

Disability Rights Education & Defense Fund **DREDF**

April 15, 2024

Via email and the Advocacy Portal  
sjud.fax@sen.ca.gov

Senate Judiciary Committee  
1021 O Street, Room 3240  
Sacramento, CA 95814

**Re: Letter in Opposition to SB 1196**

Dear Members of the California Senate Judiciary Committee:

Disability Rights Education & Defense Fund (DREDF) is a national, nonprofit law and policy center led by people with disabilities and dedicated to advancing and protecting the civil and human rights of disabled people.

For decades, DREDF and other national disability rights organizations have opposed laws legalizing physician-assisted death or weakening the safeguards associated with this option in states where it has been legalized. One of our primary objections lies in the message that these bills and laws send to disabled people, including older adults with disabilities, and to caregivers, service providers, and social institutions. These bills and laws communicate that an appropriate response to disability and disability-related needs is physician-assisted death. We fight instead for a world in which people with disabilities, including people with progressive physical disabilities and dementia, are supported, loved, and given an opportunity to maintain their relationships and daily activities and find meaning in their lives. We know that this world is not yet realized for many.

Over time, nine states (including California) and the District of Columbia have enacted aid-in-dying laws. Every single one requires that the person have a prognosis of six months or less to live, the same prognosis that establishes eligibility for hospice care. Not one deems dementia in and of itself to be a qualifying basis for physician-assisted death. SB 1196 deviates from this model and would dramatically expand eligibility for physician-assisted death in California to people with years yet to live and to *all people diagnosed with dementia* who retain capacity. This bill is bad public policy and undermines our efforts to support people with disabilities. We oppose.

## **1. The Requirement That One Have a Terminal Condition Expected to Result in Death Within Six Months is an Essential Safeguard to Prevent Harm**

Like all other states with laws legalizing physician-assisted death, California's End of Life Option Act is only available to those who are expected to die within six months. This requirement was crafted to parallel the qualification standards for hospice care. It sets a standard and communicates the message that physician-assisted death should not be used as an alternative to appropriate physical and psychosocial care, including pain management, symptom relief, and social supports and engagement, throughout the stages of life. The timing requirement prevents harm to people who have recently acquired disabilities and who are vulnerable to suicidal desires—often intertwined with society's view of disability as tragic and worse than death—that are likely to abate with adaptation and supports, allowing them to find great satisfaction in their lives.

Eliminating the six-month requirement and expanding eligibility for physician-assisted death to individuals with “a grievous and irremediable medical condition,” as defined, upends this balance and social contract. (It also introduces terminology that is not typical in law or objectively measurable, such as the word “palpable” as a requirement for the level of suffering required to access the end-of-life option.) If enacted, SB 1196 would allow people with disabilities that can cause death years later, including newly acquired disabilities like dementia that are common among older adults, to seek aid-in-dying drugs immediately. This should not be our approach to supporting and caring for disabled people and older adults. It sends the message that disabled lives are not worth living.

The proposal to eliminate the six-month requirement follows 2021 legislative changes that already eliminated most of California's waiting period and other key protections. As originally enacted in 2016, California required a 15-day waiting period between requests for aid-in-dying drugs. That period was reduced to 48 hours beginning in 2022, making California the only state to have adopted a 48-hour waiting period rather than 15 days. The State also eliminated the requirement that an individual make a final attestation affirming their choice before aid-in-dying drugs are administered. (SB-380 End of Life, Cal. Stats. 2021, ch. 542, eff. Jan. 1, 2022; Health & Safety Code § 443.3(a)). Eliminating the six-month eligibility requirement for physician-assisted death

would fully tip over any balance that now exists among the values of individual choice, the weighty moral questions raised by aid in dying, our treatment of and communication to people with disabilities, and the need to protect vulnerable people against harm and abuse.

## **2. The Proposed Expansion of Physician-Assisted Death to All People with Dementia Who Retain Capacity is Unprecedented in the United States and Bad Policy for California**

As written, SB 1196 would make physician-assisted death available to any individual with a diagnosis of dementia, regardless of stage, so long as they retain capacity (§ 443.1(h)(2) “For purposes of this part, and notwithstanding paragraph (1), a diagnosis of dementia, if the individual meets the requirements of Section 443.2, is considered a grievous and irremediable medical condition.”) This unprecedented expansion of aid-in-dying would make it lawful for people to immediately access aid-in dying upon receiving a diagnosis of dementia. This proposal must be rejected.

As an initial matter, dementia is often misdiagnosed. There are many nonterminal and treatable conditions that present similarly to dementia, such as delirium, head trauma, heart and lung disorders, liver and kidney disease, hormone disruption, infections, cancers, malnourishment, mood disorders, and other neurocognitive disorders. (James M. Ellison, MD, MPH, Medical Conditions That Can Mimic Dementia, (updated Feb. 9, 2024), <https://www.brightfocus.org/alzheimers/article/medical-conditions-can-mimic-dementia>; Kelsey Allen, It’s Not Always Dementia: Top 5 Misdiagnoses, <https://www.humangood.org/resources/senior-living-blog/top-five-dementia-misdiagnoses>; Robert Howard and Jonathan M. Schott, When Dementia is Misdiagnosed (Mar. 22, 2021), <https://doi.org/10.1002/gps.5538>).

Further, dementia is a common disability among older adults, and is a condition about which many in our society have fears and misconceptions. In fact, many people with dementia live for years with supports including technology and enjoy social relationships, daily activities, meaning, and joy. Our public policy should be to support people with dementia and their caregivers, and to teach caregivers and social institutions how to successfully engage with and support people with dementia. Rather than making it easier for people with dementia to choose death before they have even had a

chance to explore their treatment and life options, our focus should be on improving access to and quality of care.

Moreover, the expansion of physician-assisted death to dementia risks undermining the patient-physician relationship and trust in the health care system, particularly for people with other health care disparities, which include not only disabled people and older adults, but also low-income people and marginalized racial and ethnic groups. The proposal could also decrease incentives for research in the care of people with dementia. We ask whether these risks were explored and whether disability and dementia experts were consulted before the introduction of SB 1196.

Finally, this bill marks a proposed foundational shift to California public policy. Rather than support people in avoiding a painful death, this law would legalize physician-assisted death to allow people to end a life that is—or is perceived to be—painful or challenging. While SB 1196 proposes an expansion to dementia, it is not hard to imagine that the next bill might include schizophrenia, opioid addiction, anorexia nervosa, or homelessness. We can do better for the most vulnerable members of our society than offer physician-assisted death for these vulnerable and at-risk populations.

No other state that has authorized aid-in-dying has opened the door to individuals with a diagnosis of dementia or any other mental health diagnosis. California should not be the first.

### **3. We Continue to Lack Data on Use of Physician-Assisted Death in California, Preventing a Meaningful Assessment of the Law and Underscoring the Risks of Expansion**

Meaningful evaluation of California's End of Life Option Act requires that California understand the reasons why patients are choosing physician-assisted death; whether it be social stigma, isolation, lack of access to supportive care and treatment services, or pain and suffering. It requires that we understand whether and how abuses or coercion is occurring.

So far, we know that in 2022, following the 2021 changes, the number of prescriptions written for aid-in-dying medication went up 47 percent and the number of deaths from aid-in-dying medication went up more than 63 percent. (CDPH, California End Of Life Option Act 2021 Data Report (2022), at 3,

[https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH\\_End\\_of\\_Life%20Option\\_Act\\_Report\\_2022\\_FINAL.pdf](https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH_End_of_Life%20Option_Act_Report_2022_FINAL.pdf).) However, we lack appropriate data collection requirements and oversight needed to evaluate the practice. While existing law requires the Department of Public Health to publish annual statistical reports, the Department does not monitor underreporting or other forms of noncompliance with existing law. There is no penalty for noncompliance in reporting by physicians of required information. There is no collection of information from parties other than the prescribing doctor (such as providers who declined or had concerns about eligibility). The Department does not collect information from family members, friends, or care providers to learn about the physical and emotional status of those who died. Nor does the Department interview, or collect even a sampling of, information from patients prior to their deaths.

There is no method through which the public can report coercion or abuse associated with existing law, and the State appears to have no resources or even authority to investigate violations. Moreover, the law imposes confidentiality measures unique to physician-assisted death which limit the potential for thorough research, analysis, or assessment. (Health & Safety Code § 443.19(b).)

Without data collection and robust communication with stakeholders, we cannot know how many annual requests for physician-assisted death are made, why some doctors declined while others agreed, what transpired in individual cases, and trends that might impact the State's health care and public policies moving forward. SB 1196 does nothing to allow this assessment.

Expanding California's End of Life Option Act to facilitate the deaths of people with dementia and people without a terminal prognosis will disturb the statute's balanced framework and make California home to the nation's most sweeping and unchecked aid-in-dying policies. We oppose SB 1196.

Thank you for your consideration,



Susan R. Henderson  
Executive Director  
Disability Rights Education and Defense Fund