

## *Medical Futility, Rationing, and Universal Care*

May 24, 2015

Bellingham Unitarian Fellowship ~ www.buf.org

Rev. Paul Beckel / Rev. Barbara Gilday

This Memorial Day weekend as we recall those who have lived lives of beauty, courage, and purpose, let us remember as well the fragility of life for all who remain, including ourselves. Our topic today is Medical Futility, Rationing, and Universal Care: the tension that each of us faces as we embrace, *embrace* our mortality...as we recall that life is both priceless and limited.

### **GATHERING SONG**

*For All the Saints* #103

### **CHILDREN'S FOCUS**

*Fall of Freddie the Leaf*

### **READING**

*Epitaph, by Merritt Malloy*

*When I die  
Give what's left of me away  
To children  
And old men that want to die.*

*And if you need to cry,  
Cry for your brother  
Walking the street beside you.*

*And when you need me,  
Put your arms  
Around anyone  
And give them  
What you need to give me.*

*I want to leave you something,  
Something better  
Than words  
Or sounds.  
Look for me  
In the people I've known*

*Or loved,  
  
And if you cannot give me away,  
At least let me live on in your eyes  
And not on your mind.*

*You can love me most  
By letting  
Hands touch hands,  
By letting  
Bodies touch bodies  
And by letting go  
Of children  
That need to be free.*

*Love doesn't die,  
People do.  
So, when all that's left of me  
Is love,  
Give me away.*

### **SHARING OUR GIFTS**

#### **MESSAGE**

Questions about the usefulness of end-of-life medical treatment, and decisions about what insurance companies and government should pay for...these are conversations for politicians, economists, and scientists. So why would they come up here, in a religious setting? Because they are also questions about power, and religion has always been about understanding where power resides: within us? Beyond us? Among us?

End of life questions also come up in religious settings because they are all about myth—the stories we tell ourselves to help us make our most difficult decisions.

For example, there is the myth played out so dramatically, persuasively, and continuously on television, where 70% of CPR is “successful” ...while in real life only a small fraction of these electrifying, rib-cracking procedures will enable a seriously ill patient to leave the hospital. And yet the surrounding mythology puts tremendous pressure on us, and creates a fantastic disconnect between the cost and the value of health care near the end of life.

“Life is worth any cost”—I don’t know if this notion was ever helpful in the past; it’s not helpful today. The powers we now have to save lives and prolong lives—this *astonishing power for good* can also cause terrible suffering. It diverts resources away from some who might be helped only to meaninglessly extend the life of some who cannot be helped.

As Universalists we promote justice, equity, and compassion. But it’s not easy to know how to apply these principles. When resources are limited, should we divide them up equally...or divide them up in a way that is going to do the most good? People of goodwill can disagree about the ethics. Intelligent economists and administrators can disagree about what will work. I do not see us going on much longer, however, if we continue to avoid the question.

*Because our current medical mythology promotes neither equity nor efficiency.* Instead we have great health care for some, including those in prison or in a permanent vegetative state. But even though the Affordable Care Act has expanded access to some kinds of basic care, we’re left with surreal inconsistencies.

Still we have hope. We’re allowed hope; we’re *expected* to have hope. We cling to hope even as it guides us down a path to ruin. Hoping for cures from extraordinary treatments when more good can be done, more love can be expressed, more life can be experienced when we finally say “no” to futile medical treatment and move a loved one into palliative care or hospice.

My parents are in their late 80s and accumulating diseases and traumas and risk factors that put them clearly in the late-in-life category. So these questions, these decisions will be very personal for them and for me and my siblings any day now.

I’m guessing we’ll do ok. My parents and siblings and I differ a great deal in our opinions about government and market forces. We’re at opposite ends of the absurdly titled “prolife/prochoice” debate. Our theological views are similarly polarized. But in our conversations so far about health care at the end of life, we return together—like the gruff pragmatic farm kids we are—to the beautiful and comforting myth of the circle of life.

The word futility is derived from the Greek “futilis,” which was a vessel used for religious purposes. It had a wide top and narrow bottom. It was useless except for ritual.

When my parents become hopelessly ill, there may be temptation, there may be pressure, there may be all of the momentum of the system pushing us to go through with what has become the required holy ritual of “doing everything possible.” I see families caught up in this whirlwind all the time and I don’t think I’m above it. I don’t think we’re immune. But in our moments of relative calm and lucidity, we’ve had a chance to agree that medical treatment is sometimes futile. Even if caring is never futile.

*Barbara: I’d like to share a bit of my parents’ recent journey with you. As many of you know, my father died last month. He would have been 92 in June. Near the end of February, dad asked me to come and look after mother, who has dementia. They have been living in a nursing home since last August. When I arrived, my mother was seriously compromised in body and*

*mentation. Dad was in the hospital and was so frail and, I would say, looked a little lost. He's been a survivor and dying represented failure to him—not being there for mother, not being athletic, entertaining, or sociable represented failure to him. He looked very surprised when I said at one point in the next 6 weeks—“Dad, you're doing this with such dignity and courage.”*

*When he was still in the hospital, he had a conversation about whether the frequent medical interventions that were extending his life were giving him the quality of life that made them worthwhile. The doctor had a conversation with him on the same subject, and dad finally agreed that he was “ready to go down the road”—no more transfusions—he'd had 3 in the past 3 months. He was moved to comfort care only.*

*It was easier for me, a chaplain—but difficult for my brother who had not been around end of life issues. After asking all his questions from authority figures he trusted that comfort care, including no more antibiotics was the most compassionate, natural choice. In their last two years, as our parents chose repeated medical intervention, dad died by dwindling. Mother hasn't died yet, but she has dwindled considerably. She broke her hip two years ago and after the surgery her heart necessitated intervention by the crash team. She felt herself going, but thought: It's so much harder for the men with their wives die first, so she pulled herself back. She has multiple medical problems and dementia. Neither one wanted to leave the other, so they developed so many problems that they had to move to nursing care.*

*Their quality of life deteriorated as they lost their privacy, and their control over bodily functions and their mental status deteriorated. Once they both said they were done then the focus shifted from pretending they were ok to these final precious weeks and moments: various family members came. Cousins emerged, my youngest brother and I became friends after 63 years, the slate was wiped clean between dad and me, and there were poignant last weeks he shared with mother. While mother has improved in the past month, because of her multiple health issues, there is a strong likelihood that she will die within the next year. Frankly, I would rather have it that way, than see her dwindle further, because of continuous medical intervention. I wouldn't want it for myself. She is lonely—we 3 kids are far away and all but one of her friends has gone. She has said repeatedly, “I'm done, Life is no fun any more, I'm done, As the head nurse at the facility said—there is a time to let nature take its course.*

We need to look beyond the emotional and financial concerns of our own families, however. We abide in an inescapable network of mutuality, as a society we are like a giant family squabbling over the costs and the benefits of care and treatment for those we love. It's not a pretty scene.

Consider the tragedy of newborns coming into the world without a brain. A survey of ER and neonatal physicians and ethics committee chairs in 43 children's hospitals indicated unanimous agreement that in such cases ongoing life sustaining treatment is wrong. And yet almost all of these professionals acknowledged that their hospitals would probably give in to pressure to provide treatment anyway—treatment that in some cases has kept these children “alive” for years.

This may be a worst-case scenario but it happens every day. It's estimated that with all of the variations on this theme, at any given time there are 30-40,000 Americans “living” in a permanent vegetative state. I am not worried that this increases my insurance costs or my taxes. I'm crying out, rather, for those others from whom useful treatments are being withheld because we are bankrupting ourselves with futility.

Here's a particularly bizarre case: a Mexican man running across the border was hit by a car and rushed to an American hospital. Permanently unconscious, he was fed by feeding tube for over a year until he choked to death on the regurgitated contents of his own stomach. This seems a too perfect in-your-face dilemma to pose to pro-life anti-immigration folks, but it was real. And we face similar impossible questions all the time.

Some argue that those in a permanent vegetative state should be allowed to die—should be put out of their misery. But it's a perfectly logical counterargument that these people are not suffering, for they have no capacity to suffer. And yet, I can't help but compare this to the isolation of solitary confinement given as punishment in prison...or the banishment, the exile—making someone a stranger— that was once imposed by ancient societies as the worst punishment they could think of.

And still today, of course, many Americans believe that hell, eternal isolation, is God's will for some of us. I can't help but wonder if this mythology affects our conversations about public policy and what kind of care people deserve.

I should be clear: I'm grateful to live in a world with advanced medical technology. Over the years I've seen so many people in my congregations emerge from intensive care with big smiles and autonomy and years of generosity ahead of them.

But intensive caring can be just as amazing. And up till the very end of life, there is still caring to be done.

*Barbara: I sometimes felt like the Angel of Death when I came into the ICU. The story of Joe in ICU with terminal pancreatic cancer, being sent to Seattle for tracheotomy. In my visit I asked him why? His response: I can't die now—I've hurt many people. I asked: Can you ask for their forgiveness? He said: Oh, there are too many of them. I said to Joe: Could you imagine them all being in this room now and speaking to them? To my surprise, he turned to the room and although I couldn't hear what he said because of the breathing mask, he spoke to the room for about 5 minutes. He told me he would tell me his decision later that day. Later, he told he would go home on hospice.*

In full disclosure, I am probably biased on this topic because my wife, Jane, worked for many years as a hospice nurse. So I know that it was with the advent of hospice that caregivers discovered things like giving IV fluids to someone dying—even with the best of intentions—only makes them more uncomfortable.

My views are also shaped by people I have loved while they aged with tenacious grace—like Gerda, who even after both her hearing and vision had long faded, still crawled into her backyard garden to cut rhubarb for Jane and I, and used her sense of touch to weed the flower beds—both for her own enjoyment and to beautify her neighborhood.

And finally, my views are shaped from having conducted about 40 memorial services in recent years, primarily for congregation members who had lived largely satisfying lives, and whose families were tremendously grateful for hospice care—even as they spoke loudly against gratuitous medical intervention. Fun feisty folks like Eloise, who at age 90 gave me permission to tell the story about when she was once in an ambulance, and a little delirious, and she learned later that she had kept insisting to the EMTs that she had medical orders for “Do Not Inseminate.”

It's important to be able to laugh, about these situations when we can not only because they are so often heartbreaking, but because, if we are going to talk openly about competing values, we need to risk saying things that may be misunderstood.

We need to risk saying things that may be misunderstood, because sometimes people will think we care less when we are trying to care better.

*Barbara: In an Ethics course: story of an isolated town, a very compromised infant in incubator—not expected to live and if it did—serious health issues. Second infant born with need for incubator. Good chance of recovery—law prevented first child from being taken out of incubator. My recollection is that both babies died.*

There is an application online called the lottery of life. You click on a wheel and it spins and you find out where you're going to be born, and what sort of resources you will have available throughout your life—be it long or short.

Our social systems should be designed from the premise that none of us can know how things are likely to turn out for ourselves, or for the children of our children.

Market forces and individual preferences are important, but these forces alone will not lead us to efficiency or fairness. Health care choices simply will not follow the ideal rules of the open market. On the contrary, while many markets become increasingly efficient as they fine tune what customers want, health care gets increasingly inefficient as we discover new ways to prolong life without purpose. Our current arguments then, about WHO should and HOW we should pay for health care can be a distraction from an equally important question: "WHAT should we pay for?" What would be a decent universal standard of care?

*Barbara [guided meditation]: You have heard that you have a "terminal" diagnosis and 3 months to live. Doctors tell you treatment could extend your life to one year. What considerations would help you make your decision? What would your greatest desire for that time be?*

*Your parent or a dear friend is increasingly dealing with illness, and declining quality of life. If they were willing to talk about it, what issues would you want to be part of the conversation?*

**SENDING SONG**                      *Abide with Me*    #101

**BENEDICTION**

May both reason and compassion guide us—in our quest to extend our caring and well-being—as far as this may go.