

TALKING WITH LOVED ONES ABOUT LAST WISHES

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Many of us grieved the death of Nelson Mandela last spring. He was a great man. But I also grieved *how* he died. Several months before he died, his physician suggested to his family that it was time for him to be released from life support. The family was not prepared. Evidently, Mandela had never talked about his death with his family. Evidently, he had never talked to them about how he wished to die. They squabbled among themselves. His daughter kept saying he was improving. His home was turned into an intensive care unit. I felt sad.

Joan Rivers, comedian, died recently in another way. Joking to the end she twittered: “I must admit I am nervous about getting Alzheimer’s. Once it hits, I might tell my best joke and never know it.” But she became serious. She asked her daughter Melissa to be ready in case she did not survive her recent surgery. She told her daughter that she and her family would be fine. She told her that she had had a remarkable life, even if it ended that day. Rivers did not survive that surgery. Because of that conversation, Melissa was able to take her mother off life support with no guilt and no hospital complications. It’s what her mother had asked her to do.

I am one of the speakers for The Conversation Project in Boulder County. The web site is listed at the bottom of the page in your order of service: it is www.theconversationprojectinboulder.org. The Project encourages you to have conversations with your loved ones about what you value about living and how you wish to die. It offers a Starter Kit as a guide for deciding your end-of-life choices. Jean

Abbott, Tessa Davis, and Lee Carlin will introduce you to this Kit in their workshop following this service. If you are not staying, you can download the Starter Kit from the website. This Project isn't about signing your Living Will or naming your Durable Power of Attorney for Health Care though you need to do those. Nor is this Project about signing those documents and then sticking them in a drawer. This Project encourages your talking with your family (however it is configured) about what you value about living and how you wish to die before you fill out the forms.

None of us know how we will die so most of us can't orchestrate exactly how we want it to happen. Early and continuing family conversations can inform the decisions that may well need to be made. You will need to name the person you wish to make decisions for you if you cannot. Of course you want to talk with that person about your values. You also want to talk with other loved ones about who will be making your decisions and your values that will guide that person in her/his decision making. You can tell your loved ones that you do not want them to squabble at your end; you need everyone to be on board. About 40% of people will need to make medical decisions near the end of life. "Seventy percent of those will not be able to make decisions for themselves at that point (Silveira, 2010)." (Jean Abbott's REFERENCES AND FACTS THAT MAY BE USEFUL FOR COACHES AND SPEAKERS (v. 11.14.13)

Now I can tell you from personal experience that I know how hard it is to get around to such conversations with your loved ones. Many of us just move from what demands our immediate attention now to the next demand in our lives. As Ellen Goodman says, "It's always too soon to start the conversation...until it's too late." ("The Conversation Project") Often children resist your attempts to talk about your dying. Family gatherings are often infrequent and special times. You may be reluctant to interrupt these

wonderful gatherings with a conversation about your death plans. However, you can tell your family ahead of their visit that you need them to join you in Talking Turkey over Thanksgiving. You can reassure them that you are not dying but you do need to have their help in your planning. As their parent you will be modeling how to die for them.

It feels good to talk with people you love about what matters to you about living and dying. It can be the intimacy many of us crave. I have felt closer to my brother since he listened to me about how I wish to die. I value hearing what my husband feels is important when he dies. A woman called me once saying she felt she would die soon and she couldn't get her daughters to talk with her about it. I went over to help. We had a wonderful conversation with her daughters, full of love for the woman and full of listening. That woman and her daughters continued talking about her life and death as she continued living for several more years.

Now I know that most of you are younger than I. You are busy living your lives. It's hard to make time to think about dying and quite frankly you don't want to, so you never get around to it. Consider these facts:

Sixty percent of people say that making sure their family is not burdened by tough decisions as they die is "extremely important" but 56% of these people have not talked with their loved one about their end-of-life decisions. Eighty two percent of people say it's important to put their wishes in writing; twenty three percent have actually done it. Seventy percent of people want to die at home but actually seventy percent die in the hospital or nursing home. Did they tell anyone what they wanted? (www.theconversationprojectinboulder.org)

Perhaps you are thinking, yes, older people *do* need to start thinking about dying. But you may want to as well. We never know when death will come to us. Of course we hope death is later rather than now. However, “Terri” Schiavo collapsed in Florida at age 41 in full cardiac arrest. She was in a persistent vegetative state. Her husband had to go to the court to have her feeding tube removed. An automobile accident left Nancy Cruzan at age 26 in a persistent vegetative state. It was the corroborated conversations she had had with some of her co-workers that helped the court, after seven years, decide her feeding tube could be removed. A more recent case was that of the pregnant paramedic in Texas who was brain dead. It was her stated desire to her husband not to be kept alive artificially that helped him remain resolute before the court and state. Conversations count.

It’s much easier to have such a conversation now when death does not feel imminent than when you are entering the hospital because of a stroke or heart attack. UUs usually like to make decisions about how they wish to shape their lives.

I have one friend who says, “oh my family will make my decisions; they know what I want.” That sounds to me like getting mad at one’s spouse for not knowing what you are thinking. He/she is supposed to know what you want without your ever saying. Right? You might say to your loved one, “please tell me how much medical intervention you want so I can make the decisions on your behalf you would want.” You can explain that you don’t want to worry the rest of your life about whether you made the right decisions. One of my friends who was entrusted by his father for his final decisions said how wonderful it was to have his siblings’ support. Their family grew closer through his father’s death.

Having conversations with your grown children about how you wish to die is especially important for blended families. I know one man who is in his second marriage. His children from his first marriage don't like their father's new wife that much. He needs to talk frankly with his children about whom he wants to make decisions for him if he cannot and what his wishes are in dying that would inform such decisions. This conversation needs to happen well before the time comes. Otherwise, his family may be like the Mandela family--hurt, angry, blaming, suffering. A death like this can hurt family relationships far into the future. You can help your family grow closer rather than splinter in blame and guilt by simply talking with them about your wishes soon.

Here are some things you will want to be thinking about from the Starter Kit that Jean Abbott will use in the workshop following. Where are you on the continuum, "I only want to know the basics" to "I want to know as much as I can." My husband is a scientist; he wants to know everything. I'm closer to the other end. Where are you on the continuum, "Ignorance is bliss" to "I want to know how long I have to live?" Where are you on the continuum, "I want my doctors to do what they think is best" to "I want to have a say in every decision." Well, what if you can no longer communicate? ("The Starter Kit")

Here are more continuums: Where are you on "I want to live as long as possible, no matter what" to "Quality of life is more important to me than quantity." If you have Alzheimer's or a massive stroke, do you still want antibiotics to cure your pneumonia? Where are you on you on the issue of how much care is enough: "I'm worried that I won't get enough care" to "I'm worried that I'll get overly aggressive care." Dying used to be fairly natural but now your breathing and heart can be kept going by machines for years while you are in a persistent vegetative state. One person I know wants absolutely no medical intervention if he

has a heart attack or stroke. Others say I want everything medicine has to offer. Medical technology has become a two-edged sword. It can extend life and it can also prolong suffering. Are there ways of being alive that are worse than death for you? (“The Starter Kit”)

A delicate issue is the cost of healthcare. Of course your loved ones and you want you to live as long as you can. No one should ever tell you when you should die. Your life is important. However, I knew one man who was bedridden for a couple of years in his daughter’s home. He felt good about his life and was ready to die. He wanted his life savings to go to his children and grandchildren instead of being spent keeping him alive. You may not feel that way.

I started thinking about how I would like my dying to be by thinking about what I value about being alive. Here’s part of what I have written: “I do not believe life is simply biological. For me, life is emotional, relational, and aesthetic. If I cannot be relational (meaning being able to communicate and understand) and cannot enjoy music, art, nature, life is not meaningful to me. Being able to interact and communicate with people is of top importance to me. Without that ability, I do not wish to live.

“I fear three things: being in pain, not being able to communicate, and being kept alive artificially when I cannot enjoy life as I have defined it. I wish to be as physically comfortable and as conscious as possible. Painkillers that would interfere with my consciousness should be used only to ensure my comfort—to be self-administered if possible.

“I would like music of my choice played when I wish. I would like flowers and photos of my family and friends nearby. I

would like to be able to look outdoors and perhaps see a birdfeeder. I would like visitors but also to have time alone.”

These are some of my wishes, but I have talked with others who feel that when they are no longer contributing to life as they wish, they no longer wish to live. We all value different aspects of life.

The Conversation Project is not about having one conversation. At different points in your life you will want to renew the conversation. What I want now is different from what I would have wanted when our daughter was young. What I want now as I die is different I believe from what I may desire at age 90.

We don't like to think or talk about death. But there's one important statistic: 100% of us will die at some point. Perhaps if death were a part of our conversations, it would feel more like a part of life. For many people, thinking about their future death makes their living light up with meaning and joy. When we face our deaths, then we can truly live.

Talking about life and death is spiritual and/or religious. You come to this church to reflect on and experience what is important to you about living: community, service, love, justice, beauty, the world, the earth and its creatures, good living. This is the place where you can consider how the fact of your death shapes your living. Many UUs in answer to the religious question of who is in charge of our lives, will say we are. That may be overstated but most of us want to make decisions to shape our lives. Perhaps we would like to make decisions to shape our death and to help our families deal with our deaths. We also say in our seventh principle that we are not totally independent creatures; we live within a web of relationships. We want to make our decisions about dying within the web of these relationships. Your conversations with your loved ones may be your final gift to them.