# **Lessons From Dying: The Roadblocks In Helping Loved Ones Pass On Painlessly**

By Larry Berk and Delaney La Rosa, R.N. | Nov 3, 2009



The Healthcare Consumer

### Helpful things I learned recently about dying

#### Part 3 on Larry's mother passing away

Last week I talked about the role that hospice played in the last months of my mother's life.

If you spent even 30 minutes with her, the first words you would use to describe her would be "in charge." She was in charge of her life. So it wasn't a surprise to my sister, brother or me that she would want to be in charge of her death as well.

This week, we're venturing into territory that many of you may find uncomfortable: the topic of a dying family member considering options to end her life on her own terms.

Some who read this may find the concept of the choice to die objectionable. To those readers, we ask that you step back and consider what your feelings might be if a loved one faced a similar situation: having one of the most painful cancers a person might experience. A brief web search (my mother found this on her own) will drive the reader to discussions and papers regarding the difficulty of controlling pain in the final stages of pancreatic cancer. My mother knew what she was up against, and we put aside our judgments to support her quest for a humane end.

Personally, a lesson I've learned over the past six months is that death IS a part of life and that a terminally ill patient deserves to know the options they have regarding pain and eventual death. It was an odd feeling that at the exact same time my siblings and I were struggling to get answers to our terminally ill mother's questions about dying on her own terms, our national healthcare debate exploded with highly polarized views of end-of-life discussions.

I was incensed by the politicians who claimed doctors being paid for taking time with their dying patients to explain end-of life options were somehow wrong, that these would amount to "death panels."

I reflected on my family's current circumstances, the sometimes reluctance of my mother's physicians to discuss dying, and the difficulty we faced in collecting information about end-of-life choices.

Personally, I want my healthcare insurer to give doctors payment for the kind of conversation we desperately needed.

Getting back to my mother; if you spent even 30 minutes with her, you would likely describe her as "in charge."

She certainly was in charge of her life, so it was no surprise to my sister, brother or me that she would want to be in charge of her death. Initially, my mom wanted the option of hastening her own death to avoid unnecessary treatment and needless pain.

Unfortunately, that can be an almost impossible-to-satisfy request.

First, we knew there was a high likelihood that my mother's pain would reach a point that was difficult to control (this is a well-documented phenomenon in a very few cancers).

Second, the laws in place today prevent healthcare providers from assisting patients to end their lives under any circumstances.

My mother, a very pragmatic person, continually asked her caregivers for information about ending her life.

She simply didn't understand that she couldn't request a healthcare provider to assist or inform her regarding her death.

In her desperation to have a choice, my mother asked my wife and co-author of this column (an R.N.) to provide the information and support to end her life.

After a tearful conversation between the two, my mother came to understand that moral, ethical and legal restrictions prevented her from giving my mother what she wanted most.

My wife knew what my mother was facing, she had cared for others dying of pancreatic cancer, yet she was powerless to do anything but provide emotional support and comfort. This was a wrenching situation for both my mom and wife to face.

In her desperation, and without the benefit of guidance, mom came up with the idea of intentionally overdosing using an over-the-counter pain medication.

Again, my wife ultimately was left to describe the likely outcome of this attempt: My mother would likely live confined to the hospital for some or all of her remaining time facing the possibility of additional pain or organ failure caused by the drugs.

What she wanted more than anything and as we uncovered in our research is that she wanted to have a medication at hand that, should she decide to take it, would bring a peaceful end to her life.

Note that I said that she only wanted to have the medication "at hand."

We have no idea whether she would actually have taken it, but we knew that it would have been of great comfort to her if she had the option.

With only a few exceptions, it's unlawful for a doctor to write such a prescription.

Doctor-assisted suicide has been legal in <u>Oregon</u> since 1997 and in Washington state since 2008 when aptly-named Death with Dignity acts were passed.

In short, the acts allow terminally ill adults to obtain lethal prescriptions if they are deemed competent.

But the legal details are complicated.

You must usually be a resident of one of those two states and you must have an ongoing relationship with a physician there.

More recently, Montana courts have <u>ruled</u> that a terminally ill patient who finds his/her suffering to be unbearable has the right to receive self-administered medication to hasten death and that doctors cannot be prosecuted for providing that medication.

Their requirements are similar to those of Oregon's and Washington's.

Interestingly, in those states, although physicians have written many, many prescriptions, the actual number of instances where the patient has made the decision to take the medication is small. Clearly people who are near the end of their life want options.

We then discovered <u>Compassion and Choices</u>, a wonderful organization that provides consultation to people who are facing an imminent end to their lives.

They listen without judgment, answer questions and guide in the search for a peaceful, humane death.

I spoke to a counselor who agreed to talk with my mother. Something I really appreciate about Compassion and Choices is that they take over the painful and difficult discussions with your family member.

Finally, my mother had a source for information and some hope of controlling the circumstances of her death. They spoke on many occasions throughout the final two months of my mother's life, and our family was free to go about making her final days as peaceful and fulfilling as possible.

Ultimately, my mom's choice was simply to stop eating. It wasn't a hard decision for her. Food didn't appeal to her. She remained in hospice and lost weight steadily, but remaining lucid until almost the very end. We believe she didn't suffer, and we know she left this earth on her own terms.

As a footnote, it is generally unlawful in most states for a physician to provide aid in the form of writing a prescription for a lethal dose of medication in dying to a terminally ill, mentally competent adult.

But there are bills pending in 10 states around the nation to change this.

In Connecticut, Drs. Gary Blick and Ron Levine are asking a <u>Connecticut court</u> to rule that a physician who aids a terminally ill, mentally competent adult in their dying not be regarded as assisting a suicide.

We hope you'll share your opinion on this emotionally charged topic. Ours is that people who are capable of making choices should be offered the ability to make them and the knowledge to understand them.



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## 2 Responses for "Lessons From Dying: The Roadblocks In Helping Loved Ones Pass On Painlessly"

1. *CarolK* says: November 10, 2009 at 9:18 am

Larry Berk and Delaney La Rosa, R.N., I'd like to thank you both for sharing your experiences with this very difficult topic. I need to think about some of your questions but wanted you to know there are people out here listening, reading, learning and gaining from your candid posts.

Though Connecticut does not allow assisted death, I wonder if doctors and nurses are using medication to ease a terminal patient to his/her death. What are your thoughts on this?

