

Creating Your Own End of Life Care Plan

by

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Sermon

It happened again last week..... I had to sit helplessly by as a family member agonized over what to do with their loved one because no plan had been put into place. And this one was particularly difficult.

Steve's mother Sally had been diagnosed with cancer. Treatments did not work and over a year ago she decided it was time to stop and let nature take its course. Sally lived alone but Steve was nearby. She was doing pretty well but just last week she started to have some declines and her doctor felt she was ready for hospice. They set up an appointment with me and my team to meet on Monday. When we arrived, Sally was slumped in her living room chair. She had difficulty keeping her eyes open and when we spoke to her, she didn't seem to be registering our words. Her responses to us were slurred and non nonsensical.

This was an even deeper decline than Steve had seen over the weekend. We inquired about an Advanced Care Directive. Had Sally ever created one? Did Steve know who she may have selected as her agent to speak for her when she could no longer speak for herself?

Steve said he thought she had created one during a past hospital visit. We called the hospital and found out that this was not the case. Sally was still legally her own person. She had never had a discussion or indicated who she would like to have as her Health Care Power of Attorney. Without this our hands were tied and Steve's hands were tied. Because Sally was not coherent we could not trust that she understood that we were going to sign her on for hospice and we could not trust that she wanted Steve as her agent.

Sally could not stay home alone like this. According to Steve, there had never been any talk of whether or not she would be OK with moving into a facility. All she ever said was that she was done fighting cancer.

So what did we do? Thankfully the social worker on our team helped Steve to admit his mom into the hospital, there two doctors could declare her incompetent. Because the hospital would not release her without a plan for home or for facility care, they could help rush through the need for a court order to declare Steve as her guardian. Because she was still legally her own person, with no record or conversation about her wishes for end of life, this decision had to go to the courts. Steve was in anguish, still unsure if he was making the right choices for his mom. We felt helpless and yet this was the best we could do.

Don't let this happen to you.

As most of you know I am a hospice chaplain and yes, I look at death nearly every day, and yes, I have a strange comfort with the dying that may be a little odd, but I guess it is a plus in this field. My husband joking calls me the Death Maiden.

But honestly, in my work, I see how beautifully we can create our own way of leaving this world. I am not talking about euthanasia or assisted suicide. It may be quite awhile until our state looks seriously at that issue. Today I am talking about making decisions for how you would like your end of life care to be.

In my work, we try hard to get families and loved ones to begin conversations with one another about end of life care and our social workers gently but firmly encourage families to sit down and discuss just how they would like their end of life to be. I believe that if we are prepared, that when death comes like in Mary Oliver's beautiful poem, we will be able to step through the door, not with fear or regret but with full curiosity about what it is going to be like in that cottage of darkness.

Fellow UU and Fox Valley End of Life Care Advocate Dr. Nancy Homburg along with myself, see the everyday benefits of having these conversations. Dr. Homburg stresses that end of life care planning allows us to express the uniqueness of every soul and the legacy only they can leave this world. Without planning our last days, celebrations of beauty and love can not happen. With 90% of us dying of one or more chronic illnesses, death is not often a surprise. We can create a plan to help our wishes come true.

So I wonder, why is this conversation so difficult, why do we get stuck and stall with each other when it comes to talking about dying? I hear and see so many different things from families and patients in my work. Some families will say that we can't talk about dying because if we do, if we are honest about the time a patient has left, then they will just give up.

Or that talking about dying will bring it on faster. My heart goes out to families who are suddenly faced with a terminal diagnosis, or medical treatments that are not working and hospice is brought on board. But this is nonsense, tip toeing around this topic is never helpful. And usually I find that when I sit down and talk honestly about it, the patient or the family is glad that someone is finally talking about it. And studies show that patients who have a plan for their end of life care actually live a bit longer and have a better quality of life in their final days.

So what kind of decisions are we looking at when we talk about making these choices? Generally most Health Care Power of Attorney Documents have you designate an agent that will speak for you and make decisions for you when you are no longer able to do so. This is important choice. It should be someone who you trust to carry out your wishes. Sometimes this isn't always family. You know who is in your circle of loving and who will stand up for your wishes.

This form will also walk you through your wishes for where you want to live. Would you be OK with moving to a facility if need be, or do you want to remain at home no matter what? What about feeding tubes or hydration if you can no longer swallow? Do you want medical treatments, surgeries or transfusions to prolong your life, even if you are terminal? If your heart were to stop, would you want CPR to try and start it again?

I know, these are tough questions, but they all point to the quality of life that you may or may not want to have. And knowing your answers or your loved ones answers to these questions can give great peace of mind to everyone involved.

And truthfully it is not just all physical. As a chaplain, I know that peace of mind also comes from having peace of heart. On these forms you can also direct your family or friends about music and environment or who you would like to have with you near the end. You can specify if you want your pastor to visit and things you want your family to remember about you. You can be very specific and clear about your wishes.

I often tell my patients and my families that I know coming on to hospice can be a terrible thing, to hear that you may have only 6 months or so left to live, can be terrible news. But there is also a bit of light and beauty there. Because you see, we know that we are on this path and so we get to know the last things that we say to people. We may be able to give things to folks, or spend time with them or write letters or leave photos. Any number of things that create a legacy for the patient can be

done. This can be a beautiful time. I recall a beautiful summer day when my team worked hard to get one gentleman out to the lake for one last day fishing.

As a chaplain I have seen very difficult family issues resolved like forgiveness, reconnection and redemption that can occur between the patient and their loved ones. This happens in ways that could never happen to someone who dies suddenly of a heart attack or in a car accident. Many of my families share that their loved ones end of life was actually quite beautiful and they were honored to have been able to be with them as they left this earth.

You see, most of us, 90% of us will be able to create our own end of life care wishes and take advantage of that time in ways that leave ourselves and our loved ones feeling closure, feeling peace and release at end of life. 90% of us will be able to share the unique wishes of our souls with our loved ones in ways that bring us meaning and legacy before we leave this world. And yet somehow we shy away from doing this.

I am not going to shame you all publicly so I won't call for a raising of hands but I wonder, how many of you are over 18 years of age? And I wonder how many of you have created your own Health Care Power of Attorney document? I know, I know, 18, 20 even 30 years of age seems too soon to think about dying, right? Its funny because, Americans are the only people in the world who think dying is optional. We think we or our loved ones will live forever. Reluctance to face the issue of death head on is due, in large part, to the removal of death and dying from the common experience of modern western life, says writer, Ann Neumann in her book *The Good Death, An Exploration of Dying in American*.

Our society has learned to take the dying experience out of our homes. For years folks went to the hospital to die. Now most folks die at nursing homes or assisted living facilities. And it is true we are living longer, in fact many of us are looking at 25-30 years of living after retirement. I confess, more recently I have seen a trend of folks wanting to stay in their home to die and I think this is a good sign. I think this is a reflection of baby boomer's who want to die in their own way, in their own home and in their own sense of comfort. And yet, even with this shift, conversations about these wishes often don't happen.

How does having these conversations and making these choices make a difference?

Let me tell you another story, one about a gentleman that did have these conversations, and you will see how his life ended with beauty, with creativity and with peace.

Barney was an avid outdoors man. Fishing was his life, something he did as often as he could, much to his wife's dismay. But fishing was also something he did with all of his children and all of his grandchildren.

He had been struggling with COPD and other ailments for years but he also knew he wanted to be in charge of his final days. He chose to create his health care power of attorney document with one of his sons as his agent and his wife as his back up. He indicated on his document that he did not want feeding tubes, CPR or surgeries. He was clear that he wanted to remain at home, no matter what.

And truthfully that was a hard one to honor as his care became more and more intense. But his family knew his wishes and they set up schedules and took turns so that someone was there with him around the clock. Was it easy? No, but they all had a clear plan, and they worked hard to stick to it.

Hospice was brought on board and with that came a Registered Nurse who managed his health care and worked with his primary care physician. A nursing assistant came two times a week to bath

and help with personal cares. His team also included a social worker who helped the family with funeral home arrangements and other community services that helped them. I was his chaplain, offering support, opportunities for reflection, forgiveness and celebration, not just for Barney but also his whole family.

Barney knew that fishing was his legacy to his family. He gathered his fishing poles and lures and matched one to each and gave one to each of his grandkids and children. He carefully assigned his prize fishing taxidermy to his loved ones as well. He chose music and songs that he loved to be playing during his final days. He and his family worked together picking photos and songs for his memorial and lot of laughter and story telling ensued during these days. He got to hear and see what his family cherished most about him during this time.

He made a list of everyone he wanted to see and he did his best to be sure that he went to them or they came to him. I think only one visit had to be a phone call, a brother who lived out of state and had health issues of his own.

He was the gentleman that we helped to have one last day out on the dock, fishing from his wheel chair but also with his son and grandson. I never saw such a huge smile on someone like I saw on Barney's face that day.

And so as his final days finally arrived. Barney was in bed, with music he loved playing, with his closest family around him, with assurance that he had seen and spoke to everyone he had wanted to contact. Like the words in Mary Oliver's poem, he did not find himself sighing or frightened or full of argument. He was at peace and he died gently in his sleep. Barney created his final days. He left a meaningful legacy to his family and they too were at peace and ready to let him go.

You too can create a wonderful and meaningful plan for your final days and let me tell you, it will be the best gift you can give your family EVER. Because when your health starts to fail or you are in an accident that requires others to make decisions for you, your loved ones will know exactly what to do.

And let me also say, that this isn't just important for you to talk about your wishes, it is important for you to talk to your loved ones about their wishes. Again, I won't make you raise your hands, but I wonder how many of you are part of the sandwich generation that is not only raising kids at home but taking care of aging parents?

I was in this same boat a couple of years ago. Joel and I were getting kids off to college and we were also caring for my aging mother with dementia. Thankfully my parents were prepared and made their wishes very clear. When my mother was no longer able to speak for herself and she developed a bowel obstruction at the age of 89 with severe dementia, we knew that surgery was not the answer. We knew that keeping her comfortable was what she wanted and as her power of attorney we did not have to agonize over the choice to keep her comfortable and to let nature take it's course.

We did not give up on her care as some might feel, we followed her wishes and let go of her, because her next step was one that we could not take with her.

If you have not done this work, I encourage you to do so. Make it a goal of yours to do this before the end of this summer. We spend so much of our time during our lives creating our schedules our work, or free time in ways that bring us more joy and happiness. We can do the same for our end of life care. We may not know when our lives will end, but let's be honest, none of us get out of here alive. Create your end of life care plan, honor your own individual soul and give peace to yourself and

your families, you will be glad that you did.
May it be so.