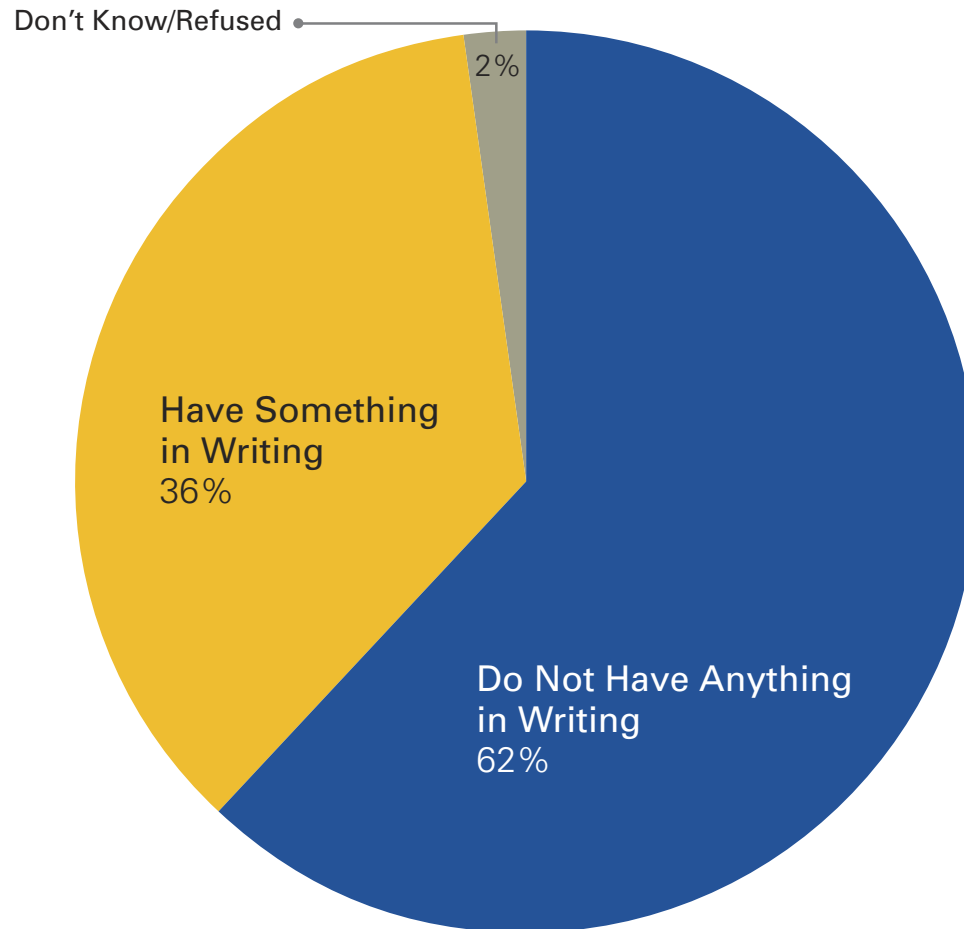
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Attitudes Toward

The vast majority, 83 percent, of Californians believe it is either somewhat or very important to have end-of-life wishes in writing.

End-of-Life Wishes in Writing, 2006

“Do you have your end-of-life wishes for medical treatment in a written document?”



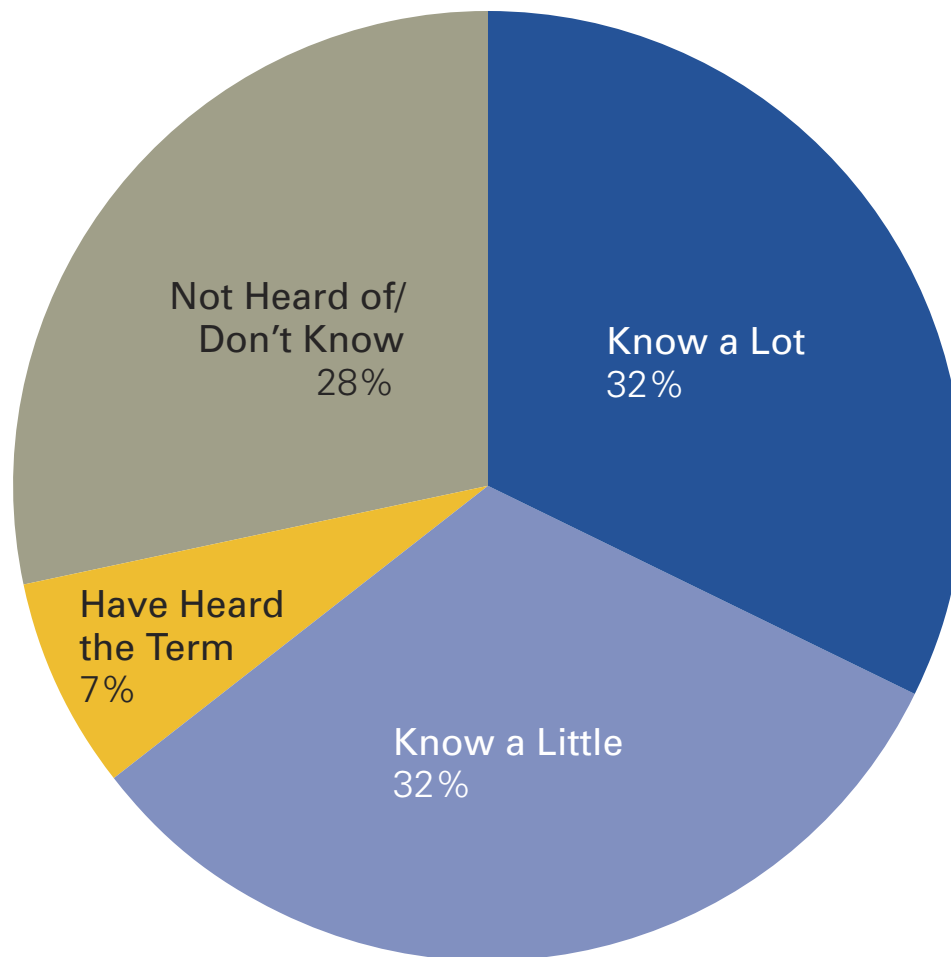
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Attitudes Toward

Although 83 percent of Californians believe that it's at least somewhat important to have their end-of-life wishes in writing, just over a third actually have a written document such as a living will, advance directive, or durable power of attorney for health care.

Knowledge of Hospice Care, 2006

“Have you heard of hospice care? If you have, how much do you know about it?”



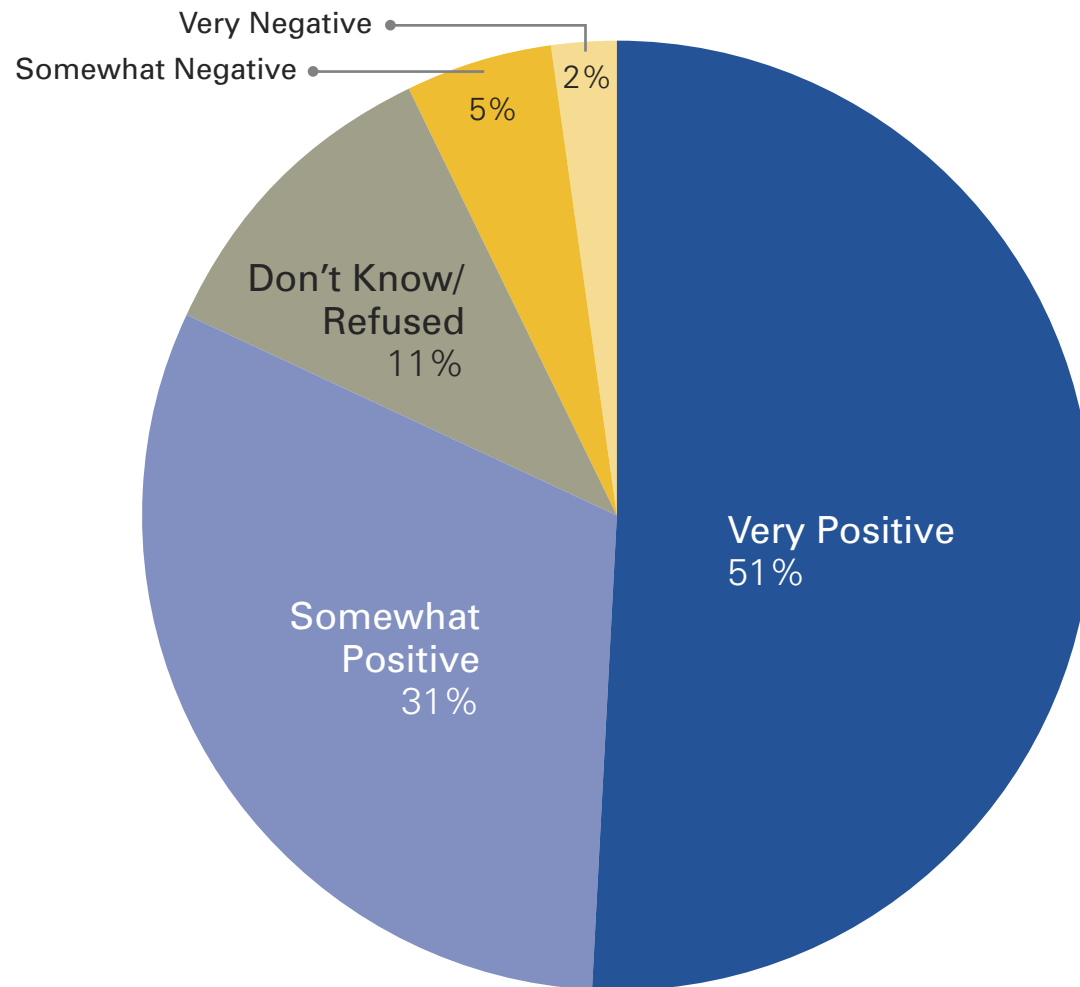
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Attitudes Toward

Nearly two-thirds of Californians have heard of hospice care and feel they know at least a little about it, but only a third say they know “a lot” about it. Almost 30 percent have never heard the term.

Opinions of Hospice Care, 2006

Among those who have heard of hospice, "What is your opinion of hospice care?"



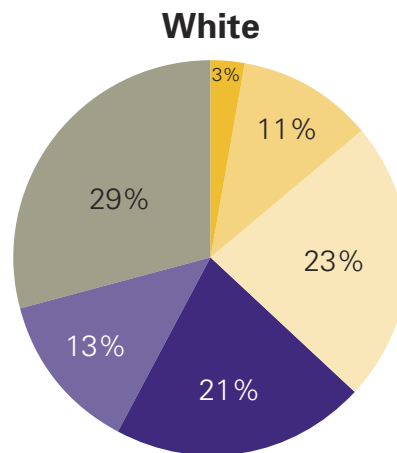
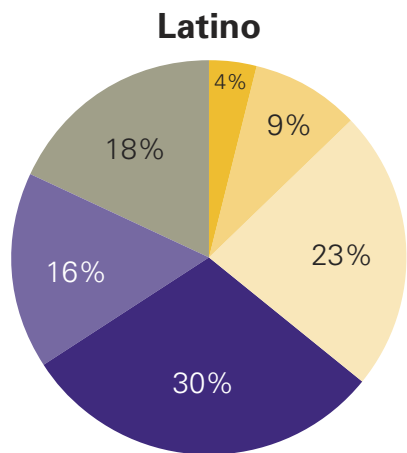
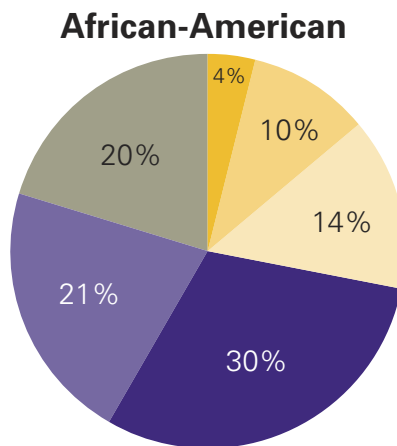
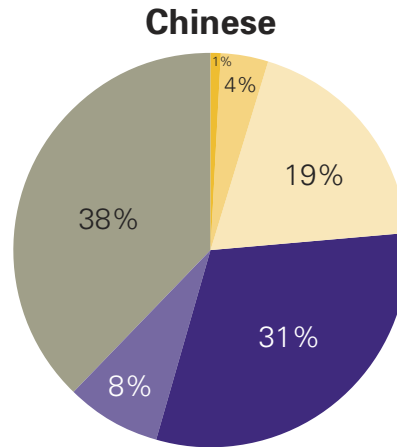
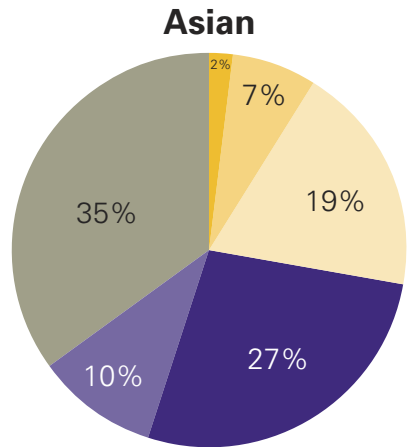
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Death and Dying Attitudes Toward

The vast majority of survey respondents, 82 percent, view it positively, and over half view it very positively.

Rating California's Health Care System, 2006

■ Excellent
 ■ Very Good
 ■ Good
 ■ Only Fair
 ■ Poor
 ■ Don't Know/Refused



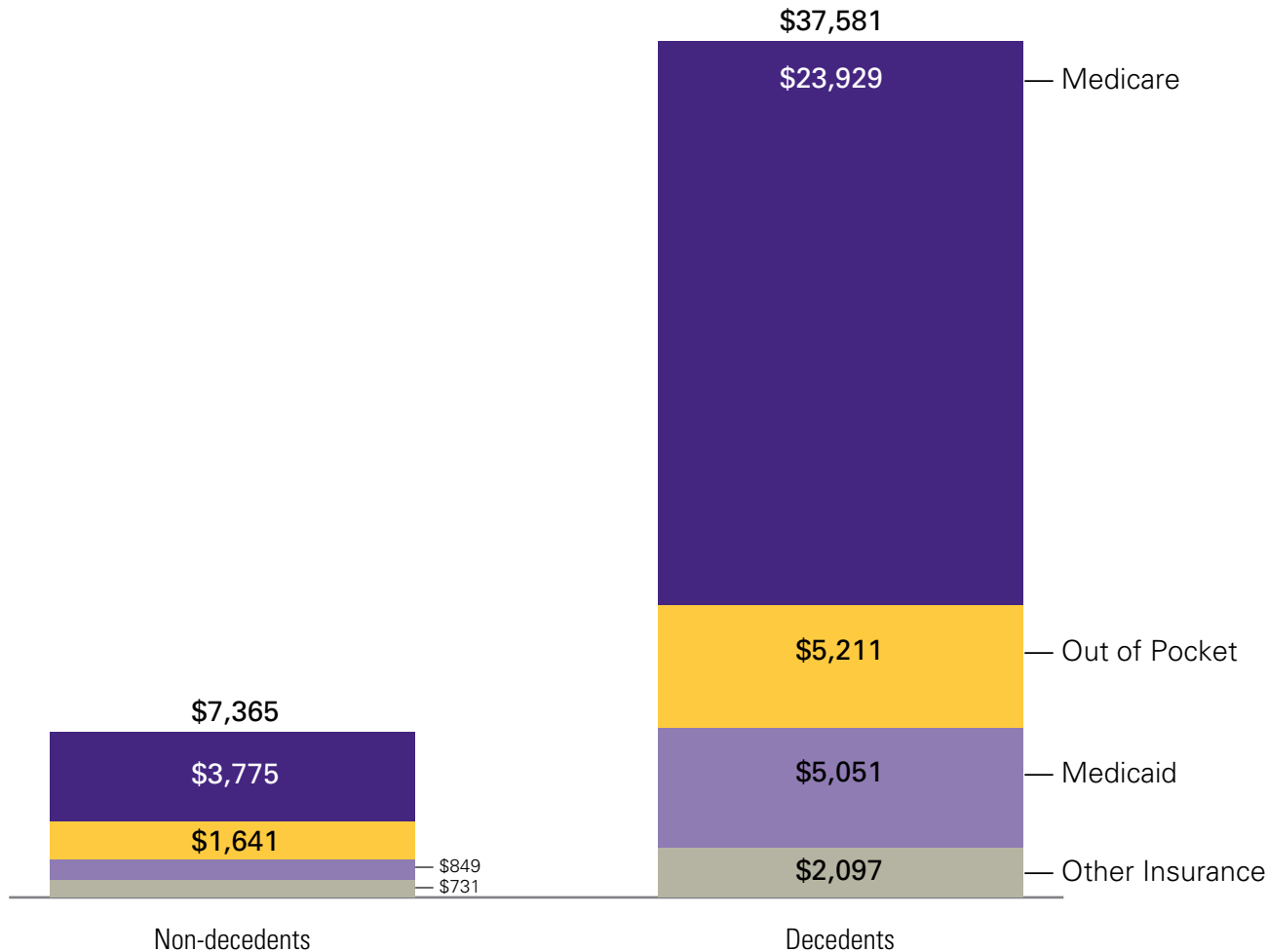
Death and Dying Attitudes Toward

Non-white Californians are more likely than Whites to give the state's health care system "fair to poor" marks in caring for those who are dying. African-Americans and Latinos are the most critical, rating the system "fair to poor" 51 and 46 percent of the time, respectively.

Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, February to March 2006.

Medical Expenses for Ages 65+, by Payer Source, United States, 1992–1996

Average Annual Expenses

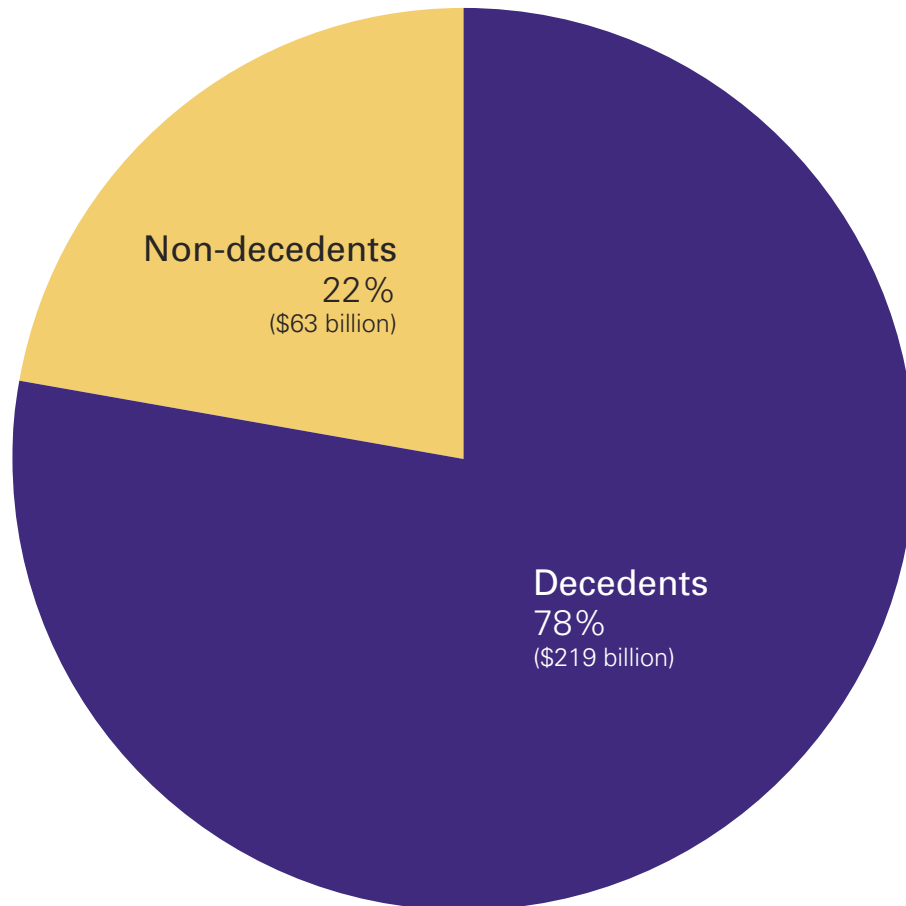


Source: Hoover, D.R. et al. 2002. "Medical expenditures during the last year of life." *Health Services Research* 37; 1625–42.

Death and Dying Cost of Care

From 1992 through 1996, the nation's average annual medical costs for those age 65 and older who died were more than five times higher than for those who didn't.

Annualized Expenditures for Ages 65+, Decedents vs. Non-decedents, United States, 1992–1996

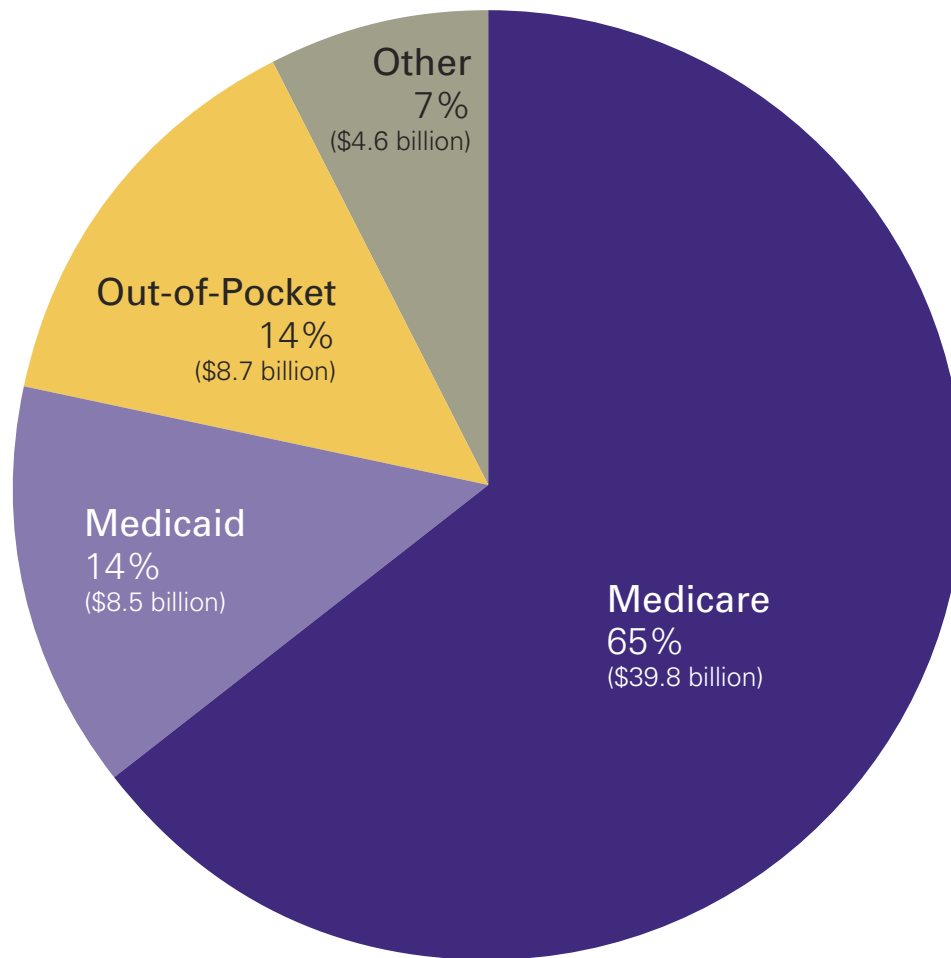


Death and Dying Cost of Care

In the United States, almost a quarter of the \$282 billion spent on health care annually for all Americans age 65 and older was for medical expenses during the last year of life.

Source: Hoover, D.R. et al. 2002. "Medical expenditures during the last year of life." *Health Services Research* 37; 1625–42.

Expenditures for Ages 65+ During Last Year of Life, by Payer, United States, 1992–1996



Note: "Other" includes supplemental insurance (includes private and employer-purchased insurance) and HMO (Medicare and non-Medicare).

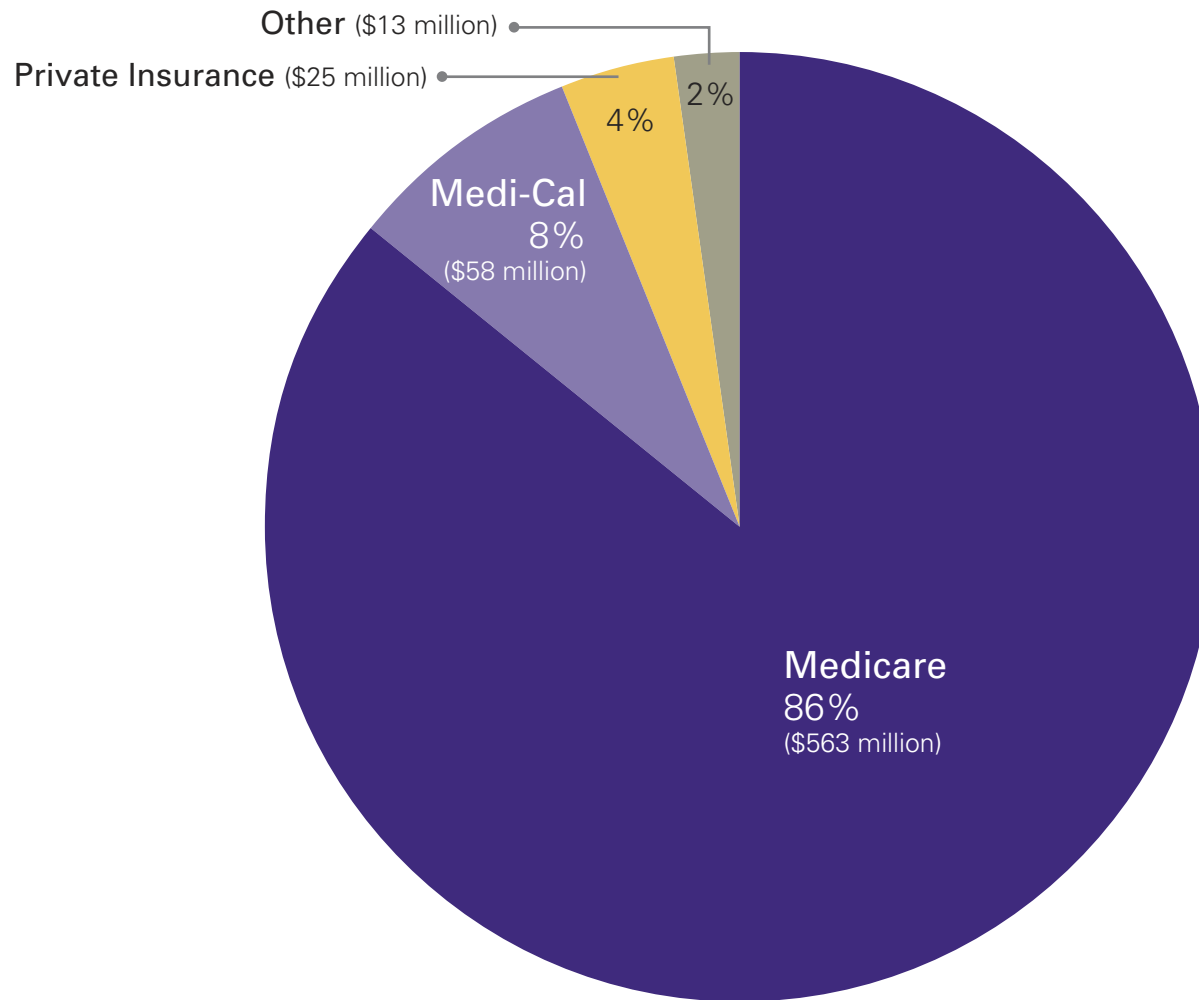
Source: Hoover, D.R. et al. 2002. "Medical expenditures during the last year of life." *Health Services Research* 37; 1625–42.

Death and Dying

Cost of Care

Medicare pays almost two-thirds of the total amount spent on health care during the last year of life for people age 65 and older.

Cost of Hospice Care, by Payer, 2004



Note: Please refer to the definitions at the end of this snapshot for a complete description of hospice.

Source: Office of Statewide Health Planning and Development, Annual Utilization Report of Home Health Agencies/Hospices. Data reported for 2004.

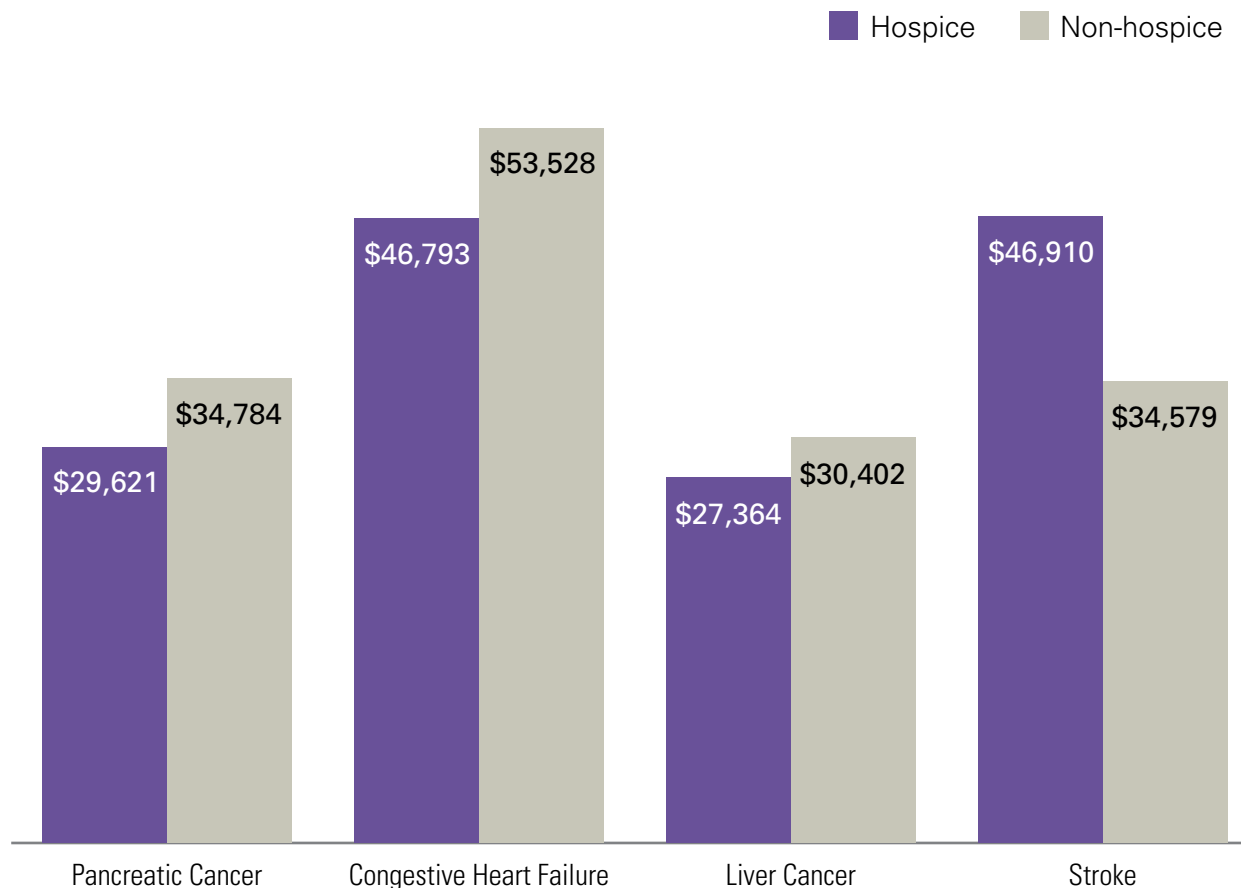
Death and Dying

Cost of Care

Hospice is an important alternative to medical intervention at the end of life, when curing illness is no longer a possibility. Since the majority of people receiving hospice care are age 65 and older, the primary payer source for hospice services is Medicare.

Cost of Care for Medicare Patients, by Illness, Hospice vs. Non-hospice, United States, 1999–2000

Average Annual Cost



Source: Pyenson, B., Connor, S., Fitch, K., and Kinzbrunner, B. 2004. "Medicare cost in matched hospice and non-hospice cohorts," *Journal of Pain and Symptom Management*, 28 (3); 200–210. 1999–2000 Medicare data.

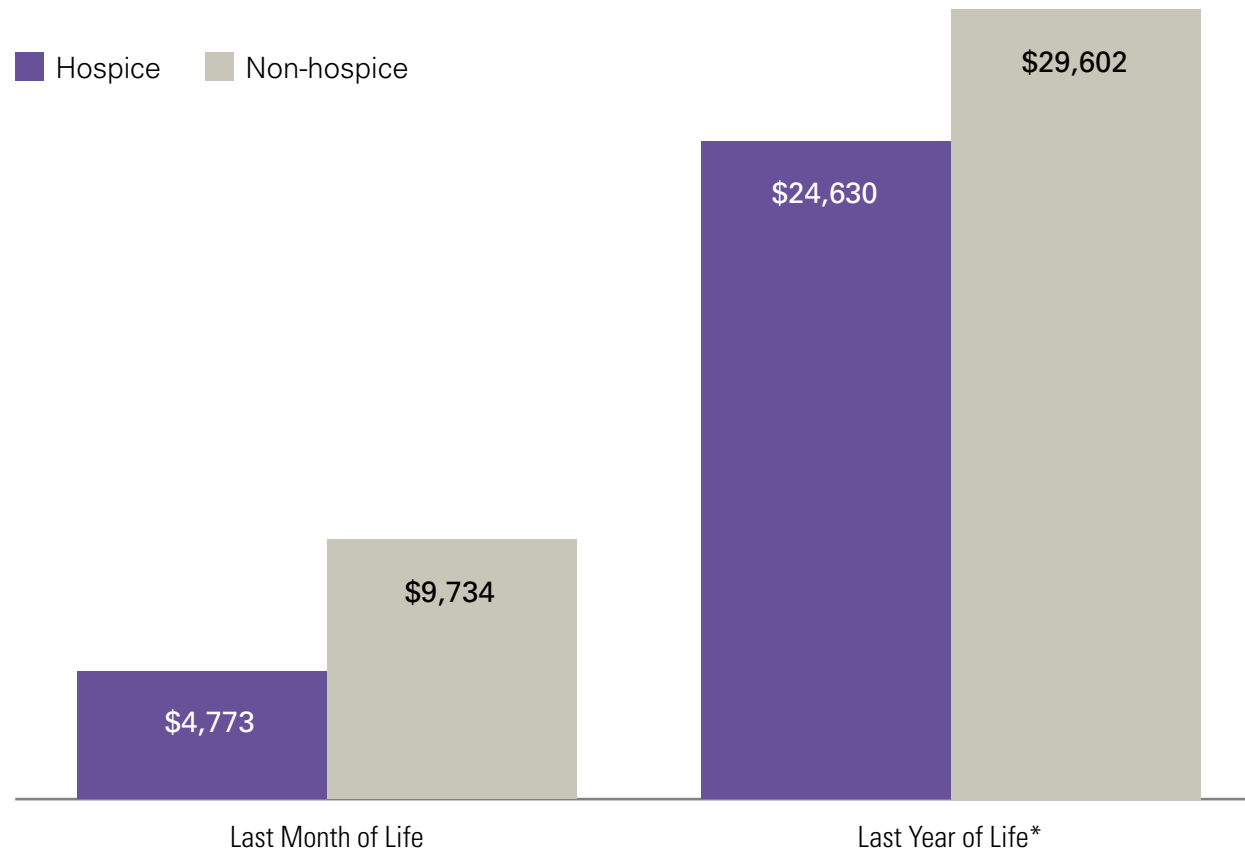
Death and Dying

Cost of Care

Health care costs for patients who receive hospice care are typically lower than for those who do not. In general, this is true because hospice focuses on relief from pain and suffering and not on curing the patient, thus costly diagnostic tests and invasive procedures are avoided.

Cost of Care for Medicare Patients, by Time Period, Hospice vs. Non-hospice, 1991–1992

Average Annual Cost



*Study analyzed only Medicare costs for patients with a primary diagnosis of cancer. Costs for last year of life include those incurred before the patient entered hospice care.

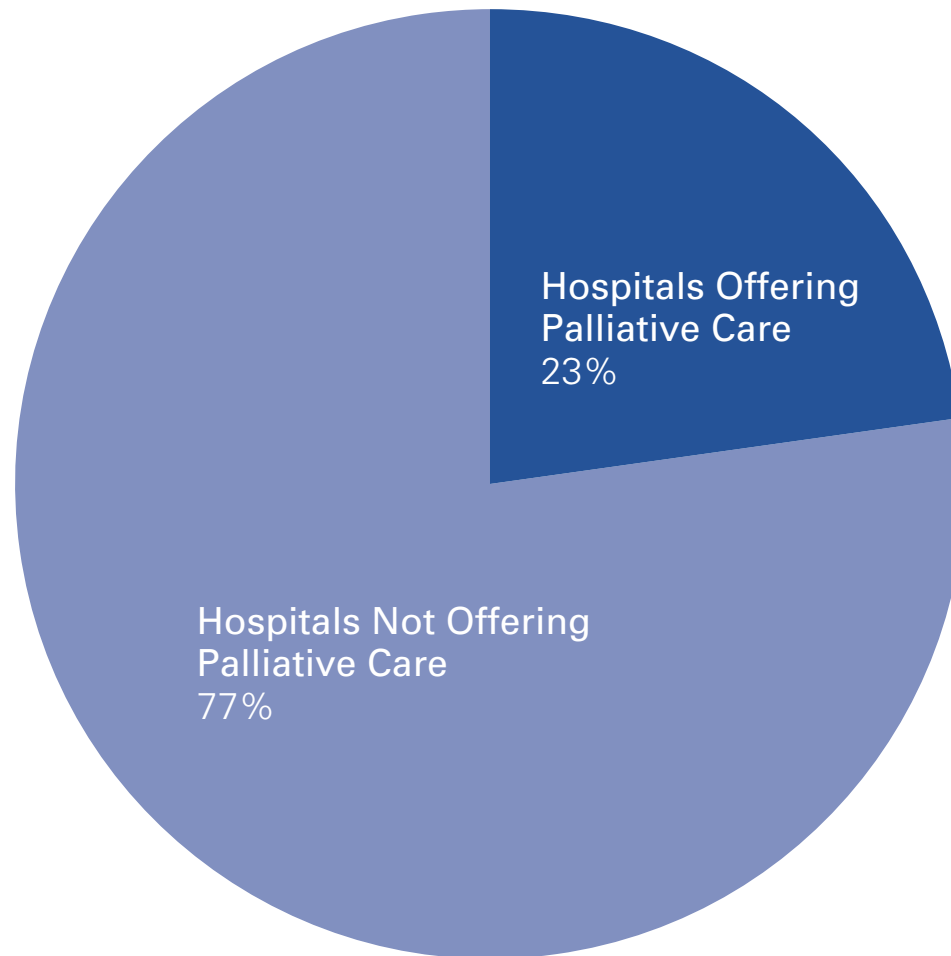
Source: Lewin-VHI conducted analysis of Medicare Hospice Benefit for California residents, dated August 23, 1995, addressed to Dr. Galen Miller, National Hospice Organization, analysis of 1991–92 data.

Death and Dying

Cost of Care

In the last month and year of life, the average cost of health care for California Medicare beneficiaries was less for patients who received hospice care than for those who did not.

Prevalence of Palliative Care* Services in Hospitals, 2004



*Palliative care addresses patients' symptoms and associated suffering, including physical, mental, emotional, social, and spiritual pain. Unlike hospice, palliative care is not limited to patients who are terminally ill and can be provided simultaneously with curative treatment.

Source: University of California, San Francisco. Personal communication with Steven Z. Pantilat, MD, on March 8, 2006. Based on 25 percent random sample survey of California's hospitals in 2004.

Death and Dying

Cost of Care

Specialized palliative care is a recent hospital service. A 2004 survey of California's hospitals found that 23 percent employed teams of health professionals to provide this service. Models of care range from palliative care units to multidisciplinary consultant teams that include medical staff, social workers, chaplains, and pharmacists.

Palliative Care Average Cost Savings During Last Three Days of Life: One Hospital's Experience, 2002–2004

COST CATEGORY	PATIENTS WHO DID NOT RECEIVE PALLIATIVE CARE SERVICES (N=718)	PATIENTS WHO RECEIVED PALLIATIVE CARE SERVICES (N=153)	SAVINGS
Pharmacy	\$793	\$31	\$762
Laboratory	\$138	\$7	\$131
Radiology	\$57	\$2	\$55
Room and Care	\$837	\$412	\$425
Services	\$616	\$16	\$600
Supplies	\$230	\$24	\$206
All Costs	\$2,671	\$492	\$2,179

Death and Dying

Cost of Care

At the University of California, San Francisco (UCSF) Medical Center, patients who spent their last three days of life in the hospital's palliative care unit incurred an average of \$2,179 less in expenses than similar patients in other parts of the hospital.

Source: University of California, San Francisco (UCSF). Conversation with Kathleen Kerr, Analyst, UCSF Department of Medicine, on March 7, 2006. Based on 2002–2004 data for 718 patients who died and did not receive palliative services and 153 patients who died and spent their final three hospital days receiving palliative services.

Key Legislation on End of Life

California

- **1976** Passed the nation's first living will law (Natural Death Act), allowing the withholding of life-sustaining procedures from adults with terminal conditions who have executed a directive.
- **2000** Adopted new Health Care Decisions Law to streamline advance directives.
Required health facilities to assess pain when monitoring patients' vital signs.
Required medical students to complete course work in pain management and end-of-life care.
Required HMOs to cover hospice care at same level as provided by Medicare.
- **2001** Required doctors to complete 12 hours of continuing education on pain management and end-of-life care by December 2006.
- **2003** Eliminated cumbersome medical prescription requirements for certain controlled substances commonly used for pain relief in terminally-ill patients.
- **2006** Directed Medi-Cal to develop a pilot that allows terminally-ill children to receive palliative and curative treatment simultaneously.
Clarified that doctors may prescribe controlled substances without fear of criminal prosecution when the patient has a medical need for the medication, such as pain management.

- **1990** Established the federal Patient Self-Determination Act, requiring hospitals, nursing homes, home health agencies, and HMOs to provide information on advance directives at the time of admission.

United States

Death and Dying Appendix

Thirty years ago, California led the country by giving people the right to express their wishes for health care in advance. California continues to be a leader in promoting good public policy regarding end of life through physician education, hospice coverage, and pain assessment and management practices.

Source: California Coalition for Compassionate Care, http://www.finalchoices.org/public_policy.htm.

Advance Directive Forms

- The California Coalition for Compassionate Care provides free forms and a fact sheet on advance directives in English, Spanish, and Chinese. Visit www.finalchoices.org.
- Local hospitals often provide free forms through Social Services, Chaplaincy, or Patient Education departments.
- The California Medical Association sells an Advance Health Care Directive Kit in English and Spanish. Cost is \$5.00. A discount is given for bulk orders. Call 1-800-882-1262 or visit www.cmanet.org.
- Aging with Dignity sells *Five Wishes*, a user-friendly advance directive, in English, Spanish, and Korean. Cost is \$5.00. A discount is given for bulk orders. Call 1-888-5-WISHES or visit www.agingwithdignity.org.
- Caring Connections provides free forms for all 50 states that can be downloaded from www.caringinfo.org.

Definitions

Advance Directive—An advance directive is a written or verbal communication that allows individuals to make their wishes known if they become unable to speak for themselves. There may be two components to an advance directive: 1) appointment of a surrogate decision-maker, and 2) instructions for future health care treatment decisions. In California, the specific term now used in state law is the Advance Health Care Directive (AHCD).

Living Will—A living will is a type of advance directive that specifies one's treatment wishes if he or she becomes permanently unconscious or suffers from a terminal illness. Despite this specific definition, the term Living Will is often used generically (especially by the general public) to refer to any advance directive document.

Durable Power of Attorney for Health Care—Until 2000, this was the main advance directive document used in California; its primary purpose was to designate a surrogate decision-maker who could act on behalf of an individual unable to make his or her own health care decisions. This function is now a component of California's Advance Health Care Directive.

Hospice—Hospice programs care for those facing a life-threatening illness who have a prognosis of six months or less and are willing to forego curative treatment. Using a team approach, services include expert pain and symptom management, as well as emotional and spiritual support tailored to the needs of the patient and family.

Palliative Care—Palliative care addresses patients' symptoms and associated suffering, including physical, mental, emotional, social, and spiritual pain. Unlike hospice, palliative care is not limited to patients who are terminally ill and can be provided simultaneously with curative treatment.

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Lake Research Partners

Death and Dying Appendix

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Was the information provided in this report of value? Are there additional kinds of information or data you would like to see included in future reports of this type? Is there other research in this subject area you would like to see? We would like to know.



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