

# «End-of-Life issues»

(Reflections on the meaning of Terri Schiavo)

**Sermon by Rev. Charlie Kast, October 10, 2005**

**Read by Rev. Patty Hanneman, October 25, 2009**

**The Unitarian Universalist Congregation of Hillsborough, NC**

Adam Copnik, writing in *The New Yorker*, told the saga of his children's betta fish. The kids wanted a dog or at least a hamster, but since they lived in a New York City apartment, the parents thought it best to start them out, Olivia age 5, Luke age 10, with fish.

Olivia bonded with her fish, *Bluie*, loved him, and confided in him, ascribing to him all sorts of human-centric capabilities.

One evening Adam noticed that *Bluie* had gotten himself stuck in one of the windows of the submerged plastic castle that adorned his fish bowl. He became alarmed - what if *Bluie* stayed stuck and died?

Luke began asking questions: "does *Bluie* know he is *Bluie*? what does he think? does he know he is swimming around? or is he just like a potato or something, only with fins, who swims and doesn't think anything? what does it feel like to be a fish?"

"Is he thinking, 'I am dying'?" Luke asked.

The fish died at five in the morning, and Adam removed him from the bowl, castle and all, and put him in a plastic bag. He was perplexed – what to do next? Like any good liberal religious person, he sat down and started to read about the question of consciousness.

He read Dvid Chalmers: consciousness is the "ghost in the machine," the irreducible presence in the mind that distinguishes humans from computers and betta fish.

He read other philosophers who think that consciousness is just an illusion.

He read Daniel Dennett's thesis: consciousness is a by-product, the sound all those processors inside our heads make as they run alongside one another. There is no 'consciousness' apart from the workings of all our mental states. It is the hum of the machinery.

"*Bluie* did not know he was *Bluie* because there was not enough *Bluie* going on in his head to make *Bluie* interesting even to *Bluie*."

At the crack of dawn, Adam, joined by ten year old Luke, carried *Bluie*, in his castle, in his white bag, down the hall to the trash room. They held their caps over their hearts as he went down the chute.

Adam's wife, Martha, came up with the solution to what they should say to five-year old Olivia - nothing: they would go to the pet store, buy another betta fish which looks just like *Bluie* (every betta fish looks just like *Bluie*) put him in the bowl, and let Olivia think it is *Bluie*.

"Does new *Bluie* know that he is not *Bluie*?" asked Luke the child philosopher.

Enter Olivia, taking one long look, then stating, "I hate this fish, I hate him, I want *Bluie*! he is a stranger, he doesn't know me, he is not my friend I talked to".

Adam concluded: "the real proof of consciousness is the pain of loss. *Bluie* himself may in some sense not have known that he had gone. But Olivia did. The pain we feel is not the same as the hum we know, and it is the pain, not the hum, that is the price of being conscious, and the point of being human.

Considering what to say and do the next morning when Olivia arose from her sleep, Adam and Martha pondered the wisdom of the world's religions, thinking they may find something there to console Olivia. Adam reported, "we made up a risen-from-the dead Christian story, the passion of *Bluie*. We considered a Buddhist story: *Bluie* couldn't be kept alive by the doctors, but what a lovely bowl he left for his family."

Olivia came to the table the next morning, sat down calmly and announced to the family: "I am going to call the new fish *Lucky*. Can I please have some ^honey nut cheerios?"

Adam concluded: "having made a grand and instructive emotional tour, Olivia had ended up right where she started. We begin with the problem in the mind, pass through the experience of pain – and end up loving the same old fish. First the mind, then the pain, and then the echo: that is the order of life."

I bet almost every parent here has gone through a similar experience with their child, trying to explain consciousness and death; when does life begin? How does it end? In fact, studies have shown that trying to answer such questions has driven many a parent who left a church back to church seeking answers.

The thing is it does not stop when the kids grow up; these questions remain to be answered as adults too and these are the kind of questions for which you need to come up with your own answers; most often someone else's answers do not help you. Many of you here today have had to make difficult decisions regarding people you love – many have companioned a loved one through their final days; many have had to make a decision on whether or not to remove life supports. Such is of ultimate concern and such is most intimate experience to be in.

These questions relate to our humanity. What does it mean to be human? What kind of activities, experiences and capacities define our humanness? How developed do these have to be before they are protected by law? Does a fertilized in a Petri dish have legal rights? How about an 8-month old fetus? How about a newborn baby? When do human rights emerge? How diminished can our

defining human characteristics become until the life sustaining them is no longer protected by law? If we have a right to life, liberty and the pursuit of happiness, what happens when nature robs us of liberty and happiness? Are we required to protect life in the absence of liberty and the potential of happiness?

Karl Giberson wrote: “To be trapped alive after one’s humanity has departed is surely a most cruel and unusual punishment. When we have lost the capacity to express love to those around us, to converse with other minds, to dream uniquely human dreams, to laugh and dance in the world of our imaginations, then we have lost our humanity.”

These are precisely the questions and considerations so strongly posited in the legal battle which surrounded Terri Schiavo’s final time on earth.

Theresa Marie Schindler Schiavo was born on December 3, 1963. As a teenager she was obese, but she lost one hundred pounds and by the time she married (age 21), she was described as an attractive, vivacious young woman. On February 25, 1990, she suffered cardiac arrest leading to severe brain damage. The cause was a drastically reduced level of potassium in her bloodstream, a condition frequently associated with bulimia.

Her death was forestalled by heroic measures, but when, after a few weeks, she emerged from coma, it was only to enter what doctors call a “persistent vegetative state,” with no hope for improvement. The principal internal organs of Terri’s body continued to function as long as liquid nourishment was provided through a tube threaded into her stomach.

The exception was her cerebral cortex, which is the seat of language, of the processing of sense impressions, of thought, of awareness of one’s surroundings and one’s inner state – in other words her consciousness. The body lived, the mind died. Terri Schiavo’s life, as distinct from her insentient organs, ended fifteen years ago.

You know the rest of the story - the story of a highly publicized and bitter court fight between her husband Michael who wanted life support removed in accordance, he said, with her prior expressed wishes to him, and her parents and siblings who wanted to keep her body alive at all costs.

The debate between those who championed her “right to die” and those who fought for “right to life” turned rancid. In fact Terri Schiavo, the person, had no further use for a right to die, because Terri had long since died – as a person – fifteen years before.

One of the ironies of the Terri Schiavo case highlighted some of our own worst fears: the loss of autonomy, the burden of care put on family members, a painful private decision, played out before the press and in public.

In the vast majority of such cases, such questions are resolved quietly, as the family weighs the medical diagnosis, the wishes of the patient, and their own ethical and moral sense of what is ordinary and extraordinary.

I urge you as strongly as I can, please, if you do not already have a written health care power of attorney, a written desire for natural death (living will), take care of that today at the latest. Then be certain those you love and may need to make decisions for you in the future have copies. Give your doctor a copy.

There are some wider, national considerations also raised by this case:

There are 44 million people in our country, uninsured, most because they cannot afford it, and we have no national health care system for insurance.

Over half of all personal bankruptcies in our country result from excessive medical costs of unexpected medical emergencies.

Some of the same people in congress who fought to keep Terri on life supports at tremendous cost were the same people working to cut federal funding for medical treatment.

She was cared for in hospice; we may want to consider what we can do to better support and fund hospices which play such a critical role.

In Terri's case, a compassionate federal government funded her care through government programs... the same programs that are now at risk of being cut by congress.

The bottom line of all this is the simple human drama, a tragedy for Terri and Michael especially, and for those closest to them.

I want to share with you another simple human drama. Also involving end-of-life decisions, but with a different outcome. At the age of fourteen, Nicholas Breach learned he had a fatal disease. He told his parents that he wanted to be an organ donor. They respected his decision and so did the doctors caring for him.

His social worker at the hospital said that his decision reflected a "maturity and sensitivity and a wish to help others" – something the boy had shown previously and often during his eight year battle with the disease to that point. She said: "I have never been to a meeting like that one before in my life. The peace that came over Nick and his family was remarkable, and once it was out that this was the end, and the decision was made about organ donation, Nick said he was happy."

His decision was redemptive. In a way it gave some good measure of meaning to his life.

What have I learned from Terri and Nick? Human life is precious. We are in charge of what we do with this one precious life we get. How we spend our life is our religion, and we get to decide many important beginning-of-life, life, and end-of-life moral and ethical issues in our lives. It is important that we express them in writing.

Today is the mid-point in the Jewish high holidays, the days of awe which culminates on Yom Kippur. During this time we are to make a fearless inventory of our lives, to confess our wrong doings and ask forgiveness of those we have wronged and seek to make restitution. This is also the fifth day of Ramadan, the Muslim month of fasting during which one is to focus on the higher things in life and to engage in reflection, and to draw closer to one's spiritual health, the spirit of life, to ponder.

This would be a good time to reflect on your life – its meaning and how you are measuring up against your own ideals and expectations. It would be a good time to reflect on end-of-life issues and to make the moral and ethical decisions you want to see played out in your life.