A personal message to the citizens of Massachusetts:

My journey from death to life

By Alison Davis

I’ve been involved in campaigns against the legalization of euthanasia and assisted suicide in the UK for more than 25 years. My personal journey from death to life may help shed light on a Massachusetts 2012 ballot initiative that would legalize doctor-assisted suicide.

I am disabled, and people in Western countries seem to find it difficult to understand the realities of living with a disability. Some seem to believe that of course I want to die, while others have an artificially rosy view of disability. Both of these are simplistic, and fail to come to grips with the realities and complexities of living with a disability.

What I want to share with you is why I changed my mind from wanting to die to wanting to live. However, in order to do this, I need to first explain more about my condition, its effects, and the effects of other people in shaping both my life and my views.

I was born with spina bifida and hydrocephalus. I use a wheelchair full-time and a respirator at night. I have suffered a lot of pain throughout my life, and now need increasing doses of morphine to control the pain of trapped nerves caused by my collapsing spine, but even that doesn’t always alleviate the pain. When the pain is at its worst, I can’t move or think or speak.

A few years ago I experienced alarming and very frightening mental symptoms also, which turned out to be due to excessive doses of morphine. I was given a stark choice—take the extra morphine and live with the mental symptoms, or take less morphine, and accept more physical pain. I chose to prefer physical to mental pain. However, it is certainly a tough road to cope with unending and severe physical pain, which I am told will inevitably get worse.

Between 1985 and 1995, due to a combination of tough physical and emotional circumstances, I lived through the most difficult period of my life.

In 1985 when I was at my lowest ebb ever, I made the decision that I no longer wanted to live. At that time, doctors believed that my life expectancy was very short. Over time, my desire to die became a settled wish that lasted about ten years. During the first five of those years, I attempted suicide several times.

My first “cries for help” included cutting my wrists to make them bleed, but not to threaten my life. This, of course, caused yet more physical pain, but seemed in some strange way to alleviate the unbearable mental pain that was with me night and day, maybe because it was a pain I could control. My friends went through the house removing sharp objects with which I might possibly hurt myself, and I can clearly remember, through the mental haze, eating scant meals with a spoon because all the knives had been removed.

Despite this, I continued to find ways to hurt myself, and made several very serious suicide attempts. I tried various methods: large overdoses of drugs and badly slashing my wrists with an old rusty penknife that had escaped the general removal of sharp objects. I was determined to succeed then—especially on one occasion.

I had taken a large overdose of painkillers and cut my wrists badly. I then drank a whole bottle of Martini, lay down in bed, cuddled my favorite teddy bear, and waited to die.

Fortunately for me (at the time I thought most unfortunately) my friend Sue arrived shortly afterwards. She was able to let herself into my house, found I was losing consciousness and called the emergency services.

I was taken to the hospital and treated against my will—the doctors just waited until I lost consciousness and then treated me. If euthanasia/assisted suicide had been legal here then, I would certainly have requested it with no hesitation at all, and I would have satisfied all the supposedly “strict criteria” which apply in countries where euthanasia and assisted suicide are legal. If it had meant travelling to the “Dignitas” assisted-suicide facility in Switzerland, I know I would have done that.

If writing a Living Will (called an Advance Decision in the UK) had facilitated my death it would have been an easy thing to write one. I would have had no difficulty in finding a doctor to verify that I was of sound mind, that I really did want to die. If euthanasia/assisted suicide had been legal here it would have been an easy thing to write one. I would have had no difficulty in finding a doctor to verify that I was of sound mind, that I really did want to die.

In retrospect I think my overwhelming wish to die was probably due to a combination of feeling that I simply couldn’t bear my life as it was and could see no hope for the future. My mind was still in turmoil from all the problems and difficulties, and nothing seemed to make me “feel better.” I would go to bed every night and hope that I wouldn’t wake up in the morning.

My greatest piece of good fortune was that I had friends who did not
share my view that my life had no value. It took them—particularly Colin, now my caregiver and also my closest friend who has shared both my house and my life for the last 23 years—a very long time to help me decide to "give life another try."

Those efforts and a trip to India in 1995, during which I visited a small project for disabled children, helped to turn my life around. Seeing these children, I felt motivated to do something for them, so Colin and I subsequently set up a charity for them. The night after leaving the project I said to Colin, "Do you know, I think I want to live." It was the first time I had thought that in over ten years.

I now realise that, had euthanasia or assisted suicide been legal when I was so desperate, I would have missed what have turned out to be the best years of my life—never knowing that the future held such good times and that the doctors were wrong in thinking I didn’t have long to live. This is one of the major problems with allowing suffering people the "choice" of an assisted death. It assumes that life could never get any better, and that doctors’ prognoses are always right. My life did get better, even in spite of continuing and worsening severe pain and suffering, and the doctors were totally wrong in thinking my remaining life would be short.

Over the years, I have taken part in many interviews on TV and radio. I have forgotten all but one of them. That one was on a radio station called Radio Northampton, and I remember it for two reasons. First of all, the interviewer was very rude and offensive, and was unwilling to listen to me. Secondly, I was extremely tired and didn’t communicate well what I wanted to say.

After the interview I felt very "down" and thought that all the effort had been in vain. Shortly afterwards, however, the program’s producer phoned me to apologize for what she called the "unacceptable behaviour" of her interviewer. I was slightly placated.

Then less than twenty minutes later she phoned me again. This time she said that she had just had a call from a young man who said his name was John. He had that very day decided to take his own life, but after hearing what I had to say, he changed his mind.

This was certainly not due to any merit on my part, as I knew I had not stated my position well. But somehow this desperate young man had heard a message of hope, despite my verbal stumblings. What he heard helped him decide to give life another chance. This experience has reoccurred several times since then, though rarely so dramatically.

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Often all that desperate people, disabled or not, need is to be given hope. What they definitely don’t need is to be told they are right to feel suicidal and that they would be better off dead. This is simply the equivalent of seeing a person about to jump off a high bridge and giving them a push.

There seems to be a difference—one that I don’t understand—between the treatment of non-disabled, suicidal people, and those who are disabled. Non-disabled, suicidal individuals are assumed to be "wrong to want death" and get the benefit of government and privately funded “Suicide Prevention Programs” that go to great lengths to help these people want to live. There is even an annual “World Suicide Prevention Day,” but it makes no mention of helping ill and disabled people to avoid suicide.

On the contrary, suicidal, disabled people are all too often assumed to be “right to want death” and are given all possible help to achieve their goal. The dichotomy seems to be based on an assumption that a disabled life is necessarily useless, burdensome (to the disabled person, their families, and/or society) and not worth living.

Some years ago I read a booklet by a young British medical doctor, James Casson, who was dying of cancer. He titled his book “Dying: The Greatest Adventure of my Life.” I think there is also a place for a book entitled “Living: The Greatest Adventure There Is.” My life has been full of pain and suffering, true. But it has also been one long adventure, with great highs and great lows. I think my eventual death will also be an adventure—but, for now, I’m content to wait for that particular adventure to come naturally, in its own time.

Notes:
1 It is not unusual for doctors’ predictions about life expectancy to be wrong. Baroness Ilora Finlay, a hospice doctor, cites one case of a cancer patient who, after being given a terminal prognosis, asked for euthanasia, yet lived for 18 more years. See “Assisted Suicide is fine in a perfect world. We don’t live (or die) in one,” The Times, April 1, 2009.

Alison Davis lives in the UK and is the national coordinator of No Less Human, an organization that promotes greater understanding of the needs of disabled people and strives to educate the public about the threats to disabled individuals’ lives. She also lectures and writes on bioethical issues and has travelled worldwide in spite of her chronic, severe pain.