

TIMING THE INEVITABLE

October 14, 2012

Waaayyy back in 1977 I discovered the First Unitarian Universalist Church in Jackson, Mississippi. It was a church of about this size, with a half time minister. We had both minister-led services, and lay-led services. Within the first two months of attending this church we had a lay-led service that featured Ms. Louisa Webster, (pseudonym) a woman of about 75 who was politically active—a left-leaning firebrand in that conservative city and state. Her presentation was so interesting and challenging that I remember it clearly 35 years later. It began something like this:

Sometime soon, maybe next week, I'm going to get in my car, drop my cat off at my daughter's and drive to the University of Mississippi Medical Center. I'm going to walk in, approach the desk, and say, "Here I am!" They may be puzzled, so I will explain: "I willed my body to you. I've used it as much as I wish to and I'm getting pretty tired, so I've decided to give it to you now. Where do you want me?"

While Ms. Webster was clearly older, she was spry and active. She had no visible handicaps, and did not claim any fatal illnesses. At the time I heard her message, I so admired her technique to command interest and attention, I thought I would HAVE to use it sometime. Clearly however, it would only work for older people. I think I'm old enough now.

She went on to make a very cogent argument about the advantages of physician-assisted suicide. I do not remember all her points, and society has changed in many ways since 1977, however, I think it is valuable to re-visit the topic.

A few years ago, the ministerial study group to which I belong, the Ohio River Group, spent a year studying and most of a week presenting papers and discussing *Death with Dignity*. We read several sources, but a primary one was Dr. Timothy E. Quill's book, *Death with Dignity: Making Choices and Taking Charge*. Maybe some of you have read it? When I scheduled this sermon I revisited his work again. He shares the story of Diane, the patient that forced him to revisit his understanding of best practices for dying patients, and published a paper that told her story in the prestigious New England Journal of Medicine.

Diane was a long-term patient of Dr. Quill's. She suffered vaginal cancer as a young woman, from which she recovered. She struggled with alcoholism for many years, as had her mother. For the last 3 ½ years she had been sober and healthy, and had rebuilt good relationships with her husband and college-age son. Then, during a check-up, her blood showed signs of leukemia. Further tests confirmed the diagnosis.

At that time the best she could hope for was a 25% chance of a cure following extensive chemotherapy, bone-marrow transplantation and whole body irradiation. Diane wanted none of that.

Dr. Quill wanted to be sure that Diane understood the almost certainty that she would die from leukemia if she did not follow the protocol. Following discussion with her family, she still refused treatment. Although her husband and son were sad, they planned to support her in her decision. Diane did not want to die in the hospital during a painful procedure—which was just what happened to previous patients.

Dr. Quill said, “She articulated very clearly that it was she who would be experiencing all the side effects of treatment and that odds of 25 percent were not good enough for her to undergo so toxic a course of therapy, given her expectations of chemotherapy and hospitalization and the absence of a closely matched bone marrow donor. I had her repeat her understanding of the treatment, the odds, and what to expect if there were no treatment. I clarified a few misunderstandings, but she had a remarkable grasp of the options and implications.” (Quill, *Death with Dignity*, p. 11, 12)

After a second opinion, psychological consultation, and much discussion with Diane and her family, Dr. Quill arranged for home hospice care and planned to keep her as comfortable as was possible. And then she challenged him further.

Diane wanted control over her death. She wanted to time the inevitable. She wanted to end her pain and suffering on her own timetable.

Dr. Quill had been a director of a hospice program, and was an enthusiastic advocate of comfort care. This was not sufficient for Diane. He finally told her about the Hemlock Society.

Dr. Quill says, “It was extraordinarily important to Diane to maintain control of herself and her own dignity during the time remaining to her. When this was no longer possible, she clearly wanted to die.” (*Ibid.* p. 12)

A week later she called asking for a prescription for barbiturates for sleep. Since this was part of the cocktail the Hemlock Society recommends, he asked her to come to the office for further discussion. He gave her the prescription and told her how to use them for sleep, and what would happen should she overdose. Dr. Quill says Diane was not despondent, and was instead experiencing love and support from her friends and family. Her relationships were healthy.

Diane lived for several more months. After she received the means to end her life, she ceased worrying about losing control. Her son stayed home from college to be with her. Her husband worked from home, so that he could assist in her care.

She reconnected with several friends, and spent quality time with the closest ones. However, the leukemia eventually became much more severe, and Diane knew her time was limited. She asked her closest friends to come over and say good-bye, and notified Dr. Quill that she would be leaving soon. He went to see her, and says:

“When we met, it was clear that she knew what she was doing, that she was sad and frightened to be leaving, but that she would be even more terrified to stay and suffer. In our tearful good-bye, she promised a reunion in the future at her favorite spot on the edge of Lake Geneva, with dragons swimming in the sunset.” (Ibid, p. 15)

Two days later, she asked her husband and son to leave her for an hour. When they returned she was lying on the couch, covered with her favorite shawl, and no longer suffering.

This story is taken from the article Dr. Quill sent to the New England Journal of Medicine, which was published. Although physician-assisted suicide was illegal in New York, and the United State Supreme Court upheld the constitutionality of states to pass such laws, Dr. Quill was never charged with a crime. He was, however, subject to persecution and harassment. He is now a specialist in palliative care at the University of Rochester Medical Center in Rochester, New York. The case marked a milestone in the national conversation around physician-assisted suicide.

Since the death of Diane and Dr. Quill’s publication of her story in the early 1990’s, our culture around physician-assisted suicide has continued to evolve. Our Unitarian Universalist Association is part of that history.

In 1988 we passed the first of several resolutions that called for developing policies and procedures that would ensure death with dignity. Unitarian Universalists were active in Oregon advocating for laws allowing physician-assisted suicide. Such a law was passed in 1994, with several conditions attached, for example, one must have a fatal illness and be within six months of death—as attested by two physicians. In 1998, Compassion in Dying was formed in Portland, with the Rev. Ralph Mero as its executive director.

Rev. Mero later served our faith as the Director of the office of ministerial finances. In a conversation, Rev. Mero shared that often patients were concerned about pain and suffering, but after receiving the materials and instructions on how to use them to end their life, they did not use them. It was the assurance that they could control their exit that was important to them. If that assurance was present, they could relax into the process.

The availability of hospice care is far more prevalent than it was 20 or even 10 years ago. I have a good friend who is the chaplain at a hospice facility. She does excellent

work with a wide variety of patients. She makes sure that the spiritual resources in her facility are diverse.

She helps select paintings that are lovely and soothing. The facility is located on land that includes a garden into which the patients can be taken in a wheelchair. It has a small pond, and woods in the background. I have known people who spent their last days there. She says the biggest problem is that people don't call on their resources and skills soon enough.

Palliative care, or comfort care has become more accepted. No longer are doctors likely to deny opiates or other pain-killers to patients with fatal diagnoses. Caring for dying patients is now a specialty with its own protocols. Dying has become—if not attractive, at least less fearful, as long as one has access to specialists and a good hospice.

And yet, and yet.....

There is another connection between our Unitarian Universalist history and the development of death with dignity policies. And it involves our own Michigan Dr. Death. The first, or at least the first public case in which Dr. Jack Kevorkian was involved was a much loved member of the Ann Arbor Unitarian Universalist Congregation. The Rev. Ken Phifer, minister at the time, share the story of the woman who sought help from Dr. Kevorkian.

The woman, who I will call Ann, was suffering from Alzheimer's disease. She was well educated and valued playing her piano. She lived with her diagnosis, growing more anxious as she forgot names and nouns and became more disoriented. She decided that when she could no longer play the piano, she would seek assistance in hastening her death. She discussed her concerns with her family, and her pastor, who promised to walk with her on whatever path she chose.

I do not know how Ann knew about and contacted Dr. Kevorkian, but she did so. Rev. Phifer tells us that "Jack was a very gentle man. What he did, he did because he genuinely cared about each person who sought his help." Rev. Phifer told us that he remained with his congregant, Ann, until she began the process of dying, but left then because he did not want to risk the effect on the church if he were arrested.

While I believe Rev. Phifer's assessment of Dr. Kevorkian, I also think that Kevorkian's "in your face" attitude set back progress on this issue by several years. Whatever you may think about him, however, there is no doubt that the issue of Death with Dignity was discussed with great interest for several years.

And I think it illustrates the Achilles heel of the hospice/palliative care movement. It is now true that physical pain can be and is controlled for most of the dying process.

Death with Little Pain is now possible and frequent. However, I'm doubtful that dignity can always be achieved.

Ann was very anxious because the effects of Alzheimer's robbed her of her personality and her ability to interact with both people and her beloved piano. As the 75 year old woman channeling Ms. Webster from Mississippi, I empathize with her.

I come from a family with a history of long life. My paternal grandmother who died at 102 suffered from Alzheimer's the last decade and half of her life. She no longer recognized us when we visited and sat slumped in her wheelchair for the extent of our visit. I do not want to repeat that history. I think I am probably not the only person who feels that way.

Although I feel confident my children would ensure that I had good care, I do not want to burden them with that—and truthfully I don't care how good the care is or if we had as much money as the Republican nominee for president, I do not want to repeat that history. I plead guilty to pride.

Thus, I think we have more evolving to do in this field. I think we need to have, with careful controls, physician assisted suicide available, and not only to patients who are near death. I think that when the personality is dying, the person should have the option to ensure that the body follows. I think we should have a choice, in this, as well as other medical decisions.

Dr. Quill has a challenge to patients, that is, all of us.

It is a four point challenge, and I have been addressing the first point today. He tells us to develop a philosophy of death. He recommends sharing stories about the deaths in your family history. I have shared several with you this morning, so you have begun the journey. I encourage you to think of your own grand mothers and grandfathers, your parents, aunts and uncles. What do they yet have to teach you?

The second point is to fill out and sign an advance directive. How many of you have done so? Let me recommend that, if you have not, you do it as soon as possible. Those of you who are really too young to be thinking about dying, are especially in need of this document.

Then, make sure that you discuss it with your primary doctor, and any specialists you encounter, especially surgeons. Make sure that your family knows about it, and where to find it if necessary.

Dr. Quill's last piece of advice is to become politically active. That's what we need, right? Another cause for which we can work. Well, we can add it to the list....

As a faith community we can endorse programs that work toward humane care of our loved ones, and all people. We can work toward a society in which all people have choices. We do not condemn those who choose to have all available means used to prolong life; nor do we condemn those who choose an early end of life.

Choice: let us endorse it for the end of life as well as its beginning. Let us support those who wish to control the timing of the inevitable.

Shalom and Saalam.

Blessed Be and Amen.