



Advocating for
disability civil rights
since 1979

September 4, 2008

Governor Arnold Schwarzenegger
State Capitol
Sacramento, CA 95814

Dear Governor Schwarzenegger:

We strongly urge you to veto AB 2747 (Berg). Despite amendments, significant problems remain. Based on a dubiously established non-problem, the bill would treat any Californian with a diagnosis (or misdiagnosis) of terminal illness as if they are imminently facing death, and would constrain the communications of doctors and other healthcare providers to their patients in a death-focused direction upon receipt of a terminal diagnosis.

We were very disturbed when, during the Senate Health Committee testimony on this bill, Dr. Robert S. Miller, representing the highly-trusted Association of Northern California Oncologists, explained that if this bill passes, the importance of the state mandate will loom so large in doctors' minds that, regardless of patient request or not, the extensive end-of-life information listed in the bill will be transmitted to every patient with a terminal diagnosis, to ensure doctors and other healthcare professionals do not run afoul of the law. Yet at the same time, he reported how the bill would tie doctors' hands, when they prefer to tailor information to the patients' needs and inclinations.

Thus, AB 2747 could trigger an onslaught of information about end-of-life care at the time of patient diagnosis, perhaps right in the doctor's office. But today, medical personnel are properly focused at that time on a patient's treatment and recovery options. Requiring an oncologist to tell a woman who has just been diagnosed with breast cancer about all possible end-of-life options would only serve to frighten her at an inappropriate time.

The trigger point of "a patient's request" is very unclear. What kind of request is meant – a narrow one? A broad one? Does a passing reference to dying, constitute a patient request? Wouldn't we prefer our doctors to be able to use their best judgment to answer our questions? Won't a deluge of information be prepared for distribution when anything related to death is broached by the patient – or perhaps whether it is broached or not – to ensure compliance with the law? And does that constitute good medical practice?

The bill's findings suggest that a lack of end-of-life information causes many problems, but without evidence. The study mentioned in proponent's testimony and in the Senate floor analysis states that *many* factors underlie problems such as late hospice entry, with lack of information being only one. For example, major reasons include late diagnosis and pursuit of curative care. Yet the bill is structured as if lack of patient information is the *sole* cause of late hospice entry and other problems – with no evidence whatsoever.

With its emphasis on end-of-life options as soon as a diagnosis of terminal illness is made, this bill forces doctors and other healthcare providers to treat any Californian diagnosed with a terminal illness as if they are imminently facing death. While it may be true that not all medical personnel are comfortable talking about death with their patients when the right time comes, this bill would *require* them to discuss death, *well before* it is imminent, in great depth, no matter what, and leaves them no discretion to judge when the right time is. It replaces a possible hesitancy to discuss death on the part of *some* practitioners, with a *requirement* to discuss it extensively by *all* practitioners. Do we really know that such a rigid mandate is the answer to any problem that truly faces medical patients in our state?

DISABILITY RIGHTS EDUCATION & DEFENSE FUND

Main Office: 2212 Sixth Street, Berkeley, CA 94710 • tel: 510.644.2555 [V/TTY] fax: 510.841.8645

Government Affairs: 1730 M Street NW, Suite 801, Washington, DC 20036 • tel: 800.348.4232

www.dredf.org



Yet we do know from medical studies, and from extensive anecdotal evidence in the disability community in which DREDF is based, that many patients outlive a terminal diagnosis by many years. How many will be pushed into desperate action based on fears of sickness, disablement, and financial burden?

Several sections of the bill allow or encourage medical practitioners to refer patients to organizations with end-of-life care case management and consultation. Compassion and Choices, the sponsor of this bill, and the similar organization Final Exit Network, both of which have their roots in the Hemlock Society, are the only such organizations, and they operate with volunteers who have no professional accreditation. Given that most terminal patients experience disabilities at some point, the disability community has significant concern about patients with disabilities being seen by these organizations, which have a long track record of portraying people with disabilities as having lives not worth living, and viewing all people with disabilities as having a low quality of life. Will they all be encouraged, subtly or not so subtly, to take their own lives?

A strange new section of the bill states that the “counseling sessions” may include a discussion about the cost of treatment options, the burdens of treatment, and referral to the “appropriate entity” for that information (who is that)? Thus, the bill now says that upon a terminal diagnosis, the burdens and costs of their treatment must, upon request (a specific request? a broad request? a passing reference?) be given to patients. This is virtually certain to make even more traumatic, something that is already extremely traumatic. Why a mandate for all the negatives at such an early, arbitrary point in the arc of a patient’s illness?

The bill ends by stating that if a doctor does not provide the information, perhaps because it is not in his or her best judgment, she or he must transfer the patient. This heavy-handed bill would leave treating physicians little room to practice their craft as they see fit.

We urge you to veto this poorly drafted, ill-conceived bill that hampers California physicians in response to a purported but completely undocumented “problem.”

Respectfully yours,

A handwritten signature in black ink that reads "Marilyn Golden". The signature is written in a cursive, flowing style.

Marilyn Golden
Policy Analyst