

# Hospice Transparency with Medical Aid- in-Dying Policy

Addressing Ethical  
Importance and  
Compliance with  
California's **End of Life  
Options Act - SB 380**

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# About Medical Aid-in-Dying

Medical Aid-In-Dying (“MAiD”) is medical assistance provided to a patient with decisional capacity to self-administer prescribed medications following an explicit request intended to end their life in a manner that is safe, certain, and painless.

In 1997, Oregon became the first state to legalize MAiD through their *Death with Dignity Act*. Ten states and jurisdictions have since enacted their own MAiD legislation or court decisions.

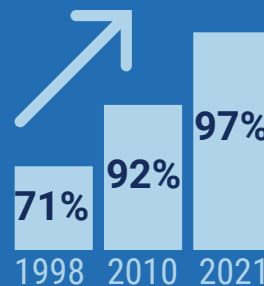
In 2022, California amended their *End of Life Options Act* to create a legal requirement for healthcare facilities to post a "notice of MAiD policies" on their public website. This represented an important step towards improving transparency and providing patients interested in pursuing MAiD with access to essential information about availability of care. Our review of compliance with this requirement, fourteen months after its enactment, reveals slow implementation of the policy mandate and failure of many institutions to provide clear policy statements that would assist patients in making an informed decision.

## Where in the U.S. is Medical Aid-in-Dying Legal in 2023?

- California
- Hawaii
- Montana
- New Mexico
- Vermont
- Washington, DC
- Colorado
- Maine
- New Jersey
- Oregon
- Washington

## Use of MAiD in Hospice

An increasing percentage of MAiD patients receive hospice care at the time of ingestion



Source: Oregon Death with Dignity Act Data Summary

**Informed consent is central to end-of-life treatment. Enabling patients to participate more actively in their care decisions demonstrates respect for their autonomy as moral agents and promotes their well-being.**

Source: Hester, D.M., Schonfeld, T. "Guidance for Healthcare Ethics Committees." Cambridge University Press, 2012.

# California's End of Life Options Act

## Eligibility Criteria

California's *End of Life Options Act* ("EOLOA") gives eligible patients the legal option of Medical Aid-in-Dying to peacefully end their life. Patients must make two oral and one written request to a physician for aid-in-dying medications. Commonly cited reasons patients pursue MAiD include: loss of autonomy, inadequate pain control, loss of dignity, and an inability to enjoy daily activities. Medi-Cal, California's public Medicaid insurance program, provides health care services for low-income individuals and families. Medi-Cal requires that providers counsel patients requesting MAiD of the importance of participating in a hospice program.

Eligible Patients must be

- 18 years of age or older
- A resident of California
- Diagnosed with a terminal illness that will likely lead to death within six (6) months
- Capable of making and communicating health care decisions
- Capable of self-administering aid-in-dying drugs



Hospice Transparency with Medical Aid-in-Dying Policy  
The Completed Life Initiative White Paper – 2023

California Senate Bill No. 380

**"Each health care entity shall post on the entity's public internet website the entity's current policy governing medical aid in dying."**

Source: Health & Safety Code § 443.15(i)

## Amendment SB 380

SB 380 was adopted on January 1, 2022 to improve the EOLOA by reducing barriers to access for eligible Californians. The amendment provides a shortened waiting period, from 15 days to a minimum of 48 hours; clarifies that aid-in-dying medication may be administered within any healthcare facility; and requires healthcare entities to publicly disclose their end-of-life policies and services on their websites for increased transparency.

Health care entities are additionally prohibited from engaging in false, misleading, or deceptive practices relating to end-of-life policy and services.

Data from Kaiser Permanente, one of the largest healthcare providers in California and throughout the United States, found that 48% of patients prescribed aid-in-dying were enrolled in hospice at the time of their first oral request. This suggests that many patients enroll in hospice between the time of first request and ingestion. Knowing whether a hospice facility's policy will support or deny access to aid-in-dying is essential information for patients who wish to pursue their legal right to MAiD while accessing other care services available to them at the end-of-life.

Source:  
DHCS Medi-Cal "End of Life Option Act Services" policy & billing information, rev. 12/2022;  
Nguyen, et al. "Characterizing Kaiser Permanente Southern California's Experience With the California End of Life Option Act in the First Year of Implementation." *JAMA Intern Med.* 2018; 178(3):417-421.

# Review of Compliance with SB 380

A majority of patients receive hospice care at the time of ingesting aid-in-dying medications. We sought to evaluate compliance by hospice facilities in the State of California with the requirement to post aid-in-dying policies on public web pages as of March 2023, fourteen months after SB 380 took effect.

## Methods

We first queried the Centers for Medicare & Medicaid Services (“CMS”) online webpage Data.CMS.gov for facilities with a CMS Certification Number (“CCN”). Hospices were included in our review if they: (1) had a primary address in the state of California; (2) were operational as of March 2023; and (3) had a publicly accessible web page. We identified 142 CMS-certified hospice providers in the state of California that met these criteria.

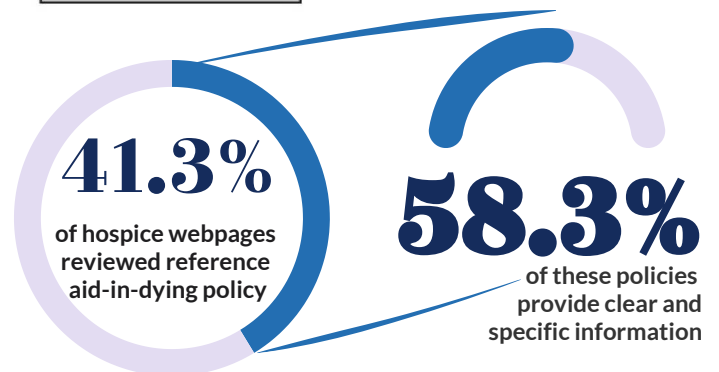
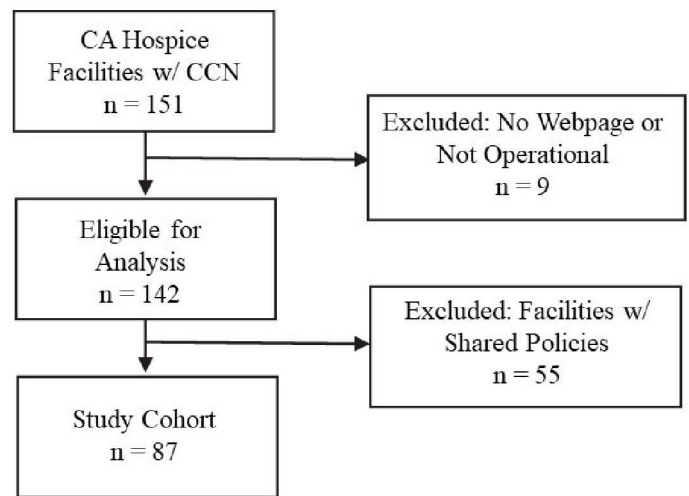
Large healthcare organizations such as Kaiser Foundation Hospitals and Vitas Healthcare Corporation operate multiple hospice facilities, each with a unique CCN, but are covered under a single organizational policy. These facilities were grouped together to avoid over-counting and skewing of data. Organizations that operate multiple facilities with unique CCN's but which post different policies or utilize different web pages were assessed as separate entities.

## Results

Less than half of hospice web pages (41.3%) that met review criteria had an aid-in-dying policy posted. The clarity and specificity of the information contained in a policy was variable.

40% of identified web pages made no clear statement on the entity's aid-in-dying policy, or used non-specific, vague terminology such as "neutral stance" or "opt out" without additional clarification or elaboration.

The American Clinicians Academy on Medical Aid in Dying (“ACAMAID”) best practice recommendations disapprove the use of non-specific terminology as it does not adequately inform a potential patient of the organization’s policy or what response they can expect to a request for MAiD.



# Discussion

## Importance and Implications

Not all healthcare entities participate in or support MAiD, nor allow for ingesting medication on-site or with staff present. Some providers hold personal objections to aid-in-dying even if their employer's policy allows for it. Terminally ill patients who wish to pursue MAiD should be aware of these policies and positions in order to make an informed decision regarding choice of provider or hospice facility.

It is necessary for healthcare entities to publicly clarify their position on MAiD and what assistance they will provide regarding end-of-life care options and "Ending Life Care" options. Ending Life Care describes the affirmative steps taken by patients with support or assistance from clinicians to relieve patient suffering at the end of life by ending life. This is distinguished from the phrase "end-of-life care" which describes all care, including curative, palliative, and ending life care (including MAiD, VSED, and palliative sedation to unconsciousness) which is administered at the end of a patient's life in response to an underlying illness or condition.

Transparency and honesty are integral components of a healthcare system that demonstrates respect for patient autonomy and the ability of patients to make fully informed decisions, especially at the end of life. Policy transparency is particularly relevant to hospice facilities as the majority of MAiD patients in California and other states are receiving hospice care at the time of ingestion. Some hospice policies reviewed under this project require the discharge and transfer of care to another facility for patients who wish to pursue MAiD (1). Lack of awareness of these policies in advance can delay access to care, lead to forced transfers to unfamiliar facilities, and extend the time that a patient suffers from their terminal illness.

Two facilities in our review used biased or misleading terms. Policy titles like "Provider Hastened Death" incorrectly characterize aid-in-dying procedures (2). Under all United States MAiD laws, patients must willingly and independently self-administer prescribed medications. The use of derogatory terminology such as "euthanasia" is deceptive. It wrongly conveys to patients that aid-in-dying is an act of killing rather than a legal health intervention available to decisionally capable, terminally ill patients who have the capacity to make their own healthcare decisions. Value-laden terminology that creates uncertainty, conflict, and distress can lead to stigmatization and the connotation that certain health behaviors are taboo. This is not an appropriate component of ethical health care policy.

Source:

(1) Emanate Health Facilities, *California's End of Life Act*: "Any person wishing to receive life-ending medication while a patient in our hospitals will be assisted with a transfer to another facility."

(2) Providence St. Joseph Health and Affiliates: *PSJH-CLIN-1207, Responding to Requests for Provider-Hastened Death*

# Proposals

- (1) All California healthcare entities should achieve compliance with the requirements of SB 380 to post their aid-in-dying policy on their public website immediately.
- (2) Policies should use unbiased descriptive language.
- (3) Policies should comprehensively address all components of the aid-in-dying process. Permitted facility and staff roles in each step of ending life care should be clearly stated.
- (4) Other states, territories, and districts with legalized aid-in-dying should be urged to enact similar transparency requirements for healthcare entities' public policy.

# Glossary

ACAMAID	American Clinicians Academy on Medical Aid in Dying
CCN	CMS Certification Number
CMS	Centers for Medicare & Medicaid Services
EOL	End of life
EOLOA	End of Life Options Act
MAiD	Medical aid-in-dying
SB	Senate Bill
VSED	Voluntarily stopping eating and drinking

