

---

# BRINGING DEATH OUT OF THE CLOSET

By Jeff Baltes and Bonnie Edelstein

Being “in the closet,” avoiding difficult conversations, and living, particularly in years past, with an abundance of caution, are familiar situations for many members of our LGBTQ community. Unfortunately, what has also remained in the closet for many of us is the discussion of death. Americans, in general, show a profound distaste for conversations on end-of-life issues, often avoiding communicating with family, doctors, and caregivers about wishes for medical intervention, advance directives, appointment of health care proxies, and even creation of a will.

An important related issue, and one that is receiving increased attention and support, is that of expanding choices of terminally ill patients who are nearing the end of their life and are fearful of being doomed to a painful, anguished, and often undignified death, frequently as a result of heroic measures that may prolong life, but do little or nothing to promote quality of life. A bill co-sponsored by Senator Diane Savino and Assemblywoman Amy Paulin is presently working its way through the legislative process in New York.

The Medical Aid in Dying Act, patterned after similar legislation in Oregon, where the procedure has been legal for over eighteen years, permits patients with a terminal diagnosis of six months or less, to request life-ending medication that is self-administered by the patient. Two physicians must confirm the diagnosis, the patient must be at least eighteen years of age, and he or she must be judged mentally competent. The request must also be made in writing and witnessed by two people, at least one of whom has no interest in the patient’s estate. Numerous other safeguards are contained in the legislation as well, including protection of the physician from prosecution and safeguarding the payment of life insurance benefits (this is not deemed death by suicide). Additionally, the underlying medical condition is listed as the cause of death on the death certificate.

Critics will often say, “Isn’t this just assisted suicide or euthanasia, cloaked in a different term?” No! Individuals who request this medication are not suicidal—they would choose to live (and often have been fighting strenuously to do so) but their disease is winning. Those who are suicidal typically suffer from depression, are often disconnected from reality and society in general and often suffer from other personality disorders. Furthermore Medical Aid in Dying bears no relation to euthanasia, as the medication is self-administered at a time determined only by the patient. All decision making remains with the individual.

As a result of the momentum this movement has gained, we have formed a relatively new local, grassroots group, Death With Dignity-Albany, working in conjunction with Compassion and Choices, a national organization with similar interests and objectives. In just over a year, we have built a following of 500 members/subscribers to our email newsletters. Our programs throughout the year are well attended and energize support for the initiative, and we receive regular media coverage and are often invited to make presentations to organizations interested in this important topic.

Our efforts have successfully energized support around New York’s proposed legislation, including our presence together at a table at



this year’s Pride Festival. We were gratified by the interest, the positive comments, and the genuine concern voiced by the hundreds of people who stopped by our table to talk, get more information, and to sign up for our email list. These two organizations have partnered to not only develop support for passage of the legislation but also to educate about related issues as well. Our goal is to help people understand the components of the legislation, provide opportunities for advocacy, and heighten awareness about the importance of making conscious decisions around end-of-life issues. The legislation is NOT about dying; rather, it is about living life to the end on one’s own terms, having personal choices honored and respected, and providing yet another option for those facing a terminal illness.

In states where medical aid in dying is legal, a large percentage of the prescriptions requested actually go unused, but patients are comforted knowing that the option is available to them. In fact, in Oregon, the quality of end of life care has been judged improved due, in large part, to increased conversations between patients and their doctors. Referrals and access to hospice care have also increased significantly.

National polls, conducted as recently as 2015, show 68% support by the general public for the measure, cutting across all demographics. For many, that support is very personal, fueled by the struggle of a loved one facing a tortured and painful death. Such is the story of Amanda Cavanaugh, New York Outreach Coordinator for Compassion and Choices. She and her partner Chrissy Connery met just one year before Chrissy’s stage 4 cancer diagnosis. A few days before Chrissy’s 26th birthday, she went to Samaritan Hospital due to severe stomach pains. Following a battery of tests, she was given a cancer diagnosis, with a grim prognosis.

After countless chemotherapy treatments, loss of her job as a NYS



## Frequently Asked Questions...

*How is this intervention different from hospice or palliative care?*

Aid in dying provides another medical option to reduce suffering and give comfort at the end of life. Aid in dying, however, permits the patient to make a conscious and deliberate choice in assuring his or her wishes are achieved.

*Could a participating doctor jeopardize his or her medical license?*

The proposed legislation provides protections from criminal or civil liability and from professional disciplinary action.

*Does the proposed legislation cover debilitating diseases such as ALS, Huntington's and Alzheimer's?*

Existing laws and the proposed NY legislation do not include these illnesses. Experts in the political and legislative process in NY strongly advise against adding these measures as they are considered too controversial and open up many ethical questions along with potential risks for abuse of the law.

Corrections Officer, and a fighting spirit that wouldn't give up, Chrissy was briefly pronounced cancer-free. However, the period of remission didn't last long, and the cancer returned, invading every part of her body. After an exhaustive search for options, additional surgery, and painful treatments, Chrissy succumbed to her illness. Says Cavanaugh, "The details of her death are tragic. If there is anything to take away from those nightmarish last three days it's this: it is not the death that Chrissy would have wanted and, most importantly, it is not the death that she deserved.

"Chrissy may have chosen to use medical aid in dying, or she might not have; I cannot say for certain. But what I can say is that she would have liked to have the option. Because of that, I advocate for the Medical Aid in Dying Act, I advocate for choice, I advocate for peace of mind, and I will continue to do so until all New Yorkers have that right."

What can YOU do to advocate for medical aid in dying? Write, visit, and call your legislators, urging support for the legislation. Become informed—and take the opportunity to inform others. Have "the conversation" with your doctor, loved ones, and caregivers, informing them about your end of life wishes. Correct misinformation and help others to find accurate information on the topic. Both [www.compassionandchoices.org](http://www.compassionandchoices.org) and, locally, [www.deathwithdignityalbany.org](http://www.deathwithdignityalbany.org)

org provide current and helpful resources. Sign up for Death With Dignity-Albany's email list, check our program listing for opportunities to learn about this issue and other matters related to end of life care and preparation, and contact us at [info@deathwithdignityalbany.org](mailto:info@deathwithdignityalbany.org) for more information. There is strength in numbers—and the world has indeed been changed by committed people working to make a difference!



Bonnie Edelstein is the founder and Director of Death With Dignity-Albany. She spent many years working as a consultant to non-profits and colleges through her consulting firm, People Work.



Jeff Baltes is the Deputy Director of Death With Dignity-Albany. He is a retired educational administrator and former Vice-President of the Pride Center Board of Directors.