

**Informational Hearing
of the
Assembly Aging & Long-Term Care Committee**

A Matter of Life and Death: What Are the Choices?

**February 19, 2013
State Capitol, Room 126 at 2:00 pm**

ISSUE PAPER

There aren't many subjects more difficult to discuss than end-of-life. Death, although universal, is distressing to contemplate, even taboo in some cultures. Although we may enjoy longer life-spans due to advancements in modern medicine, we are faced with more chronic illness and a resulting range of issues at end-of-life—issues that test our personal and collective boundaries and understanding of life and death. Even where the issue can be discussed, the implication of medicine's objective often produces an imperfect fit with the demands of end-of life palliative care, where the recovery of a patient is unlikely and the task to cure instead becomes the task to minimize suffering as death approaches.

The state of California maintains ample data on death and dying¹. According to statewide tracking data, roughly 233,000 people die in California each year. This breaks down to roughly 115,000 women and 118,000 men. About 169,000 are over the age of 65 and about 59,000 are between 18 and 64. Men are more likely to die from heart disease (30,083) than cancer (28,776) with accidents (6567), chronic lower respiratory diseases (5996), stroke (5723), Diabetes (3633) and Alzheimer's (3506), suicide (2972), liver disease (2797) and flu (2737) rounding out the top-ten causes of death. Women face about the same risk in dying from heart disease (27,951) and cancer (27,348). Death by stroke figures more prominently for women (7843), as does Alzheimer's disease (7324), and chronic lower respiratory disease (6932). Accidents (3541), diabetes (3394), flu (3119), renal failure (2226) and nephritis (1494) round out the top ten causes of death for women².

¹ State of California Department of Public Health, Death Records

² State of California Department of Public Health, Death Records DEATHS AND AGE-ADJUSTED DEATH RATES FOR LEADING CAUSES OF DEATH BY SEX, CALIFORNIA, 2006-2010

In 2010, 233,143 people died in California³. 154,529 66.3% were white. 38,345 or 16.4% Hispanic; 20,032 or 8.6% Asian/Pacific Islander; 17,209 or 7.4% black; 1,772 people identified as multiracial; 971 American Indian individuals, 285 people of other, or unknown background. Death rates are another way to express data on dying. Death rates are expressed in “per 100,000 population” in specified groups. Between 2007 and 2010 total age adjusted (using year 2000 U.S. Standard population) death rates declined in California by 6.7% from 662.8 per 100,000 to 618.4 per 100,000. For Blacks, the death rate decreased 10.8 % during the same period from 990.7 to 883.5 per 100,000. Death rates among Hispanics decreased 5.9% from 525.4 to 494.1. Death rates among whites decreased 4.9% from 721.3 to 685.6. Death rates among American Indians decreased 16.9% from 483.5 to 401.8.

This data represents California's experiences with death in a population that is roughly 12.8% 65+. The California Department of Finance's Demographic Research Unit estimates that California's 65+ population will grow by 43% by 2020. Then, the 65+ cohort will grow another 39%, to 8.83 million by 2030; and then by an additional 21% to 10.5 million Californians over the age of 65 by 2040, representing over 20% of the population.

So what are the choices people face at the end of life? When it comes to end-of-life choices, all decisions have complex ramifications and consequences which could impact quality of living and quality of dying. Today's hearing is intended to assess and discuss the choices in the matter of life and death. What are the choices being made by the nearly quarter-million Californians and their families and networks of care and support who die each year?

As will be presented by the California Healthcare Foundation during today's hearing, when it comes to end-of-life issues, Californians have preferences. Most Californians would prefer to die a natural death at home without becoming a burden on family. Californians say the most important factors at the end of their life are making sure their family is not burdened financially by the costs of care (two-thirds of those surveyed say this is extremely important) and being comfortable and without pain (66%). Most prefer that family members are not burdened with difficult decisions about their care. Most prefer a natural death while fewer than 10% want all heroic measures to prolong life. Most know it is important to express their wishes in writing.

According to a recent survey performed by the California Healthcare Foundation assessing the differences between what Californians want and what they experience at end-of-life, over 82% of Californians say it is important to have end-of-life wishes in writing, although only 23% say they have done so. Even though 80% of Californians think it would be a good idea to speak to their doctor about end-of-life wishes, only 7% have done so, and while 70% say they would prefer to die at home, only 32% do.⁴

³ State of California Department of Public Health, Death Records DEATHS BY AGE, SEX, AND RACE/ETHNIC GROUP, CALIFORNIA, 2010

⁴ Snapshot: FINAL CHAPTER: Californian's Attitudes and Expressions with Death and Dying, February 2012

As people approach the end of their lives they and their families commonly face tasks and decisions that require a broad array of choices ranging from simple to complex. For example, dying persons and their families are faced with choices about what kind of caregiver help they want or need, and whether to receive care at home or in an institution. Dying persons may need to decide to what degree they want family members involved in care giving and decision making. They often must make decisions about wills, advance directives, durable powers of attorney simultaneously while making choices about how to expend limited time and energy. As the committee will hear during testimony, although such concerns are extremely prevalent, terms like "advance directives" and "palliative care" are understood by fewer than 40% of Californians.

Nonetheless, advance directives are demonstrating promise in combating the high costs of care at end-of-life. Data shows that generally, about 25.1% of the care one receives from Medicare is delivered during the last month of life⁵. Testimony today will show how one community in Wisconsin has achieved nearly 100% compliance with advance directives and the results are beginning to show marked decreases in the costs of health care—the theory being that unnecessary care is minimized thanks to the guidance patients express in their advance directives.

Multiple witnesses will discuss the range of documents that support end-of-life decision making, and assurances that such wishes are carried out. Preferences regarding non-medical care require documentation that is different from preferences that do impact medical care. Statutory Power of Attorney, Durable Powers of Attorney for Health Care, Physician Orders for Life Sustaining Treatment, Do Not Resuscitate (DNR), all carry different levels of documentation, witnesses and confirmations. Yet, all are essential to assure that one's personal wishes, values and preferences are adhered to.

Medical end-of-life decisions have the most sensitive and challenging ramifications for terminally ill people and those who care for them. Navigating issues of personal value systems, cultural concerns, options for care, care giving, and availability of services all play an important part.

For those on public social services, hospice care is available as a Medi-Cal benefit. Hospice care is a form of medical multidisciplinary care designed to meet the unique needs of terminally ill individuals with life expectancy of six months or less. Hospice care in the Medi-Cal system is used to alleviate pain and suffering and treat symptoms, rather than cure illness. Items and services are directed toward the physical, psychological, social, and spiritual needs of the patient/family unit. Patients must elect hospice care as an alternative to the usual course of treatment, and upon notification, certain curative benefits are waived. As the Affordable Care Act (ACA, Section 2302) is enacted, hospice eligible individuals under age 21 will be allowed to receive curative and palliative care simultaneously.

⁵ Health Services Research 2010 April; 45(2): 565–576.

Hospice care under the United States Veterans Administration (VA) system is very different from hospice under Medi-Cal. Like Section 2302 of the ACA, veterans are afforded the option to receive curative therapies while receiving palliative care. Representatives of the VA system will offer testimony on this matter.

Planning for end-of-life can make the process manageable for all parties, even empowering, according to Margie Jenkins, author of "You Only Die Once." If you care about your loved ones and want to make your death easier for them, it is vital that your desires, decisions, and instructions be discussed with the important people in your life. The author has also published a personal planner to accompany her self-help guide to deal with over 100 decisions which must be made within a very short time of a person's death. Carolyn Brent, Author of "Why Wait" addresses the issue from a different perspective: as a baby-boomer with an aging parent. She will present information on strategies to prepare emotionally, financially, and legally for a parent's death.

Today's hearing will offer timely and important insight into an aspect of life most people avoid until it is too late. Given the rapid increase in the population of people who will be aged, and therefore nearer to death, understanding how end-of-life choices are managed and addressed can have a significant impact upon the development of better public policy.