

Reading
October 16, 2011

Marty got the call at work - - her father had had a stroke, and was in the hospital. She called me, we went home and packed, got plane tickets, and left that afternoon. By the time we arrived at the hospital, Hugh had had some kind of seizure; he was in the ICU in a coma, on a feeding tube and ventilator, with virtually no brain activity or hope for recovery.

Over the next several hours, Marty's remaining brothers arrived. Fairly quickly, the family – Marty's mother and all five of the siblings – approved a Do Not Resuscitate order. But what to do about Hugh, being kept alive on machines, when who "he" was, was already gone?

The family agonized over whether to remove him from life support. Hugh had never talked about what he would want in a situation like this. Marty's mother had the decision-making authority, but she looked to her children to help decide. There was disagreement.

Over the next few days, after many discussions and prayers, everyone reached a level of comfort about a decision to "pull the plug." He entered the ICU on Wednesday; they removed him from life support on Monday. Marty's mother sat with him through the process. None of the children wanted to witness it, so I went in to provide support. They turned off the machines, and we sat with him as he died. Marty's mother read from the Bible, a peaceful and Holy moment.

Preparing for Death

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I am going to talk about a difficult subject today. I'm going to talk about death. We all know we're mortal. Most of us have had someone close to us die, for some of us it's a painfully recent event. We know it's a part of the circle of life, the way we return to the mystery from which we came, but it's hard. We don't like to think about death, certainly not our own death.

I attended a seminar several years ago, and in an exercise we were encouraged to guess the year and even the day when we would die. We were reminded that not only will we die one day, but it will be on a *particular date*. Every year we pass that date, not knowing it's the anniversary date of our own death. Death is not just a possibility, it is a certainty. One to a customer.

The final illness and death of Marty's father was hard because of the circumstance – it was sudden, he was relatively young – but it was made harder by the confusion that surrounded their need to make a decision. What would he want? Nobody knew. What were his views of life support? - - Or what one should do if the doctors say there's no hope of recovery? Nobody knew. What were the family's positions on it? Nobody had thought about it before. They were trying to feel their way through their decision in the midst of crisis and grief.

My mother's death was easier in that way. She had long talked about her desire to not be kept alive on life support. When she died, she wanted to die naturally, not hooked up to machines. Long ago, she had completed a Living Will, and designated me as her health care agent.

When she got cancer, her mind was unimpaired and she made her own decisions about her medical care. That is... until the cancer spread to her brain. They gave her steroids to reduce the swelling around the lesions, and an anti-seizure medication. An apparent overdose put her into a state where she was barely conscious. Her mental function was impaired by both the disease and the treatment. The doctors said there were so many lesions that the only thing they could offer was whole-brain radiation. Did we want the treatment? Without it, she would die in 2-3 months. With it, she might gain an additional 3 or 4 months, but she would not be able to live independently. Whether we got the treatment or not, she was looking at the rest of her life in a nursing home.

Should we pursue the treatment? She had wanted the most aggressive treatment of her cancer up to this point. Wouldn't she still want the same? Well, fortunately, we'd had plenty of conversations about those kinds of topics, not just during her cancer but for many years before she got sick. I had no doubt that she would never want "heroic measures," especially for only a short extension of life, and ESPECIALLY if she weren't able to maintain an independent life. For her, getting 3 extra months in a nursing home would not be a benefit. In fact, she wasn't going to want to be in the nursing home even for the time she did have left. My brother wasn't as sure as I, and he kept saying "But what if...". I kept bringing him back to what mom had always said about how she wanted to live. "She wouldn't want that," I would say, and he would realize that was true. She did get her 2 ½ months in a nursing home. The family spent a lot of time with her, to help her last months be as good as they could be. She died comfortably in bed, with us present. It was a good death.

But it doesn't always go so smoothly. When I was working in the hospital as a chaplain this past summer, I found that a lot of people, even terminally ill people, don't have an Advanced Directive (or a "Living Will"). These are documents, easily obtained through a google search, that can be filled out to name a health care agent and to state what your preferences are for end-of-life care. If you are terminally ill or in a permanent state of unconsciousness, with no hope of recovery, do you want to be put on life support or do you want to be allowed to die naturally without the intervention of machines to keep you alive? If you've been put on life support but your condition is one that won't improve, do you want to be taken off?

When you don't make your wishes known, it can lead to unnecessary distress and confusion for those who need to make the decisions. There can be disagreement about what to do, and feelings can be strong. Sometimes the person who gets to make your decisions by law or policy, when you haven't chosen ahead of time, isn't a person who shares your values and understanding of life.

It can be very difficult to remove someone from life support, or to approve a Do Not Resuscitate order. Sometimes we worry that removing someone from life support is killing them, although in actuality it's their condition that's killing them. Sometimes we simply don't want to let our mother or father, spouse, or – God forbid, our child – go. We want a miracle. We don't want to be left alone. We can't imagine how we can go home and go on once that final breath is taken. This is when it's helpful to know what that person would want.

If we are the one facing a terminal illness, there can be an ever greater resistance to thinking about the end of life. Maybe if we just keep our eyes shut and don't look at it, it won't come. And you know, maybe it won't, at least not right away. Doctors don't know everything, and there is a mystery in our mind-body connection... in the spirit's holding on to hope and to life, that does affect medical outcomes. But sometimes, death does come. And eventually, it comes without fail.

How do we want to live out our life when we see death approaching? How do we want to get our affairs in order? Have we told the people in our lives that we love them? Is there anyone we need to forgive, or reconcile with? Do we need to forgive ourselves for anything?

I witnessed the power of an end-of-life reconciliation during my chaplaincy work this summer. I had walked into one lady's room who was just hanging up the phone. Numerous medications hung from an IV rack next to her chair. She was smiling ear to ear. Before I could introduce myself, she said she had just spoken to her son, who had been estranged from her for the past eight years. She told me about the family arguments that had driven him to another state as soon as he was old enough to move out... about her rebuffed attempts to make contact... about her feelings of loss and desolation. She told me about how he has found himself and established a good life, and about how wonderful their 2-hour conversation had just been. She talked and talked about what a gift this was, to have reconnected with him. Finally, she wound herself down. "And who are you?" she asked. "I'm Kim," I said, "the Chaplain. I stopped in to see if you wanted to talk."

It can be flat scary to face up to our own impending death. What if I try to reconcile with someone, and they don't respond? Well, that happens. But would you rather leave this earth having tried, or do you want to be the one who was still hanging on to the broken relationship? And besides, what will death be like? Will there be anything after? Will it hurt? One man I spoke to was dying of lung disease. There was nothing more the hospital could do for him, so he was going home to die there. He and his wife spoke about where to put the hospital bed. "In the living room," he said, "where the action is. I don't want to be shut up in a back bedroom." He was fearful. He was already having trouble breathing and having occasional anxiety attacks, and was on oxygen. He asked the doctor, "What will it be like? You know, when I die?" The doctor said "You won't be gasping for breath, if that's what you mean. And we can give you medication to control anxiety. At the end, your breathing won't provide enough oxygen to support your body

function. As your brain loses oxygen, you'll lose consciousness. You most likely will feel sleepy, and just drift off into a sleep that you won't awaken from. It will be very peaceful." "I want to die at home," he said. "This makes me even more sure it's the right decision."

This guy was making his own decisions about how his death would be. His wife was on the same page with him, and supporting him. They had clearly talked about what they wanted, out of the options he had. She knew he didn't want to be on life support, or to be resuscitated when he was slipping away.

It doesn't help us, in fact it only hurts us, when we don't talk about what we want. And frankly, the best time to do it is before a crisis. We tend to think that our death is somewhere in the indistinct and distant future, and perhaps it is. But anyone can be in a car accident. Anyone can get a surprise diagnosis.

To talk about end-of-life issues with your family is a loving thing to do. You can document your preferences by filling out an Advance directive. That provides a guide as to what you would want for yourself, and it allows you to choose a health care agent who knows and will respect your wishes. Filling out the form can also be a vehicle to start these conversations, if you haven't had them yet.

Of course, not everything can be anticipated. That's why it's so important to talk about how you feel about life, death, and end-of-life care with the person who will be making decisions for you if you can't. As the Reverend Dr. Mark LaRocca-Pitts said during one of my recent classes, a person may feel that being in a wheelchair in a nursing home provides a good quality of life as long as she can reach out her arms to catch a ball and then drop it so it rolls back to her grandchild. Someone else – my mother, for example – may feel that quality of life is so diminished by the lack of independence in a nursing home that it doesn't make sense to extend life. Having a health care agent who knows your values and what you would want allows for a flexible response to your medical circumstances.

Having these discussions with your family and filling out an advanced directive doesn't mean you're ready to jump into the grave. When people were admitted to the hospital where I worked, everyone was asked whether they had – or would like to fill out – an Advance Directive. I've helped people fill them out who were in the hospital overnight for something minor and for young adults in their 20s as well as for people with a terminal condition. Even if you don't need the thing for another 20 or 30 or 40 years, it's good to have thought about your wishes in

advance and written them down, so nobody has to try to figure out what you would want in the moment of a crisis. Also, most people don't realize that when you die in a hospital, they are obligated to keep you alive as long as they can, by performing CPR, or by putting you on a respirator if you can't breathe on your own. It's only if you have a Do Not Resuscitate order, or DNR, that you will be allowed to simply pass peacefully if that's what you wish.

There are no right answers or wrong answers to these end-of-life questions about health care. It's simply important for the person making decisions for you to know how YOU feel, and what YOU would want.

I don't want this sermon to feel like a complete downer. It's not all bad. We will all die someday; we know that. When we die, our heart will stop and we'll stop breathing. The tricky part is what can happen along the way, like being on life support or having to make decisions about aggressive end-of-life care that may or may not stave off death.

I encourage all of you to consider where you would draw the line, if anywhere, in limiting treatment or allowing natural death to occur if you were in a terminal condition. I encourage you to talk to your families about these matters – if you haven't already – and maybe even circle back to the conversation if you have. I encourage you to think about any unresolved issues in relationships, and whether there is anything you can do to bring them to peace and resolution, even if it's only on your end. For the deaths I have attended, people who had already talked about life, death, medical what-ifs, and end-of-life care were much better equipped to make decisions and less traumatized by the final circumstances that led to death.

Hopefully we will all die in our sleep, well advanced in years. But in the meantime, let's not only live into our values, let's make sure we can approach our end of life with our integrity intact. Be kind to yourself and to your family. Start these conversations well in advance of a crisis. It's a way to honor our living and to honor our dying, ultimately closing the circle of life with forethought, autonomy and love. May each of us live well, and die well.

Blessed be.