

“A Conversation About End of Life Care”
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Fox Valley Unitarian Universalist Fellowship
Appleton, Wisconsin
www.fvuuf.org

July 13, 2014

If you are of a certain age, you know Casey Kasem as the radio DJ for American Top 40. I recall Sunday nights hearing his voice on the radio sharing the week's top hits and listeners calling in with long distance dedications for loved ones who were far away. Or perhaps you knew him as the voice “Shaggy” in the beloved cartoon Scooby Doo. His distinctive voice is forever ingrained in the American psyche.

Casey Kasem died just last month. Sadly and tragically in his last months, family members were not at his bedside sharing loving memories but instead were in the courts fighting over his end of life care wishes and who should be in charge of his care. Although his unique and recognizable voice will be remembered by most of us here in this room, his voice was not heard at all at the end. Because of dementia and illness his own voice was silenced about what his wishes were for his end of life care because he had never voiced his wishes when he was still able.

Denial and lack of planning about end of life care decision making can bring legal, financial and emotional woes greater than we can ever imagine. Many of my patients come on to hospice services with dementia or other illnesses that affect their decision making abilities. Families and social workers scramble to activate health care power of attorney documents. And even when this happens, I can't count the number of times that I have talked with families who have had no idea what their loved ones choices would have been for end of life care. They admit that they never had that kind of conversation with one another.

Today I hope to begin a conversation with you and help you to imagine. Imagine how you would like your end of life care to be. Imagine how you might begin the conversation with your loved ones about how they might like their end of life to be. I truly feel this is a sacred gift that we can give to one another. It is a gift of preparation. It is a gift of dignity. It is a gift of peace that can provide great relief to family and friends during a very difficult time.

Talking about dying, talking about end of life wishes is difficult; I know that. Yet, studies show that people who are willing to begin this conversation and share their wishes are much more likely to be at peace at end of life. Families report less stress and more confidence in decision making for their loved ones at end of life.

So go ahead, use me as a scape goat. You could say, “Ya know, on Sunday the minister at the Fellowship was talking about end of life care planning. I think we should talk about this together;

I want to be sure that we are all on the same page about what we want for our care at the end of life.” Go ahead use me as a way to start a difficult conversation; I won’t mind.

I knew a family that threw a huge party in their garage; they called it “The Demise of Ernie and Mavis.” (Their names have been changed of course.) The parents, Ernie and Mavis, were starting to have some trouble living independently at their home. Their five kids knew that they needed to sit down and have a conversation with them but they just didn’t know how to start the conversation. I am not sure who got the idea for the party but it was perfect. The family had always thrown parties, in true Wisconsin fashion, in their garage, for birthdays, anniversaries or graduations. Coming from Minnesota, I have never really understood this unique practice of entertaining in the garage but it is what it is.

So, they decorated the garage. They brought out photo albums and pictures and old memorabilia. It was just the kids and their families but they sat around in the garage and told stories about their parents and showed them how much they loved them. And then they asked them some hard questions about how they saw themselves living as they got less independent. Did they want to stay in their home? Would they be willing to move to a facility of some sort when things got difficult? When did they think they might have to give up their driver’s license? Who would they like to represent them in their health care discussion making? Did they want life saving interventions if their heart stopped?

Some things were easy to answer and other things the parents wanted more time to think about. But the conversation was started and it began when the parents were still of sound mind and body.

One of the first questions you want to ask yourself or your loved one is who do you want to make decisions for you or them when they can no longer speak for themselves? This is a big responsibility. This person is called a Health Care Power of Attorney. This needs to be someone that you can trust to make difficult decisions about your care.

Sometimes family members are not the best choice for this because they can be too emotional. They may not want to let you go. Or perhaps you have relationship issues that make family too unreliable or untrustworthy. You know who is in your circle of loving. You know who will be in your corner. It is smart to pick someone who is fairly nearby as well as they will be the one called when something occurs.

Once you choose this person, talk with them and see if they are willing to be your representative when you can no longer speak for yourself. I had our secretary, Cyndi, attach two different documents that Wisconsin accepts as legal for designating health care power of attorney to our weekly newsletter. If you are interested please download them at home and if that is not possible, I have some hard copies in the Fellowship Hall today that you can take as well.

When filling out this document it must be signed and witnessed by two people who are not family members. They serve as witnesses that you made this choice and have created this document.

Copies should then be given to your representative, your doctor and one copy kept with your documents.

Here is the clincher, the thing that so many of my patients don't realize... once you select your health care power of attorney and the document has been filled out and witnessed, it is still not activated until two doctors examine you and determine that you are no longer able to make your own decisions. This is a good thing in that it protects you or your loved ones from any one taking advantage of them and signing off their ability to make their own choices but it is also a challenging dance that patients, family members and the medical team have to deal with as you are still your own decision maker until two doctors examine you and say that you are not.

As you are considering who you want your health care power of attorney to be, it is important that you know that person will be able to handle following through on some tough choices. They will be called to follow your wishes for medical treatments and care, if and how to keep you alive and if and when treatment should be started or stopped. This person should be able to interpret your wishes and values about your end of life care.

So what kind of things are we talking about here? This is where it can get difficult and this is where having these decisions made before hand can make all the difference and can offer peace and comfort to you and to your loved ones. Your representative should be able to consent to admission to an assisted living facility, hospital or nursing home and know what your wishes are about this. Let them know if you are OK with going to a facility or do you wish to remain in your home at all costs? They should know your wishes for pain medications or if you want simple procedures to reduce pain or increase comfort.

Here is an example of what I am talking about. Let's say that you have cancer, you have gone through all the treatments, but it didn't work. Your doctor says there is nothing left to do and recommends hospice so that you can enjoy your last days in comfort and peace. You are no longer treating the cancer and your nurses are just providing comfort treatment.

But what happens if you develop a bladder infection or pneumonia develops in your lungs? These are things that can easily be treated and generally cleared up by taking antibiotics.

Do you want that? It is not going to stop you from dying from cancer, but it might make you live a little longer and with more comfort. I have patients who seek treatment with simple antibiotics for these things while on hospice. I also have others who do not, who decide they will let nature take its course and just be given medications to remain comfortable.

I think age makes a difference here; I think readiness to leave makes a difference here. Let's say that the same situation occurs to a 40 year old, with young kids still at home. They may say, yes, although I still have cancer and we have stopped treating that, let's treat the pneumonia. But a 90 year old may think differently. Sometimes pneumonia is called an old man's best friend. As you create your health care power of attorney document you can make provisions for this kind of care and if and when you want it.

Considering care and age are important. I just turned 54. If I had a heart attack today, I would want CPR and interventions to get my heart started. I am pretty healthy and still have things I imagine I want to do yet. If I went into a coma today and my brain was still active, I would want intubation, feeding tubes and fluids. But I have designated in my health care power of attorney document that if doctors determine that my brain is no longer active, then I would no longer want to be kept alive by artificial means.

These are the concerns you can address for your own life. These are measures that your representative should know what your wishes are for.

Each of us comes at this differently. We all have different health issues, past stories, family commitments, desires and fears. There is no right or wrong here. By declaring your wishes about these kinds of interventions and whatever stage you are in your life, you can be sure that if something were to happen, your family and your health care team will know what you want and when.

My own mother is 90 and has dementia. She is ready to go, she has told me hundreds of times. If her heart were to stop today she has been very clear that she does not want her heart restarted. She wears her DNR bracelet and her family and her health care team know her wishes.

Any or all of the decisions that you might make can always be changed when you create a health care power of attorney document. People come and go from our lives, we move, people die, life changes, we change. I say this because so many people feel that if they make these decisions now, it is written in stone and that causes some concern. Sometimes we are not always sure exactly what we want until we are in a situation.

Your decisions can always be changed, it is as simple as ripping up the document and creating a new one. But you are responsible for your choices and you are the only one who can speak for yourself. Although your voice may not be as recognizable as Casey Kasem's, unlike Casey, you can insure that at the end of your life your voice will be heard.

As I mentioned, in the Fellowship Hall and online I have made a couple of forms for creating your own health care power of attorney document available. One is a shorter and fairly simple. The other is called Five Wishes and it is much more conversational in helping you consider the care and compassion that you or a loved one would like to receive at end of life. Both of these documents are legal and accepted in the state of Wisconsin.

This is an important conversation to begin. I know many of you have already done this and to you I say, "Good job." You will not leave your family wondering about your wishes and feeling helpless or stressed during an already stressful time. Sadly, statistics tell us that less than 30% of us have shared our wishes for end of life with anyone. Yet more than 70% of us have ideas and wishes for what we want our end of life to be and haven't formalized it. Let's change that here in our community of loving. Let's make our wishes known.

As I read articles about families struggling at end of life, some had email responses from folks

who had experienced challenges with their own loved ones.

One man wrote;

“My dad died 20 years ago and I still regret that I did not honor him in the way I think he would have wanted. He had cancer and never quite came out of the surgery the doctors recommended. They talked us into putting him on a ventilator and feeding tubes. He hadn’t wanted extraordinary measures if he had no chance of recovery but nothing was formally written so it fell to us to decide what to do. Since it was early on we had no way of knowing how it would play out. But somehow, Dad knew what was going on. He grew combative and tried to pull out the tubes. It was an awful time. Throughout his last months I felt guilty that I couldn’t do something so that he didn’t have to live on machines. My mother was numb and in denial. She could not seem to make a decision either so we let it go on and on. One day his heart stopped but we did not have a DNR in place so they brought him back. I asked the doctor how he was and the doctor said, “It’s awful!” in just those words.

Thankfully my father passed away that night but for the last 20 years I have carried the pain of not doing the right thing by my dad. No one gives a course in what to do when that time comes. I so wish that we would have had something formally in place about his wishes. I feel some comfort in having put together my own plan for end of life care so that my children will not have to go through the same thing.”

This action, this preparation for end of life is nothing short of loving one another fully. Honoring someone’s end of life care wishes is showing respect and dignity for ourselves and our loved ones. Honor the light and life that is you or your loved one’s and make a plan for end of life care. If you haven’t already done it, start the conversation soon. Let your voice be heard. You and your loved ones will be glad that you did.

May it be so.

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