**Letter to the Disability Community about Assisted Suicide**

by John B. Kelly, New England Regional Director, Not Dead Yet

Like much of society, disabled people fear dying in pain and suffering, and fear a medical system that may abandon us. Some disabled people want to know whether there is a safe way to word a law to allow for assisted suicide when suffering becomes unbearable. Let’s take a look:

First thing to do is get rid of our images of people being connected to tubes and machines against their will, dying in pain. It doesn’t happen anymore. We all have the right to refuse ANY medical treatment we don’t want. We, or the people acting on our behalf, can say no to everything. We get to stay in control.

Second, there IS a problem with how people have been dying, and it is the lack of palliative care. Palliative or “comfort” care has improved dramatically over the last generation. The problem is that it is not as available as it should be.

There is a great palliative care doctor in Vermont, Ira Byock. In his testimony last year before the Vermont legislature <http://www.dyingwell.org/download2012/Byock%20-VT%20Senate%20testimony-S%20077%20-01-31-13.pdf> , he said:

One thing on which good people on both sides of this issue agree is that far too

many people suffer needlessly as they approach the end of life. If I thought lethal prescriptions were necessary to alleviate suffering I would support them.

In 34 years of practice, I have never abandoned a patient to die in uncontrolled pain and have never needed to hasten a patient’s death. Alleviating suffering is different from eliminating the sufferer.Allowing a person to die gently is importantly different from actively ending the person’s life.

Palliative care works. Our priority must be to make palliative care available to everyone, so that no one experiences pain or discomfort as they die. For example, there are specific medications for treating common symptoms like shortness of breath and anxiety. In the most difficult cases, carefully managed sedation enables people both to say goodbye and be comfortable. For example, good palliative care would prevent any feeling of suffocating.

Last year, our disability group Second Thoughts worked with the Massachusetts Hospice & Palliative Care Federation to pass a bill that will make palliative care more available, while specifying that it not include assisted suicide.

Suicide becomes an answer when it feels like there are no other options. I think of the example of Larry McAfee, a quadriplegic who was denied the right to live in his own state by Georgia. He was shipped from out-of-state nursing home to out-of-state nursing home until he saw suicide as the only way out.

A court agreed with him based on its prejudice about his quality of life. But when Georgia ADAPT members Eleanor Smith and Mark Johnson got him out of those nursing homes, and into his own place, he changed his mind. So just as independent living, not suicide, is the solution to being stuck in a nursing home, palliative care is the solution to our fears of suffering. Just as independent living respects our basic humanity, and allows us maximum autonomy, so does palliative care both respect our physical comfort and our wishes regarding treatment.

Medically speaking, an assisted suicide program is impossible because there just is no way to accurately forecast when someone will die. One out of every six people who go into hospice will be kicked out because they are alive at the end of the six month period. Ted Kennedy was given 2-4 months to live, but went on to live 15 months. In the disability community, many of us have been at one point considered “terminal,” and are happy to be alive years later.

Assisted suicide also has a negative impact on society. It puts at risk people who are in a period of depression, who may not be able to make a rational decision. That’s what being depressed means! That’s one reason that people from the “lived experience” community, who have dealt with mental health issues, oppose these bills. Here’s what Ruthie Poole of MPOWER said last year,

"I thought I supported Question 2 [assisted suicide bill] ---I saw it as an issue of self-determination: something that we folks with mental health conditions feel passionately about. However, after hearing from other people with disabilities opposed to Question 2, I realize now it is much more complicated than I thought. I hadn't thought about elders & people with disabilities who are coerced, either subtly or more obviously, by their families; who may be feel like they are a burden to loved ones. I was shocked that in Oregon in 2010 & 2011 only a few of those who got help from physcians to commit suicide were first evaluated for depression. As someone who has suffered from major depression in the past, I can relate to the desire for "an easy way out". Depression is treatable and reversible. Suicide is not. I now join other people with disabilities in Second Thoughts and strongly oppose Question 2."

It also puts at risk people experiencing abuse – there is no witness required at the death, and one of the witnesses to the drug request can be an heir. In order to put in safeguards that would truly protect people, the system would have to be so burdensome that people wouldn’t support it. And no matter what, doctors who think that life with a disability isn’t worth living will still be making decisions about people’s lives.

And where assisted suicide is legal, it turns out that it isn’t pain or physical suffering that motivates people, but the disabling aspects of their conditions. Doctors report people losing their dignity because they became dependent on others for their care. Independent living teaches us that depending on someone else for personal care has no impact on our dignity and ability to lead a fulfilling life. Doctors report people wanting to die when they are incontinent – this is an issue for a lot of us. People want to die when they feel like a burden, but we know that no one should feel like a burden, that everyone has the right to quality home care.

This kind of thinking leads to people making unfortunate choices, such as the Indiana hunter Tim Bowers, who less than 24 hours after breaking his neck, was told that he would be paralyzed and have no quality of life and never get to hold his baby. We know that he was cheated of personal fulfillment, and his family was cheated of his loving presence. I’m sure glad that no one gave me this “choice”.

I want all of us to live well all the way until our deaths, comfortable and taken care of by a medical system that respects us. We can make that happen!