WHAT ARE YOU TALKING ABOUT

a sermon given by the Rev. Rosemary Lloyd Sunday, October 12, 2014 at the Foxborough Universalist Church

Jane Kenyon was working on an anthology of collected poems when she died at 47 from leukemia. Her poet husband, Donald Hall, published this poem, written after her diagnosis, posthumously in 1996. It's entitled *Otherwise*.

I got out of bed on two strong legs. It might have been otherwise. I ate cereal, sweet milk, ripe, flawless peach. It might have been otherwise. I took the dog uphill to the birch wood. All morning I did the work I love.

At noon I lay down with my mate. It might have been otherwise. We ate dinner together at a table with silver candlesticks. It might have been otherwise. I slept in a bed in a room with paintings on the walls, and planned another day just like this day. But one day, I know, it will be otherwise.

Such a tender, elegant poem. Knowing that *Otherwise* was written by Jane Kenyon as she was living with leukemia, I find it also a profoundly life-affirming poem. With her words, she show us the world in all its ordinary beauty—the visceral beauty of *strong legs, sweet milk, ripe, flawless peach*—and renders her view as a clear-eyed vision of a limited future.

Jane Kenyon gave us an enduring gift of beauty that we can share this morning in this sacred space because she continued doing the work that she loved—with her heart and eyes wide open. Living with her illness, and living fully awake to the horizon she knew she would meet "one day," she create a work that is a testimony to her deep spiritual courage, as well. That's what it takes to live knowing that, one day, it will be otherwise: spiritual courage.

We are seekers of Truth, you and I. Even when the truth is difficult to welcome into the comfortable, sun-lit rooms of our lives, our faith tradition encourages us to keep welcoming Truth.

One of the hardest truths of life is that birth is fatal...Yes, even here in the greater Boston area, the mortality rate is still 100%.

That's a truth that is hard to get your arms around, to embrace. For some in this room, in this moment, it is especially difficult. If you or someone you love is living with a frightening diagnosis, please know that I am so sorry. I hope that the words I share with you today are some small help to you.

IF you have recently experienced the death of someone dear to you, I truly am so very sorry for your loss. I pray that what I say may pass the test of reining true to your experience.

We don't know each other at all, do we? I don't know where you are on life's path.

Yet, here I am, on this lovely Fall morning, presuming to ask you to enter into a tender inquiry with me. I am risking casting a shadow in this sanctuary because I am betting that you may be willing—as I am—to face the intense truth of our mortality for the sake o something very important. What's so important as all that? Three things to start:

For the sake of transforming how we die in America;

For the sake of encouraging you to express your wishes for how you hope to be cared for through the end of your life;

And even more, for the sake of discovering what matters most to you about living. So what are we talking about when it comes to the end of life?

Well, not much, as it turns out.

It seems that, as a culture, we are very good at avoiding talking about the ending of our days.

I've been a close observer of the end of life conversation for forty years. I remember reading Elizabeth Kubler Ross's influential book On Death and Dying during my nurses training in the 1970's (published 1969).

It was influential in the culture, and it made a huge impact on me. At the time, I was a young nursing student and my maternal grandfather had colon cancer. We were all very awkward about talking to Grandpa about his diagnosis, his surgery, or the prognosis. In fact, we were mostly silent.

But I had Kubler-Ross's book! In it, she was addressing the experience of someone who is living with a terminal illness—a topic that no one else seemed to be

talking about. It was a pioneering work, and it gave me the opening I needed to talk with grandfather.

It turned out that he had given his mortality plenty of thought. He was a devout Catholic and seemed at ease I telling me that he was not afraid to die. He was almost matter of fact, reminding me that we all have to die someday. What he wanted was to enjoy the days and possibly years ahead still. He asked me not to worry, but to please learn to play a song he like—the old Coke commercial that began with the lyric: "I'd like to teach the world to sing in perfect harmony." If I could get it right, would I play it for him on the pianos outside his room when I came home on school holidays? We don't hear that song on the radio or television anymore, but I can still hear it in my head, and it always reminds me of my grandfather's forthrightness, faith, and courage.

Kubler Ross brought the conversation about dying out of the closet, and, as a culture, we tentatively began to talk about it.

SO much has changed in end of life care since I was a young nurse in the 70s. The first hospice in the United States was founded in Connecticut in 1974. There are now more than 5,000 hospices in the US but people are still underutilizing this compassionate service. Designed to help care for someone through the last six months of life, most people enter hospice for just a week before they die.

There have been progressing improvements in pain management, with an entire new medical specialty called Palliative Care finally emerging to help keep us more comfortable while living with chronic and terminal illness. Still, our attitudes and our willingness to talk about our preferences for care at the end of life need some adjusting.

I don't generally like to use statistics in a sermon...They seem so....so...statistical! But these numbers tell a dramatic story:

• 60% of people say that making sure their family is not burdened by tough decisions is "extremely important,"

yet 56% have not communicated their end-of-life wishes.1

• 70% of people say they prefer to die at home.

while 70% die in a hospital, nursing home, or long-term care facility.2

Wouldn't it be great if it were possible to narrow the gap between what we hope for and what is happening at the end of life? What if we could put something in place that would help assure that our wishes were honored? What if part of the legacy we left our families is that they feel of sense of peace knowing that they honored our wishes? Having a conversation can make all the difference. And now is the time to be having it.

Pulitzer-prize winning journalist Ellen Goodman wrote, "We all think it's too early until it's too late" to have these conversations. She tells this story:

"My mom was one of those people who could talk about your problems until you were bored with them. We talked about everything except one thing: how she wanted to live at the end of her life.

¹ Source: Survey of Californians by the California HealthCare Foundation (2012)

² Source: Centers for Disease Control (2005)

Once or twice when we heard about a relative or friend who was comatose or on a feeding tube, she would say, "If I'm like that, pull the plug." But, of course, when the time came, there was no plug.

In my mom's last years of life, she was no longer able to decide what she wanted for dinner, let alone what she wanted for medical treatment. So the decisions fell to me. Another bone marrow biopsy? A spinal tap? Pain treatment? Antibiotics? I was faced with cascading decisions for which I was wholly unprepared. After al the years I had written about these issues, I was still blindsided by the inevitable.

The last thing my mom would have wanted was to force me into such bewildering, painful uncertainty about her life and death. I realized only after her death how much easier it would have been if I heard her voice in my ear as these decisions had to be made. If only we had talked about it. And so I never want to leave the people I love that uneasy and bewildered about my own wishes. It's time for us to talk."

So in 2012, Goodman founded a non-profit organization called The Conversation Project.

The Conversation Project aims to help normalize talking about our wishes for end of life care. In other words, let's be having these conversations at the kitchen table, not in the ICU.

The Conversation Project has a great website where you can find The Starter Kit. It is just that. Step-by-step, easy-to-follow suggestions and exercises on how to get started on the conversation. The Starter Kit will guide you to gather your thoughts, explore your feelings, and share your reflections with the people closest to you.

The first step in having your wishes respected is to articulate them—and to share them with someone else. We all know that we need to be sure we have made out a will, and chosen a health care proxy, right? Would it surprise you to learn that 82% of people say it's important to put their wishes in writing, but that just 23% have actually done it? ³

These documents are important! So please do them. But don't just sign them and file them away in a desk drawer. It is equally important that you take what you have dutifully drawn up with your lawyer and discuss it with the people who are most likely to be in a position of making decisions for you in the event that you cannot speak for yourself. We need to have the conversation with someone—especially the person you have named as your health care proxy in your formal documents.

These a not only medical decision making conversations that can wait until a critical moment in your life or the life of someone you love. These are conversations about what matters the most to you about what makes your life worth living. And who you trust to be there for you when you are at your most vulnerable.

Moreover, these are conversations that require and also cultivate spiritual courage. For to learn the answers to our probing questions means that we have to dive deep into our hearts and minds and search our conscience. We need to grapple with how we deal with challenge, how we face the unknown, and who is there to uphold us when we must walk through the valley of the shadow of death.

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³ Source: Survey of Californians by the California HealthCare Foundation (2012)

Social psychologists used to fear that thinking about death might be destructive and dangerous—that such a contemplation could fuel everything from prejudice and greed to violence.

Encouragingly, recent studies are demonstrating that "subtle, day-to-day death awareness" can "motivate increased expressions of tolerance, egalitarianism, compassion, empathy, and pacifism." It can also lead to healthier behaviors, like using sunscreen, stopping smoking, and increasing exercise. And it can help us "re-prioritize our goals and values." The authors of one study concluded: "The dance with death can be a delicate but potentially elegant stride toward living the good life." 4

And there is this spin on talking about our tough subject: "If it wasn't for death, the trivial would become significant. Inconsequential things like fashion, recipes, entertainment, and leisure [would] become the ... things that matter. In light of the inevitability of death, we can prioritize our life. We can see that certain things are more important than others."5

Contemporary culture presses pretty hard trying to make inconsequential things significant. So if you want to be countercultural, take time to sort out and express what is significant for you, what your priorities are, what certain things are more important than others and make your life worth living.

If thinking and talking about death and dying—cultivating a subtle day-to-day death awareness--can help us to live better lives, then starting this conversation with you this morning seems a worthwhile undertaking (to use a word).

Although I can't be the actual conversation with you, I hope that my beginning it will free you to raise it with people closest to you. It could be your opening gambit, "You know what the minister talked about in church on Sunday? I wonder if we could talk about this sometime? Let's take a look at that website she mentioned. What was it again? Oh, The Conversation Project dot org."

I know that Tim House will support you in having these conversations. And if you think you might like to attend a workshop on using the Starter Kit, let Tim know, and perhaps we can get a date to do that here at Foxborough.

The more we can talk about our mortality and our wishes for care through the end of life, the greater the possibility that our wishes will be respected. Perhaps we will even how we transform how we die in America....!

Let's not delay, because, one day, it will be otherwise. AMEN.

Friends, as we prepare to close this hour together, I charge you: Cultivate a day-to-day awareness of death. Do so that you may elegantly strive to life a life that reflects your highest values and dreams, your deepest compassion and joy, and your inherent dignity and worth.

⁴ http://www.sciencedaily.com/releases/2012/04/120419102516.htm, viewed 10-26-12.

⁵ http://www.shoutsfromthewilderness.com/2011/07/12/how-is-death-a-good-thing/