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**Reading** - from: *Letting Go; what should medicine do when it can't save your life?*

by Atul Gawande, M.D.  
in the August 2, 2010 issue of *The New Yorker*  
(a physician, general surgeon, writer and author)

Recently, while seeing a patient in an intensive-care unit at my hospital, I stopped to talk with the critical-care physician on duty, someone I'd known since college. "I'm running a warehouse for the dying," she said bleakly. Out of the ten patients in her unit, she said, only two were likely to leave the hospital for any length of time. More typical was an almost eighty-year-old woman at the end of her life, with irreversible congestive heart failure, who was in the I.C.U. for the second time in three weeks, drugged to oblivion and tubed in most natural orifices and a few artificial ones. Or the seventy-year-old with a cancer that had metastasized to her lungs and bone, and a fungal pneumonia that arises only in the final phase of the illness. She had chosen to forgo treatment, but her oncologist pushed her to change her mind, and she was put on a ventilator and antibiotics. Another woman, in her eighties, with end-stage respiratory and kidney failure, had been in the unit for two weeks. Her husband had died after a long illness, with a feeding tube and a tracheotomy, and she had mentioned that she didn't want to die that way. But her children couldn't let her go, and asked to proceed with the placement of various devices: a permanent tracheotomy, a feeding tube, and a dialysis catheter. So now she just lay there tethered to her pumps, drifting in and out of consciousness.

Almost all these patients had known, for some time, that they had a terminal condition. Yet they—along with their families and doctors—were unprepared for the final stage. "We are having more conversation now about what patients want for the end of their life, by far, than they have had in all their lives to this point," my friend said. "The problem is that's way too late." In 2008, the national Coping with Cancer project published a study showing that terminally ill cancer patients who were put on a mechanical ventilator, given electrical defibrillation or chest compressions, or admitted, near death, to intensive care had a substantially worse quality of life in their last week than those who received no such interventions. And, six months after their death, their caregivers were three times as likely to suffer major depression. Spending one's final days in an I.C.U. because of terminal illness is for most people a kind of failure. You lie on a ventilator, your every organ shutting down, your mind teetering on delirium and permanently

beyond realizing that you will never leave this borrowed, fluorescent place. The end comes with no chance for you to have said goodbye or “It’s O.K.” or “I’m sorry” or “I love you.”

People have concerns besides simply prolonging their lives. Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars. The hard question we face, then, is not how we can afford this system’s expense. It is how we can build a health-care system that will actually help dying patients achieve what’s most important to them at the end of their lives.

### **Sermon**

I am very glad to be with the Emerson UU Community today. A little bit of introduction. While I am a UU minister ordained since 1981, I do not work for any UU congregation and have not served as a Parish Minister since the 1980’s. I grew up here in the Saint Louis area however, and am currently active in the Eliot Chapel UU community.

My day job is working at a hospice. I work as a Hospice Chaplain and Bereavement Coordinator, meaning that I provide spiritual comfort and support to patients and family members before death, and grief counseling and support after someone has lost a loved one. I’ve been working in hospice care for over five years now, serving three different companies during that time.

Now when I say I am a Chaplain, whether by way of introduction to patients and families or outside of the hospice in the larger community, I can literally see the hood of the Grim Reaper fall over my head. People imagine I am going to make them break down and cry if they spend any time talking with me. Many will respond by saying or thinking “Oh that must be very hard.” Actually it isn’t for me—most of the time. It’s a lot harder for me to get up here and deliver a sermon, for example, than it is to offer presence and support to the grieving and the dying.

That's because as a Hospice Chaplain, I am doing less talking, more listening. At least I am when I am doing my job well.

What I do is intense, and the conversations I have with patients and those who must face end of life issues can be difficult—for them, if not for me. The emotions are strong. For me it's whether I'm going to get it right, not be brutal, but not be dishonest also. The emotions are negative a lot of the time, full of anxiety, fear, emotional difficulty and pain, doubt and uncertainty—but not always. What is hard about hospice care is all the sadness, and what I perceive as spiritual pain and suffering. What's hard is the helplessness in the face of suffering. The fear that the answer to the question “Am I going to die?” is going to be yes, you are.

Well, we all are going to die, we know that. And we all want to deny that and put off the question of when. We put off the conversation as to how we want to die, for as long as we possibly can. Especially when faced with life threatening illness. Surely there are sadness's and difficult conversations in my field. When blessed with good health, youth, or vigor, we put off talking about illness and last things. But we also don't want to think about the end—at anytime. And no one wants to prepare by discussing last wishes or end of life issues. Even with loved ones, much less with your doctor. That has become painfully obvious in the debate during the health care reform bill, where such physician initiated discussions were left out of the bill, having been labeled “death panels.” As a society we are not yet able to handle even the four most simple questions for a doctor to ask a patient regarding what do you want to have happen when faced with a life threatening illness. Those questions are:

1. Do you want to be resuscitated if your heart stops?
2. Do you want aggressive treatments such as intubation and mechanical ventilation?
3. Do you want antibiotics?
4. Do you want tube or intravenous feeding if you can't eat on your own?

Making these wishes known in advance can relieve a lot of psychic suffering. But the wishes aren't static; they change. They change depending on your state of health, on your degree of suffering, on your desires to stay alive for as long as you can. Answering them sooner than later, however, and continuing to answer them—with a doctor, with family, with friends—can relieve a great deal of distress for all.

Atul Gawande, in his article, “*Letting Go*” tells the story of a palliative care specialist Dr. Susan Block and her father, Jack. Jack was a professor emeritus of psychology at UC Berkeley and faced a decision about a surgery on his spinal cord in his neck. The surgery carried a 20% chance he would end up paralyzed, versus a sure thing he would be a quadriplegic if he didn't have it. Susan was his health care proxy, but the evening before his surgery, she realized, “Oh my God, I don't know what he really wants,” if he ends up becoming critically ill. Even to this expert in end of life discussions, the conversation was difficult. But she was able to ask him the crucial question: “I need to understand how much you're willing to go through to have a shot at being alive and what level of being alive is tolerable to you.” To Susan's surprise his answer was: “. . . if I am able to eat chocolate ice cream and watch football on TV, then I am willing to stay alive.” And Susan had never seen her father watch football in her life.

But that conversation helped her immensely. It helped her care for her father. Jack had the surgery and lived for another ten years. But when the end did come, and the doctors explained what each procedure would do, she had a guide for his care.

Loss is hard. We never want to face it. Yet from our first days we face loss. I Corinthians 13 states, “When I was a child, I spoke like a child, I reasoned like a child, I thought like a child.” As we get older we put innocence behind us, and put an end to childish ways. Still, there is faith, there is hope—most importantly, there is love. I believe that our knowledge of love tempers our experiences of loss. It doesn't take them away, but love gives us reasons to respond to suffering and to affirm life—even in the face of loss. It was the

psychotherapist and author Sheldon Kopp who said, "The most difficult part of love is dealing with your helplessness in the face of a loved one's suffering."

We are helpless, and yet we can respond. What I can do, as part of the hospice team is just be there. Spiritual presence is what I offer. Listen. Just listen. I listen for the stories, listen for the fears, listen to the unspeakable thoughts and questions. People want to know what it's like. What is death like? Will I suffer? Will I be at peace? Will I be remembered? Will I be alone?

I don't know what death is like; just this past week a patient told me that she believed no one has ever come back to tell us what it's like. This from a faithful mother of a Church of God in Christ congregation. Perhaps it isn't true, however; maybe we do know. The author and playwright Mary Zimmerman was interviewed by Bill Moyers five years ago after her play *Metamorphosis* came out. He asked her about death, "What do you believe about death? What do you think happens at death?" She replied:

*Well, I'll tell you, I don't know what happens at the moment of it, of course, but I have a friend who very simply said, why does everyone ask us what's life after death like, what's death like? We already know what it's like, we've been there. We were dead before we were born. It's just like that.*

As a Hospice caregiver, most people aren't sure what to do when they first meet me. They walk around being awkward, not knowing what to say. When I reach out to those who already have lost a loved one as a Bereavement Coordinator, they may be so grief stricken they cannot share it at all. Some are fine; others are so much at sea, so depressed, so angry—holding in too much unresolved grief. If you offer the wrong kind of help, say giving out pamphlets or literature on loss and grief, they are liable to just say: "What can you do? I just lost my son, my wife, my loved one, and you want to give me some pamphlets? You want to send me to some support group?"

Well, that's me. Except I don't focus on giving out pamphlets and referring people to groups. Those things may help, that's not what I am there for as a Bereavement Counselor. I get that.

My work is to find a way to be present—to be present in the face of the suffering—the suffering of those facing the end of their life or those who have lost someone they loved very much. The bereaved are helpless, exposed, awkward; you don't know what to say or do. And you have nothing to offer another but caring, compassion and presence itself. All I can offer is the reaching out and attempt to connect with them mentally or emotionally or spiritually where it will matter the most. Sometimes trying to touch such a painful place is too much, and they know that is what I'm there to do. And so they push me away—say they don't need to talk or have me visit. Or they vent and show you their anger and disappointment. They really don't want to be touched because. Because it just hurts too much. There was a reason why mourning periods in the past were populated by the bereaved dressing in black. The black suit or dress, the black attire, told others, “Don't touch. Not just yet. It still hurts too much.”

And yet you still offer to do so. And come back later to offer again, when perhaps the wound has begun to heal a little, to heal from the inside out. All you offer is presence. As the grief therapist, Alan Wolfelt writes, “As a bereavement caregiver, I am a companion, not a “guide” (which assumes knowledge of another's soul I cannot claim). To companion, to companion our fellow human beings means to witness and learn as opposed to playing the ‘scientific expert’.”

Sympathy is not what the grieving are looking for. They are in pain. Spiritual pain, emotional pain, sometimes physically ill itself—from the psychic wounds caused by such a deep loss in their life.

Our culture still has a hard time with death. I'm not sure it will ever be easy to comfort those in pain from loss. Hospice and palliative care has been a great solution to many families where a patient has run the course of treatment options. Hospice is becoming more accepted, more known. And it can educate us as to what to

expect, encourage us to face the unknown, allow us to deal with the denial, anger, the fear and depression that comes with mortality and loss. It helps us heal from the inside out. Still, there are many who have not had exposure to or participated in the palliative care hospices provide. When people do, they are greatly appreciative of how much relief from suffering it can bring.

As much as I am familiar with the process of grief, as much as I know about dying and dying well, I really know very little. There is a passage in a poem "The Last Time" by the poet Marie Howe where she writes about her brother's death from AIDS at the age of 28. She writes:

*The last time we had dinner together in a restaurant  
with white tablecloths, he leaned forward*

*and took my hands in his hands and said,  
I'm going to die soon. I want you to know that.*

*And I said, I think I do know.  
And he said, What surprises me is that you don't.*

*And I said, I do. And he said, What?  
And I said, Know that you're going to die.*

*And he said, No, I mean know that you are.*

We don't like we know we are going to die. Especially when we know of others who seem much closer to death than us. They aren't closer, though, even if they are older or sicker. We are all just that close, as close to death as the other. As close as the next person alive is.

What happens after we die? Some are certain they know that for sure. Some are too afraid to even ask. My faith says that it isn't important. What is important is what happens before we die. What's important is today—how can this day be the best day possible. Here, now, when we are alive. Being alive means that one-day we must die. What matters, is our quest for love and the effort to be compassionate and kind in this life. It's not what you believe. It isn't the hopes you have, or the fears or resentments or all the guilt that you harbor. What is eternal—what endures—is love. What you believe about what death is like doesn't matter. It's just like it was

before you were born. What matters is how you express compassion—caring--love. And how you can express compassion here, now.

I believe this attitude is a very Universalist attitude. The doctrine of universal salvation teaches that all souls shall be saved. Universalists believed that was the true teaching of Jesus. God loves you no matter what. God will redeem you in spite of your limitations, your humanity—not because of it. You are charged and challenged to love the other, the mystery, what is divine in everything and everyone with all your heart and soul. And to love your neighbor as yourself. Love endures. Love is everlasting. This love without condition, love in the face of suffering, doubt and mystery is available to everyone without exception. We will know the power of love in life, and in the mysterious other some call God.

And so of faith, hope and love the greatest of these three is love. What is the most difficult part of love? It is the helplessness you feel when you see a loved one suffer. The hard part for those with life limiting illness is to let go. In the Buddhist tradition, there is a passage called The Five Remembrances. They are:

1. I am of the nature to grow old. There is no way to escape growing old.
2. I am of the nature to have ill health. There is no way to escape having ill health.
3. I am of the nature to die. There is no way to escape death.
4. All that is dear to me and everyone I love are of the nature to change. There is no way to escape being separated from them.
5. My deeds, my actions, are my closest companions. I am the beneficiary of my deeds. My deeds are my salvation and the ground upon which I stand.

I know there is a difference, a big difference, between giving up and letting go. My goal as a Hospice Chaplain is to allow others to let go, so that they can know that everything will be okay. Caring and compassion is primary in letting go.

No one can be sure that they will say the right thing at the right time in the dying process. It's hard, I know to say goodbye. It can be hard to say it's okay, I'm sorry, I love you and will love you forever and ever.

But in truth, all that makes a difference is presence, just letting the conversation happen, so that one can talk about their own life, or about the life of one they loved. Just showing up and being there, as you are able and willing to do. Just talking, just being human, being a companion, with all the limitations our humanity implies. All that matters is letting people know that they are not alone and that there are others who care about their suffering and the suffering of the ones they love.

Love is the reunion, the connection, between two separate and distinct entities. A reunion, because once, and perhaps now, we are all one, all connected, all part of a love which is beyond faith, beyond hope, beyond all understanding. And yet we strive to connect, make the connection, to connect the dots and show up and be there, in our work, our family our friendships.

Long before life there was love. We are united in this quest: to embrace compassion, to find a greater understanding of who we are, of what in us is true. No matter what you believe about god, faith, hope, life after death, there is the immortal consecrating power of love. And long after life there will be love. For love is eternal. Love will endure forever.