



HELP THEM TALK

The Vital Role of Faith Communities in The Conversation Project

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INTRODUCTION

The Conversation Project is designed to help families, communities, and clinicians engage in meaningful and effective conversations around quality of life and end of life (EOL) care. We aim to have all conversations result in the appointment of an informed medical decision-maker, and relieve families and friends of the stress and suffering around crucial decisions as age or illness progress.

To this end, we meet people where they live, work, and pray. Faith communities are often the safest environments to “talk about talking” and help individuals and families design a future of hope and respectful care-giving.

This short e-book provides some fundamental tools to faith leaders. Many resources are available on [The Conversation Project](#) website, and [Rev. Rosemary Lloyd](#), Advisor the the Faith-Based Community, is always available to assist with helping faith leaders reach and teach their congregants.



Seven reasons why we are invested in sharing The Conversation Project in congregations:

1. They are existing communities of people that are committed to living according to shared values, and to advocating for vulnerable populations;
2. They are places that encourage living with more compassion and less fear—things we all need if we are going to engage in these kinds of tender conversations;
3. Congregations are story-telling communities—and really, so much of this work is about sharing our stories: what happened when someone died; what works and what doesn't; what we hope and what we fear—this is the heart of storytelling;
4. Some congregations are places where the seeds of cultural change are planted—from abolition to equal rights—and we can all agree that we need some culture change on this topic;
5. Faith communities seem to like to eat together. We are seeing wonderful success with programs like Let's Have Dinner and Talk about Death (or "Death over Deli" as one congregation billed their gathering) where people get to talk in comfortable settings over comfort food. The resulting conversations are remarkable for their intimacy and liveliness;
6. And faith communities are places that are positioned to support care-providers who are sandwiched between caring for young children and older parents.
7. Starter Kit workshops are a good way for clergy leaders to gain practice and skill in having The Conversation. Like doctors, clergy are often called upon to support

people through illness and dying. But--also like doctors—clergy do not all receive training in how to have these crucial conversations. Using the Starter Kit is a gentle way to begin having the Conversation with loved ones as well as with congregants.

It is said that 11:00 on Sunday morning may be one of the most segregated hours in America—with different racial, ethnic, and class groups gathering in their own congregations. By working inside and across faith communities, The Conversation Project can reach a very diverse population where they live and pray and gather.

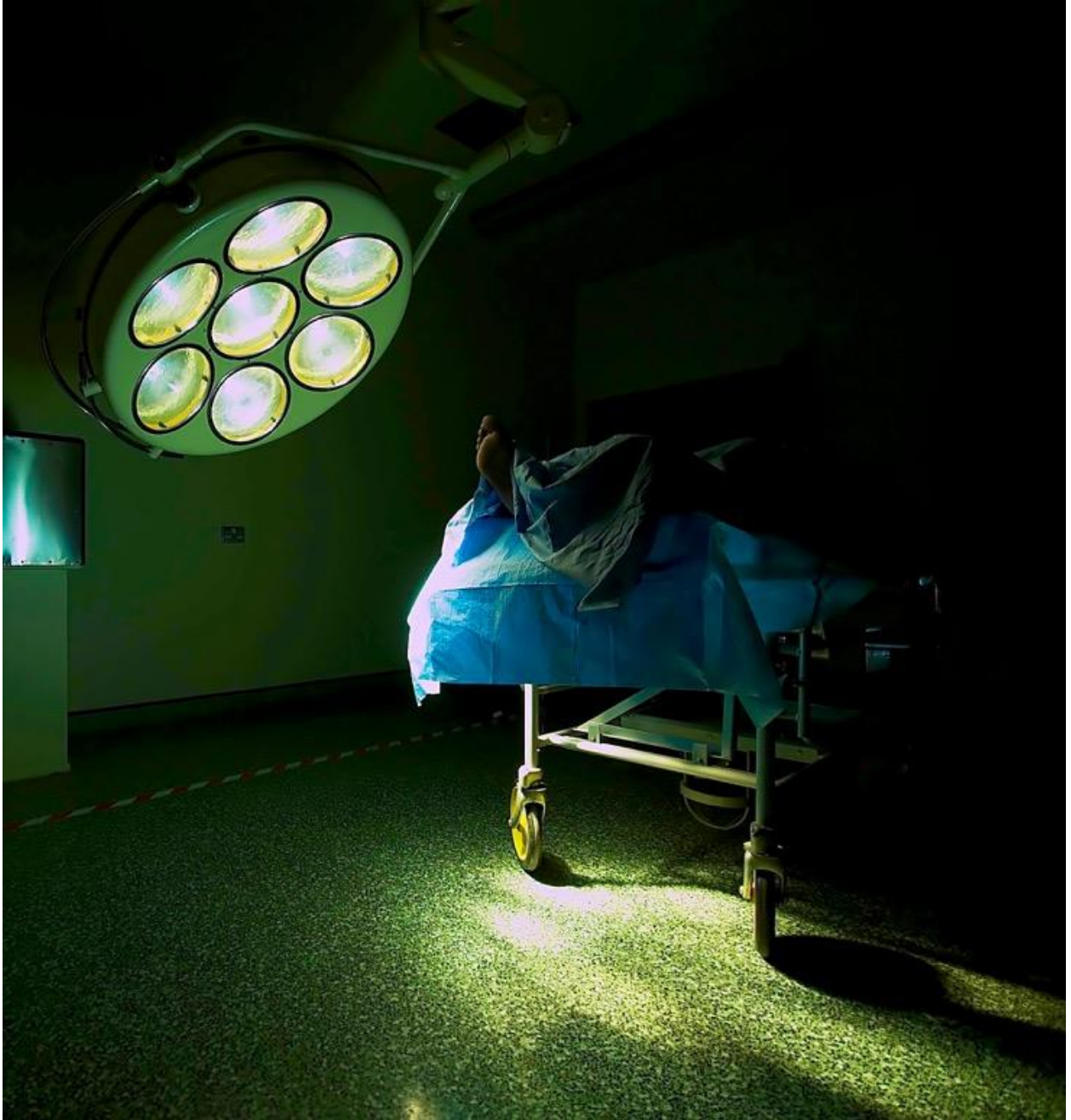


photo by Stephan Ray

[DEATH ON THE ICU](#)

By Phyllis Coletta, JD as published on [Lion's Roar](#)

There are no words to describe an intensive care unit death. It is often preceded by barbaric medical interventions. Machines, wires, drugs, and pumps sustain a body until bereft family members find a way to stop the aggressive treatments and let nature take its course, often feeling like they are committing a crime rather than releasing someone from a prison.

When I worked as a Buddhist chaplain in a medical ICU, I was shocked by the suffering every day as families anguished over what to do next. The ICU is no place for siblings or children to have conversations about what a parent or loved one would have wanted. It's like trying to teach a drowning man to swim. Families — as well as their neighbors, faith communities, and clinicians — would benefit if we could all stop being fearful and address end-of-life care and decisions.

What if we could talk about about end-of-life care over dinner? What if priests and rabbis and pastors fostered values-based “upstream” conversations about how we want to live and die, knowing they are intimately connected? What if it was not taboo to talk about the kind of treatment you want — or don't want — before you die?

Eighty percent of people want to die at home, but seventy percent die in institutions.

The pain I saw on the ICU was the most excruciating emotional suffering I have ever witnessed. But some of that suffering can be mitigated. When a family truly understands the patient, they can effectively advocate for the kind of death their loved one wants. According to [a survey by The Conversation Project](#), about 80% of people want to die at home, but 70% die in institutions. The vast majority of people want a mostly pain-free natural ending at home with loved ones. Why shouldn't they have that and why is the divide so deep?

Physicians and medical machinery can easily overwhelm patients and families. But we can reclaim the process, and instead encourage one another to talk about what we want our dying to look like. [The Conversation Project](#), for instance, is a grassroots vehicle for helping communities have these difficult —

though sometimes also joyful and freeing — conversations about life and death. The organization was founded by Ellen Goodman, a Boston-based journalist who felt completely lost when charged with her own mother’s end-of-life care. I serve as the director of the Boulder branch. We seek to foster effective, values-based conversations around life and death, starting in families and communities. Neighborhoods band together to keep their streets safe; they can be powerful change agents on the block. What if we had champions of end-of-life discussion in our neighborhoods and churches?

The Conversation Project offers a simple tool for talking to loved ones about what matters most to you, in life and in death. Dr. Atul Gawande has written a bestselling memoir, *Being Mortal: Medicine and What Matters in the End*, which fearlessly examines how barbaric our treatment of dying patients can be. PBS featured him and other physicians on a Frontline special, well worth watching, about how clinicians struggle with talking to patients about dying.

Fifty percent of us will be unable to make decisions about end-of-life treatment. So now, while we can, we just need to open our hearts and start talking to those who will. I want to spare my three boys the anguish inflicted on families by fear or aggressive medical treatment. I’d like them to be with me as I move out of this life, untethered to machines or specialists, their loving arms catching me as I fall.



SAMPLE SERMONS

Rabbi Philip H. Sherman
Yom Kippur: Yizkor 5774
Saturday, September 14, 2013
Temple Beth Elohim



Talking Through Loss

“A man seeks employment on a farm. He hands his letter of recommendation to his new employer. It reads simply, ‘He sleeps in a storm.’

“The owner is desperate for help, so he hires the man.

“Several weeks pass, and suddenly, in the middle of the night, a powerful storm rips through the valley.

“Awakened by the swirling rain and howling wind, the owner leaps out of bed. He calls for his new hired hand, but the man is sleeping soundly.

“So he dashes off to the barn. He sees, to his amazement, that the animals are secure with plenty of feed.

“He runs out to the field. He sees the bales of wheat have been bound and are wrapped in tarps.

“He races to the silo. The doors are latched, and the grain is dry. “And then he understands. ‘He sleeps in a storm.’”¹ Albom, Mitch. *Have a Little Faith*. P. 93.

On Yom Kippur, our liturgy is characterized by language about life and death. We pray for forgiveness, for our lives to be sustained by God, while also recognizing that in the end we all return to our Creator. This season is a time for taking stock of how we live, for developing awareness of how we might wish to improve or change our ways. On Yom Kippur we often wonder if we have done enough. Have we secured our animals and wrapped our bales of wheat? That is, are our lives in order and our relationships in line with where we wish them to be?

When we live mindful and intentional lives, when we care for the things that are important to us, when all is right with those we love, we will not be troubled by thoughts of a life unfulfilled and we can sleep in a storm.

This morning, we stood before God and asked, “who shall live and who shall die?” The whole day is in many ways a reminder of our own mortality. It is impossible to observe Yom Kippur without developing a new awareness of the fact that our lives are bound by time. In fact, Yom Kippur is also considered by our Sages to be an annual dress rehearsal for death. We observe the rules of Yom Kippur by abstaining from food, drink, and other pleasures and necessities. We do this in order to remove distractions and have a spiritual experience without concerning ourselves with physical needs. Some may choose to wear white, the color worn by God’s legion of angels, and as a reminder that at the time of death, we are traditionally buried in a kittle, or white shrouds. In the words of Rabbi Shefa Gold, “For the whole day of Yom Kippur, we act as if it is our last day, our only day to face the Truth, forgive ourselves and each other, remember who we are and why we were born.”(² <http://www.rabbishefagold.com/RehearsingDeath.html>)

Soon, the sun will begin to set and the gates of repentance will slowly begin to close. We may feel eager at this point in the day to move on from death to life. Yet, before we can be fully present for the ending of Yom Kippur, we take time for the Yizkor service, a powerful and important part of transitioning into the new year ahead that asks us to recognize the people in our lives who have died, and reminds us to evaluate how we are living in light of our own mortality.

Talking about death and dying is not easy; it can bring up fears for the future and painful memories from the past. It is a topic frequently avoided in society today. We often discuss death in hushed voices and far away from children who might be considered too young to understand. In fact, many of us are taught from a young age to think that death is scary, and so we are afraid to talk about it even as adults. However, death is a reality of life and a universal experience for all of us. How can we become comfortable talking about dying more regularly so that our conversations on loss do not take place solely on Yom Kippur or in the wake of a death?

Even though talking about loss is challenging, it can be viewed as an opportunity to elicit a more positive end of life experience when that time arrives.

Having difficult conversations about death earlier in life can free us to focus more of our attention on the holiness of dying and the lived lives of the deceased. Rabbi Abraham Joshua Heschel understood the importance of this idea saying, “In the presence of death there is only silence, and a sense of awe.”³ Brown, Erica. *Happier Endings*. P. 294) When we have to make detailed arrangements about end of life choices in our last moments, this sense of awe may not be present. Erica Brown, in her book *Happier Endings*, suggests that this is a reason for making last memories full of the sacred, having ideally, already dealt with the details. Returning to my earlier metaphor, if we have prepared our farms for the inevitable storm, we can be truly present for our loved ones in their last moments and move through loss with more awe.

The Torah, our tree of life, includes an example of the power of having a conversation about one’s after-life wishes prior to the time of death. At the end of the book of Genesis, our beloved patriarch Jacob is dying. He calls his family together to give blessings for each of his sons.⁴ He then goes on to share an extensive dialogue in which he communicates his last wishes. “I am about to be gathered to my kin,” he says. “Bury me with my fathers, in the cave which is in the field of Ephron the Hittite, the cave which is in the field of Machpelah, facing Mamre, in the land of Canaan, the field that Abraham bought...”⁵ Jacob faces the reality of death head-on by initiating this conversation, creating a useful model for how future generations can candidly talk about loss.

In an effort to create these meaningful conversations among members of our congregation, we are launching, The Conversation Project here at TBE this fall. The mission of The Conversation Project is to be a “national public engagement campaign to ensure that each person’s wishes for end-of-life care are both expressed and respected. The project has its roots in the growing understanding that too many people are dying in ways they would not choose and that too many loved ones are left feeling guilty and uncertain about whether they did the right thing.”⁶

As an initiative of the Caring Community Team, we hope to open these conversations in our TBE community. Beginning in at the end of October and early November, we will offer workshops that will introduce this project and provide skills to make

it a reality in our own families.

According to The Conversation Project, “The ultimate goal...is... to change the cultural norm from not having these conversations to having them.” They believe that “to change that norm, we need to impress people with the importance of the conversation, provide them with tools to make it easier to have the conversation, and encourage these critical talks to take place at the kitchen table before there is a crisis.”⁷

It is my hope that we can all understand the importance of planning for death—even when it seems far off—and begin to have these difficult conversations with our loved ones ahead of time by making the topic of dying less taboo. Yet, sometimes we feel like we had no time to prepare, a death happened too quickly, too soon, or against our wishes. However, even in these cases we can still prepare ourselves by having these conversations with our families, and by doing so, we can open up the possibility for *happier endings*.

Studies performed by The Conversation Project, suggest that when people have these conversations about death during life, they experience less guilt and depression after the loss of a loved one. In being honest and realistic in talking about the end, we can be more alive in the present, more aware of the fragility of life, and more appreciative of the people and things that make us happy. The ability to recognize the reality of death can ultimately bring us more happiness and fulfillment in life.

Two weeks ago, Mike Winston, a high school friend of mine, died of ALS also known as Lou Gehrig’s disease. Mike fought a long battle with ALS, but eventually its slow and crippling effects took his life. In the last few years as his condition deteriorated, I watched my friends in the Minneapolis Jewish community and around the country come together to support him in his courageous battle, and I was reminded that the process of preparing for death has much to

⁴ Genesis 49:1

⁵ Genesis 49:29-30

⁶ The Conversation Project - <http://theconversationproject.org>

⁷ Ibid.

teach about strength and courage. For many, Mike was a teacher of these things. The unending perseverance he displayed even as his body was failing him little by little was a sign of hope to others. Whether attending ongoing physical therapy to adapt to the gradual loss of muscle movement, organizing ambitious fundraising efforts for ALS, or using his eyes to navigate and control his computer to communicate with friends via email and Facebook, Mike fought each and every day. His sense of purpose even in the face of death inspired others to appreciate their own mortality and live life fully as a reflection of his example.

The other day I spoke with a friend back home and we were reminiscing about Mike. He told me that each time he received an email update on Mike's condition, he was struck by all the simple things that he takes for granted that Mike could no longer do, like picking up a glass of water, getting dressed in the morning, or walking up the stairs. He shared with me what it was like to visit Mike after he was completely paralyzed. He found himself helping to carry him up the stairs, and for the first time fully realized the impact of Mike's condition.

Overwhelmed, he almost dropped him. Mike, who was attuned to his friend's experience and jokingly said, "don't feel sorry for me, or I'll punch you in the face!" Mike was determined not to let his disease get him down; he kept his sense of humor and he expected those close to him to do the same. He truly allowed his friends to find new meaning in living. The reality of his and every death is that it can show us how fortunate we are to be alive.

Soon we will recite the words of Yizkor which serve as a reminder of many things. First and foremost, the deaths we have experienced in our personal and communal lives. It compels us to consider the limits of the human condition, and it encourages us to live our lives with more gratitude, compassion, and joy. Yizkor gives us the opportunity to acknowledge the reality of death, to talk about and share the experience of death communally, reminding us that candid conversation can be a powerful and comforting experience. As we recite the memorial prayers in the Yizkor service today, let our words of memory remind us of the fragility of life and the charge we have to take advantage of the possibilities in our current realities. In remembering people we have lost, let us recognize how they brought joy and contentment to our lives.

As we move into prayer, I offer a blessing for this sacred moment of remembrance: May the one who blessed our ancestors, Abraham, Isaac and Jacob, Sarah, Rebecca, Rachel and Leah, bless this holy community as we come before You, God, to recite Yizkor. Guide us to honor the memories of our loved ones who have died, and to appreciate the ways in which we have grown and changed since their passing. Grant us courage and strength to overcome pain. Compassionate one, we turn to You in times of sorrow, saying "though I walk through the valley of the shadow of death, I fear no evil for You are with me."

Grace us with your continuous presence, that we may find joy in realizing the sanctity of human life, and live always with the memory of those who are no longer with us today. Blessed are You Adonai, our God, who bestows on us compassion, grace, and love, giving us the ability to have meaningful conversations, and to not only be prepared for a storm, but also to feel the warmth of the sun after it passes.

Zichronam Livracha – May the memories of those we have lost be for a blessing, now and always.

Old South Church in Boston
December 15, 2013 - Third Sunday in Advent
Generation to Generation, a sermon by Nancy S. Taylor, Senior Minister
Based on *The Magnificat*

Every arrival portends a leave-taking. Every birth portends its own death.

Mary knows it. Did you hear it in her song? Her song is triumphant. It is exultant. God bless her, she's pregnant! She's going to have a baby! Yet, even as she celebrates and anticipates birth, she cannot help but foresee, dying. Hers. Her unborn child's.

Every arrival portends a leave-taking. Every birth—even Jesus' birth—portends its own death.

The Magi knew it. No sooner is the Christ child born than they arrive with their old men's gifts: frankincense and myrrh. Spices with which to prepare the body for burial. Happy Birthday, Jesus.

It is not easy for me to say this to you. As your pastor, it is not an easy thing to say, but it is my duty: you will die. Each of you. All of you. Every single one of you.

The death rate among us: 100%. Even Jesus died. Apostles Creed insists: *He was crucified, died, and was buried*. The ancient creeds are particular on this point. They want you to know this was no resuscitation. *Jesus was crucified, died and was buried*.

The death rate among us, including Jesus: 100%. We know it: this hard-as-steel-truth. But it's not easy to face. Not easy to bear. Not easy to talk about especially, God help us, with our own families.

But it is not so for young Mary. Mary is marvelously, wondrously tuned in to, reconciled to the hard- as-steel-fact of passing on. Here is why. Here is Mary's secret to being reconciled to death: Mary links the fact of passing on (the fact of her own passing on) with the art of

passing down ... of bequeathing.

Think of Mary's song as her last will and testament. In it she bequeaths her son to the ages.

As if the gift of her son is not enough, there is more. This young woman, this girl-child, gifts us with a song – a song that is itself a kind of kaleidoscope: with shifting and overlapping glimpses and fragments of past and future, of ancestors and descendants, of remembrance and inheritance, of a promise that shimmers and shifts in the light. A promise passed down and taken up: generation by generation, taken up, parent to child, teacher to student church to church, down through the millennia. A promise taken up here, now in our own arms in this season of Advent. A promise carried in white lights and fragrant greens, in memorial poinsettias, in carols and in candles to pierce the night

Every birth portends its own death. Every arrival portends a leave-taking. But, listen now! Hear this! With every leave-taking, there can be a leaving, a bequeathing, a gifting, a passing down.

Let me say it clear: When you link the fact of your own dying with your own gifting to the next generation—it will take the sting out of death. I promise. So help me God.

Some examples:

Benjamin Franklin, a child of this church, was like Mary, reconciled to his own dying and marvelously and wondrously tuned in to the way the generations are linked. He linked the fact of his own passing on to the art of passing down.

Listen!

I, Benjamin Franklin... do make and declare my last will and testament as follows:

I have considered that, among artisans, good apprentices are most likely to make good citizens, and, having myself been bred to a manual art, printing, in my native town of Boston, and afterwards assisted to set up my business¹ in Philadelphia by kind loans of money from two friends ... which was the foundation of my fortuneI wish to be useful even after my

death, if possible, in forming and advancing other young men, that may be serviceable to their country... To this end... I give one thousand pounds sterling to the inhabitants of the town of Boston...

The said sum... shall be managed under the direction of the selectmen, united with the ministers of the oldest Episcopalian, Congregational, and Presbyterian churches in that town, who are to let out the sum upon interest... to assist young married artificers in setting up their business...It is my desire that this institution should take place and begin to operate within one year after my decease ...In witness whereof, I have hereunto set my hand and Seal this twenty-third day of June, Anno Domini one thousand Seven hundred and eighty nine.

B. Franklin.

The institution Benjamin Franklin imagined, and named and provided for in his will? Located blocks from here, in the South End, the Benjamin Franklin Institute of Technology educates young men and women from Dorchester, Mattapan, Roxbury ... young men and women of every nationality and ethnicity ... educates and equips them with practical skills: automotive technology, HAVAC, opticianary, computer science and more.

Benjamin Franklin has passed on ... but not before passing down, not before gifting to the next generation a part of his own self and soul.

Then, there is Mary Norton. Mary Norton is perhaps best described as the mother of Old South Church. She is our Sarah, our matriarch and progenitor. She too linked her own dying, her own inevitable passing on to the art—the high art, the generative, imaginative, affectionate art— of passing down. Listen!

In the name of God, Amen. The twentieth day of August In the year of Our Lord, one thousand, six hundred and seventy-seven., I Mary Norton of Boston....Relict Widow of The Rev. John Norton... commend my soul to God who gave it, and my body to the earth... I give and bequeath unto (Old South) Church in Boston, my now dwelling house with all the land belonging to the same, as it is situated near the Meeting House ... with all profits, privileges, rights and appurtenances whatsoever

... for the use of said Church successively forever. In witness thereof, I the said Mary Norton, have hereunto set my hand and seal the day and year first above written.

Mary Norton was one gutsy woman and Old South would not be here without Mary Norton. During her life she gifted us—to be precise, she gifted a rag-tag band of rebellious Puritan young couples ... young couples determined to make the waters of baptism ever more available ...determined to adjust the flow of the waters of baptism from a trickle to a gush because God's grace is more gush than trickle.

During her life, Mary Norton gifted us the land on which we built our first meeting house and then our second meeting house.

Later, in her will, in her dying, she gifted us with yet more land and with her own house and home ... which became the parsonage for generations of our ministers (until the house perished in Boston's Great Fire).

Mary Norton's last will and testament enabled this church to carry on...to give bold witness, extravagant witness to this: the grace of God is more gush than trickle and that we have no business controlling the valve.

Now, lest you think a worthy will, a worthy gifting to the next generation requires property and wealth, Steve and Liz Morgan (who are still very much with us) have drawn up ethical wills. Wills in which they make a stand against capital punishment in a most poignant statement. Listen!

I, Stephen V. Morgan, resident of and domiciled in the Town of Amherst, County of Hillsborough, and State of New Hampshire, do hereby make, publish and declare this to be my last will and testamentI hereby declare that should I die as a result of a violent crime, I request that the person or persons found guilty for my killing not be subject to or put in jeopardy of the death penalty under any circumstances, no matter how heinous their crime or how much I have suffered.

Sisters and brothers, as your pastor, it is my bounden duty to tell you this hard truth: you will die. This embodied, earthly gig, this sweet, sweet gig—the one that comes with the taste of strawberry ice cream and the aroma of fresh ground coffee and the sound of an infant’s squeal—it is temporary.

I know you know it. But I also know it’s not easy to face. Not easy to bear. Not easy to talk about especially, God help us, with our own families.

That’s where Mary comes in. Mary links the hard-as-steel fact of passing on with the strong, imaginative, generative, affectionate art of passing down, of bequeathing.

Every arrival portends a leave-taking. Every birth portends its own death. You will die. Yet, here is my promise to you: If you take up the art of passing down, it will soothe the sting of passing on. So help me God.

So Mere Mortal, let me put the challenge clear. How might your dying beget a birthing? How might you gift the generations to follow? How might you take up the strong, imaginative, generative and affectionate art of passing down?

If you set your heart to this challenge, it will ease the sting of death. I promise. So help me God.

TALKING WITH LOVED ONES ABOUT LAST WISHES

October 5, 2014

The Rev. Catharine
Harris UU Church of
Boulder

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)."

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.

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 of 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.

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 all 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 are 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.

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 live 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/>

THOUGHTFUL ENDINGS PLANNING DOCUMENT

The following is an example of a project undertaken by a faith community in Boulder Colorado, where a series of workshops were offered regarding these critical conversations. The planning document included here is the culmination of the group work done over several months. You can use, amend, or add to it in any way that best serves your community.



Thoughtful Endings -- Planning Document

This document provides you with an opportunity to organize your thoughts, records and practical information related to a serious illness and death. Doing so is a gift that you give to those who care about you and may provide you with the peace of mind that comes from "having things in order". It is important to make copies and share this with your family and your caring religious community. A confidential file will be maintained at BVUUF.

PLEASE PRINT

Member: _____

Home Address: _____

Home Phone () _____ Cell Phone () _____

E-mail _____

Primary Contact: _____

Relationship: _____

Home Phone () _____ Cell Phone () _____

E-mail _____

Secondary Contact: _____

Relationship: _____

Home Phone () _____ Cell Phone () _____

E-mail _____

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Thoughtful Endings -- Planning Document

Please share a copy of this with BVUUF and your loved ones.

IMPORTANT END-OF-LIFE DOCUMENTS

I have completed the following:

_____ **Medical Durable Power of Attorney**

It names _____ as my decision-maker/agent. The alternate, in case my first choice is unable or unwilling to serve, is _____.

Agent's* Phone Number: () _____

Alternate's* Phone Number: () _____

**These individuals, chosen to speak for you, should have copies of all health care documents. This document allows space for instructions for your agent. THIS is the most important document.*

_____ has a copy

Contact Information: () _____

_____ **Advance Directive for Surgical/Medical Treatment (Living Will)**

**Provides more specific guidance about what you would want under certain circumstances.*

_____ has a copy

Contact Information: () _____

_____ **Cardiopulmonary Resuscitation Directive (CPR)**

**Must be signed by you or your agent and your physician and should be displayed in your home and offered to emergency medical personnel and staff in a care facility.*

_____ has a copy

Contact Information: () _____

_____ **Medical Orders for Scope of Treatment- MOST form**

**For chronically ill or seriously ill people. Must be signed by you or your agent and your physician and should be displayed in your home and offered to emergency medical personnel and staff in a care facility. While the CPR Directive is valid, this document provides direction on treatment decisions beyond CPR. This form should be available at your medical provider's office.*

_____ has a copy
Contact Information: () _____

NOTE: All of the documents listed above are available at www.ColoradoAdvanceDirectives.com

_____ **I am an Organ Donor**

**Being an organ transplant donor (different than donating organs or your whole body for research) is a generous and worthwhile decision. Know that only limited tissues (no organs) can be harvested if one does not die in hospital. Donating for research is a more viable option for one who dies at home, such as on hospice. Be SURE that your family knows your wishes and is on board with your decision.*

Other helpful documents may include:

_____ **The Conversation Project Starter Kit** - basis of a values-based discussion with those who care about you. www.theconversationprojectinboulder.org

_____ has a copy
Contact Information: () _____

_____ **Dementia Provision** - prepared by Compassion and Choices.
www.compassionandchoices.org/userfiles/Dementia_Provision.pdf

_____ has a copy
Contact Information: () _____

_____ **Legacy Letter/Ethical Will** - *You might find great satisfaction in creating a document that embodies your life values; something that can be passed onto future generations.*
<https://celebrationsoflife.net/ethicalwills/>

_____ has a copy
Contact Information: () _____

ESTATE PLANNING DOCUMENTS

_____ **Last Will and Testament**

_____ **Power of Attorney or Personal Representative**

Identified person (s) _____

_____ **List of accounts and passwords**

**Whoever is going to be handling your financial matters after your death, should have a copy of or know where to locate passwords for your computer, your phone, and for your accounts.*

Location of documents: _____

OBITUARY PREPARATION

Person in charge _____

Home Phone () _____ Cell Phone () _____

E-mail _____

**You may wish to write your own obituary so that it reflects what you would like to world to know about the life you have lived. It can be done at any time but it is wise to entrust someone with the responsibility of updating it at the time of your death.*

_____ **Photo attached**

(If you have a photograph that you prefer be used with your obituary and related matters, please attach a copy to this document here.)

MEMORIAL SERVICE PLANNING

**You may wish to plan your service with the BVUUF minister or with someone else. Your family will appreciate you having made choices about location, music, readings, etc. This can be done in advance of an illness or impending death.*

The following are my choices regarding a Funeral or Memorial Service:

Location: BVUUF _____ Funeral Home _____ Other _____

Preferred officiant: _____

Participating Organizations:

Military _____ Fraternal _____ Other _____

Music and other elements I would like included:

Hymns:

Other Music – Solo, Choir, Instrumental, Recordings:

Readings & Poems:

Special Presentations, Performances, or Exhibits:

Memorial Donations should be directed to the following:

Following the service I prefer for family, friends, and guests:

A reception with refreshments and food to be served:

At the church _____ At my home _____ Alternate location _____

Notes: _____

DISPOSITION OF BODY AFTER DEATH

Immediately following my death:

_____ I would prefer to have a funeral provider take care of my body

_____ I would prefer to have my family and/or community care for my body at home

My preference for final disposition of my body:

_____ **Traditional Burial**

Funeral Home in Charge: _____

Contact Information: () _____

Designated Burial Site : _____

Graveside Service: Yes_____No_____

Pallbearers:

_____ Contact # _____

_____ Contact # _____

_____ Contact # _____

_____ Contact # _____

_____ Contact # _____

_____ Contact # _____

OR

_____ **Cremation**

Designated Organization: _____

Cremains to be:

_____ scattered (desired location: _____)

_____ distributed

_____ inurned to be buried

_____ inurned to be placed in a columbarium
_____ other _____

Contact Information: () _____

Designated Recipient of Cremains: _____

Relationship: _____ Phone () _____

OR

_____ **Green Burial**

Designated Organization: _____

Preferred burial container: _____

Contact Information: () _____

Relationship: _____ Phone () _____

OR

_____ **Donation of Remains to Scientific Research**

Designated Organization: _____

Contact Information: () _____

SIGNATURE

These are my wishes and directives.

_____ /

Signature / Date

Witness Signature / Date

Witness Signature / Date

The complete Starter Kit is available free on [The Conversation Project](https://www.theconversationproject.org/) website.



Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.



Institute for
Healthcare
Improvement

the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

Here is a sample of the kind of values-based questions used in The Starter Kit.



NAME _____

DATE _____

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. We developed the **Conversation Starter Kit** to help you talk with your loved ones about your—or their—wishes for end-of-life care. After you have the conversation, you can use this Conversation Starter Kit Summary Sheet to record your wishes, and share them with your doctor or others as you wish. And you can return to it over several conversations.

When should you have the conversation?

Even if you're in good health, it's still important to make sure your loved ones, and your health care team, know your wishes, since anyone's health status can change suddenly. It's particularly important to have the conversation if you or a loved one has a chronic or serious illness. Every conversation will help your loved ones and your care team understand what matters to you.

.....

? As you think about how you want to live at the end of your life, what's most important to you?

Now finish this sentence: What matters to me at the end of life is...

(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

Where I Stand Scales

Select the number that best represents your wishes. (You can write on the dotted line below each scale if you'd like to explain or add notes about your answer.)

As a patient, I'd like to know...

- 1 2 3 4 5
 Only the basics about my condition and my treatment All the details about my condition and my treatment

.....

If I had a terminal illness, I would prefer to...

- 1 2 3 4 5
 Not know how quickly it is progressing Know my doctor's best estimation for how long I have to live

.....

As doctors treat me, I would like...

- 1 2 3 4 5
 My doctors to do what they think is best To have a say in every decision

.....

How long do you want to receive medical care?

- 1 2 3 4 5
 Indefinitely, no matter how uncomfortable treatments are Quality of life is more important to me than quantity

.....

SUMMARY

Faith communities can be an invaluable resource in relieving suffering for individuals and families. As faith leaders charged with the honor of walking people through difficult times, you are in a unique position to make a lasting difference between a “good death” and a bad one. The latter experience leaves a legacy of suffering that can affect generations.

By intervening as a community and allowing and fostering meaningful conversations around medical care and quality of life, faith leaders can quite literally change the course of a person’s life and a family’s history.

Thank you for your time and attention. We encourage you to learn more, and to commit to Conversation Sabbath by [registering here](#). And for more resources and support, visit [The Conversation Project](#) webpage. If you want the game that helps to start conversations, it’s [My Gift of Grace](#). In my opinion, a really well-named exercise. Best of luck and thank you for helping others and relieving suffering.

Phyllis Coletta, JD
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