



Polio Survivors Association

A 501(c)(3) Non-Profit Corporation - www.polioassociation.org
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September 12, 2015

Edmund G. Brown Jr., Governor
State Capitol, Suite 1173
Sacramento, CA 95814

RE: AB2x15

Dear Governor Brown,

In the debate about assisted suicide, we often hear proponents talk about “quality of life versus quantity of life.” It is as if there was some legal or moral yardstick to identify what a quality life is, and that any sane person would recognize this. My question is, who decides what a quality life means? I am a survivor of acute poliomyelitis. Twenty-four hours after diagnosis I could not move, swallow, or breathe. I was given a tracheostomy and spent six months in an “iron lung.” In most locations, even large cities, I would have died, because most physicians would think, “This person is not going to have a good outcome. Is it compassionate to be aggressive, when he will spend a long time in a huge steel tank and probably never live a normal life? Let’s wait and see if there is some improvement.” During this wait the patient usually died. I was fortunate to live in an area (Los Angeles County) where the medical team worked differently. The doctors had an unspoken standard. It was, “If the thought of a tracheostomy (or other aggressive procedure) enters your mind ... do it now!”

Although I remain with significant disability, and still use a ventilator, I am active in life. I am president of the Polio Survivors Association, a lay speaker in the United Methodist Church, and an advocate for home-based, long-term care. I have had many friends with various disabilities, and a wide range of ages, who have had their lives written off by decision makers who believed that they wouldn’t or couldn’t live a quality life.

This is not some abstract situation. Several years ago, in a prestigious medical journal, a case study article appeared about a man who came to an emergency room with acute pulmonary failure. His pulmonary failure was precipitated by the late effects of polio, commonly known as post-polio syndrome. He was admitted to the ICU, given a cuffed tracheostomy, and placed on a ventilator. He was stabilized, but a few days later communicated his wish to be allowed to die. The two main reasons he gave for his decision were loss of control over his life, and his inability to speak. His inability to speak was his primary concern. A cuffed tracheostomy prevents normal speech.

Two medical ethicists were called in to evaluate the man's desire to die. He wasn't able to speak, and the article never mentioned the method of communication, but the ethicists confirmed that his desire was legitimate. Unspoken, but obvious in the article, was the fact that the man never left the ICU and was never given an opportunity to meet another person with a tracheostomy.

Many polio survivors have had tracheostomies. Few, if any, require a cuffed tracheostomy. They can all speak. And yet, these "medical ethicists" confirmed this man could not speak and, therefore, he would not have a quality life. So ... the medical team sedated the man, disconnected his ventilator, and watched as he died.

Would the inability to breathe on one's own be classified as a terminal condition by SB2x15? Would the determination by two "medical ethicists" be classified as "Medically confirmed." This bill, as written, carries so many risks to those with disability that it frightens me.

In section 443.1 (f) "Counseling" is listed as a means to determine if the person is mentally competent. In my illustration above, the patient was determined to be mentally competent and his desire to end his life was legitimate. But, the "counseling" was done by individuals who lacked any understanding of the patient's underlying disease process or interventions that are readily available to ameliorate this condition.

Life itself is a terminal illness. Without nutrition or hydration everyone would die in less than six months. This bill states that coercion is not allowed. Does coercion include withholding information about interventions that could help, or medications that will allow comfort, or payment for treatments that prolong life? If "coercion" is prohibited, how is this enforced? Who makes that decision?

In section 443.1 (i) "informed decision" includes, "The feasible alternatives or additional treatment opportunities, including, but not limited to, comfort care, hospice care, palliative care, and pain control." You might be alarmed at the lack of knowledge by many physicians in these areas. I won't take the time to list these, even those from my own personal experiences, but they are numerous.

The similar law in Oregon, and the media hype over Brittany Maynard's decision to end her life, which I believe is the legislature's justification for SB2x15, is wrought with errors and false assertions. Supporters of assisted suicide often cite pain as the primary reason people should have the legal right to die. But Oregon's latest report shows that those who took "advantage" of that state's assisted suicide law were primarily concerned with loss of autonomy (91 per cent), loss of dignity (71 per cent), or being a burden on their family (40 per cent). These figures appear to indicate that ill people are choosing assisted suicide because they feel they are not wanted by society. Former Colorado Governor Richard Lamm proclaimed publically that, "We've got a duty to die and get out of the way with all of our machines and artificial hearts and everything else like that, and let the other society, our kids, build a reasonable life." Is this going to be the official policy of the State of California?

Throughout this bill the term “self-administered” is used. I have listed some of my objections to this bill as written. But, if it is passed, and you sign it, doesn't the bill preclude some individuals from taking “advantage” of this bill to end their life ... even if they qualify in all other aspects. I am suggesting that a number of people cannot, because of significant disability, “self-administer” any drugs ... life ending or life enhancing.

SB2x15, as written, has so many loopholes and inconsistencies that I am very concerned that it will be an open door to abuse. In addition, this bill sends the signal that a burdensome life is not worthy of support. I urge you NOT to sign SB2x15.

Very sincerely,

A handwritten signature in blue ink that reads "Richard L. Daggett". The signature is written in a cursive, flowing style.

Richard L. Daggett, President, Polio Survivors Association
Member, American Academy of Home Care Medicine
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