

It's in the Living: Lessons on Dying

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My Great Uncle George, who was 90, died last spring, and I have had all summer to think about how hard he made it for himself to die, how his grief silently stacked within him during his life, filling him with rage, and how he refused to openly say anything in life, let alone “good-bye” in death. His death is instructive about how not to live, and how not to die.

When I was a girl growing up in Youngstown, we saw George and his wife, Mary, at least once a month. Mary was a formal, intimidating, elegant Scotswoman. They married late, had no children, traveled often, and collected antiques. George never said much, Mary taught me manners.

While growing up I didn't know that George was rich. I didn't know that George and Mary were feuding with my father's parents (George and my Grandmother, Helen, were brother and sister). I didn't know that when George's mother died, he and Mary went to her house and took everything of value out of it, including the things my Great-Grandmother had wanted to give her other three children (like my Grandmother). My parents knew and just ignored it. George was my Dad's uncle, and even though my Dad's parents weren't on speaking terms with George, my father and mother talked to everyone, and so did I.

George was a Hoover and Hoovers don't talk. They don't phone. They don't choose to communicate. I wrote George and Mary when I was a young adult even though they did not return communication. It wasn't their way. My Dad, who is half Hoover, calls when prodded, and he and George seemed to have a good understanding of their shared ways. My father was George's only nephew, and after Mary died ten years ago, by far his closest relative, and truly a lifelong friend.

After Mary died, some strange, but not really new things started to happen. George joined a church, became good friends with the minister's wife and another female member. Mary's jewelry disappeared. He said it was stolen. We wondered if it went to these women as gifts (my mother noting that Mary would be rolling in her grave). About five years ago my father, sisters, and I realized that George would give his money to the church. That was OK with us. It was his money.

What we didn't expect was that when the will was read, my father, George's lifetime companion, the best man at his wedding, would be entirely cut out. Not even a sentimental item, like his coin collection, left to my father. The minister's wife and other church member were executors. They too cut my father out completely, selling everything of value in my Great Uncle's house at auction, without even telling my father who would have come and graciously bid on items. Likewise George's brother, my

Great Uncle Glen, was also cut out of the will. We all agreed that this would have been the time for George to finally return that Shingledecker desk to Glen (always meant for Glen, but unfairly taken from their mother's house when she died).

My uncle lived like he died and it wasn't pretty. Three days before his death he whispered to my father that he was afraid the minister's wife was only interested in him for the money. Compare this to the roshi able to enjoy cake. Compare and think. Although these women professed to be his friends, true friends would have attempted to get my crotchety uncle to reconcile with his family instead of just believing whatever he told them about my family being "bad" and "ignoring" him. They could have realized that he never chose to contact any of us. People make strange choices. (And...talk about faith and a congregation not helping)

But in retrospect, the traces of George's death can be found long ago in his living, in hoarding the family furniture, which I think goes back to some old grief he had with his parents. I think George didn't feel loved, and then withheld his love from everyone else, particularly his siblings and their descendants, and then died more emotionally alone than he wanted. I have wondered if he died thinking his will was a mistake. I am sure when he wrote it, it seemed so clever. He said to my sister once "I wish I could be a fly on the wall when my will is read." Clever doesn't help you die, or live well.

George died ten minutes after my father, his nephew, and his last living brother, Glen, stopped by to see him before my father returned Glen to the airport. He also died wearing a shirt my father had given to him. Family was what George wanted and needed, although he spent his lifetime pushing us away.

In his song "Live Like You Were Dying" country music star Tim McGraw sings "If life were just a gift/and you had eternity to think/what would you do with it/what would you do with it/what would you do if you could do it all again?" McGraw goes on to suggest skydiving, rocky mountain climbing, bull riding, reading the "Good Book," talking sweeter, loving deeper, and watching an eagle while it is flying. I wish my uncle had chosen to live like he was dying.

My uncle did not make this choice, but you and I can. All our lives we are dying. As Dror Mevaorach notes in his article *Apoptosis* (which refers to the continuous process of death in life)

Death is present from the very first days of an embryo's life. A five-week-old fetus already has a hand, but the fingers are joined in a web. By the sixth week, the fingers have separated, following the death of cells located at the web between the fingers. The death of these specific cells allows the appearance of the hand as we know it.¹

All our lives we are dying. This awareness alters our living, raising our awareness that life is a gift to be enjoyed, which is why I like the story of the roshi with the cake. It is very Zen. You have to think about this story, what it shows and tells about living and dying. It is more than humorous. What I have learned as your minister is that we

¹ Dvor Mevorach, "Apoptosis" in *Parabola* (Summer 2002), 50.

approach our lives like we will approach our deaths. I believe the adage “Grumpy old men were grumpy young men.”

There are exceptions to this. A disease like Alzheimer’s eventually alters the personality and cognitive reasoning of an individual beyond his/her control. Accidental, sudden, and violent deaths make it impossible for individuals to take time to say good-bye or plan some parts of their death. Other individuals are impaired by mental illness. These circumstances are somewhat different than what I am talking about today, living with depth and integrity to honor a finite life.

Almost all of us have the choice to face our death. A first step in this realization is to create a will now, to select a custodian for your children now, to give someone power of attorney and legally specify your wishes if you are brain dead now. We just don’t do it because we are afraid to live like we are dying. A recent article by Robin Marantz Henig in the *New York Times Sunday Magazine* entitled “The Struggle to Create the Good Death” notes “Half of all Americans said they were counting on friends and family members to carry out their wishes about how they wanted to die – but 75 percent of them had never spelled out those wishes to anyone.”² Caring for our loved ones and ourselves means completing these tedious documents now. No excuses.

Peter and I did not have a will until Adam was born, then we found a lawyer and drafted one. It was very challenging. I had to regularly think about dying. I had to imagine more than one scenario. What if I were brain dead? What if Peter were brain dead? If Peter and I both die, who raises our son? What if our first guardian also dies, who raises our son, then? This was not a world I wanted to think about, but if Peter and I ever die when Adam is still young, someday he will know we loved him because we took the time to legally clarify who could raise him well. And then we took out life insurance so his guardian can afford to raise him. And after all this was agonized over and done, our lawyer looked us in the eye and said “You will need to update this will again several times in your life depending on the age of your son and your financial circumstances.”

And so will you. Do it now and then go skydiving. Live like you are dying so you can get to the great stuff, and prevent the worst stuff, an abusive relative raising your child, no clarity on your wishes about ventilators and resuscitation, no knowledge of where to find your will or lawyer or bank accounts. Do it and know that death, like life, will continue to bring changes. Secrecy won’t help. Inflexibility won’t help. Avoidance won’t help.

Henig explains, “What we are addicted to, it seems, is the belief that we can micromanage death. We tend to think of a “good death” as one that we can control . . . But often our best-laid plans can go awry. Dying is awfully hard to choreograph.”³ I recommend taking care of the obvious details to cover your bases, but after that Henig is correct. Dying is awfully hard to choreograph. Most of us are afraid of death. I am afraid of death. However, what I have learned from you is that a good death is not

²Robin Marantz Henig, “The Struggle to Create the Good Death,” *Sunday New York Times Magazine* (August 7, 2005), 68.

³ Henig, 33.

controlled, because death can't be controlled, just openly faced and explored regardless of fear.

Please understand what I am saying. You can't control death by remaining alone in your house when you are frail. You can't control death by refusing to see a doctor. It will come to you all the same, only because you did not plan, you will have fewer choices. If you avoid these important decisions now you create more problems and suffering for you and your family in the long run. Death cannot be controlled, but it can be openly faced and explored. Face it. Explore it so you can make and choose your best decisions.

The reality is also that no matter how much you have legally clarified, end of life medical decisions are profoundly complex. I have known couples and individuals who have chosen to end cancer treatments because the side effects were not worth the minimal cure. There is no guidepost for this, only what fits you, and you have a right to choose this decision.

Likewise, when my Grandfather Ernst was dying quietly at home one night, with only my Grandmother present, she did not call 911. She did not want him resuscitated, because another reality is that whatever you legally clarify, if you call 911, the medic team will attempt resuscitation. It is their job. Likewise, no matter what you have specified, you might want resuscitated by that medical team because you are not ready to die. This happens too, and it is okay. The best we can do is honestly respond to what happens, and be willing to change if it if necessary.

My Grandfather had Parkinson's and was very frail. It was not clear that night that he was actively dying, but I think my Grandmother had an intuition. She just held him for hours, even after she finally knew he was dead. In the morning she called 911, and 911 was angry with her for waiting to call. But she chose well. My Grandfather, that gentle soul, needed to die, and Grandma was ready to let him go.

Dying is hard work for the living and the dying. Henig notes "Surveys indicate that about 70 percent of Americans say they want to die at home, few realize how grueling the work of dying can be. Almost everyone eventually needs care from either a paid assistant or, more often, a relative – and the toll is enormous."⁴ I encourage to you to choose, as best you can, the location and resources for your final illness.

People with slow, deteriorating illnesses can benefit from hospice, but I regularly see families who don't call early enough to receive the full benefit of services. Hospice accepts clients who they think have less than six months to live. Hospice can be offered at home or in some institutions, and some hospices now let you continue treatment (in the past you had to agree to discontinue treatment). Hospice is great with pain management and round the clock care. They are also terrific coaches for the living, letting you know how to touch and speak to your dying loved one.

Unfortunately, most hospice patients die within two to three weeks of being accepted, before they can utilize all the benefits.⁵ The Homans called hospice early and had a terrific relationship with their hospice nurses, who they got to know over the course

⁴ Henig, 30.

⁵ Henig, 30.

of a couple of months. I met these nurses and they were wonderful. This level of pre-planning had a lot to do with Frank who chose to quietly and openly plan for his death. It is really a privilege and a joy to sit with a parishioner who can talk about his/her final illness. It does not prevent suffering and loss, but it makes everyone feel connected, it makes the dying person feel connected, safe, comfortable. It is the way I hope to die if I have any choice in the matter.

In regards to hospice Henig notes, “Most sick people still don’t ask for it; it seems too much like giving up. Doctors are hesitant to recommend hospice, because it requires them to speak frankly about the inevitability of a patient’s death – something that most physicians are unwilling to do and that most patients are unwilling to hear.”⁶ I have been at family conferences where this has happened. If you are afraid to talk about death, your doctor probably will be too. Doctors are human beings too. They have too many patients to fight everyone who is unable to talk about dying, and some of them are just plain bad at it. So do yourself a favor, live like you are dying and talk about it so you can get more information to make better choices.

Several years ago, one of our long time members, Jim Percival called me up and said “Sharon, I have been accepted to hospice.” Jim had never called me before so I realized the importance of this call and went over to eat lunch with him that day. By Monday he was dead. This shocked me. He was still his feisty, Jim self on Friday. But Jim was also very open. He was in hospice. He was dying, and I think he was ready to die. His daughter told me that the evening of his death he stopped talking and seemed to be concentrating on internal matters. Shortly thereafter, he died.

But dying doesn’t always go that way. I had a chance to visit Duane Christy two days before he died and I put it off. He died before I got a chance to see him again. I remind myself that we can’t control dying, but I still wish I had gone to see him that day. I tell you this story because I know that many of you will have this experience, someone you wanted to see before he/she died, but you won’t quite make it. It is hard. I feel badly. You will feel badly and it happens. Death is impossible to control.

I also remember the many hours I spent in the hospital with Esther Muhlberger’s family. Esther had quietly gone in for surgery, did not do well, and died a few days later. Although Esther was in her eighties, her death was unexpected, but I saw that her children responded well because Esther was open and generous with people in her life, including her children. They knew she loved them. It was easier for them to face saying good-bye to her, telling her in the hospital that she could let go because they were clear about her legacy of love and joy. Esther had long lived like she was dying. But I will be honest with you, not a lot of families have that, which makes death harder for the living.

My Uncle George’s death has been hard for everyone, and I don’t think there was any way around that. His choices made it harder for everyone, especially him. And they were his choices. We did not have the power to change that. In his anger he left many of us confused and angry, uncertain of how to help him when he was living or remember him in death. He stacked his grief in life and in death, and now I, and my family (especially my father), will need to mourn, to feel a string of confusing emotions (love and anger), and eventually choose to release this experience so neither embitters us nor

⁶ Henig, 34.

becomes our legacy of how to die. It is a journey, a slow journey. I'm still angry with my uncle for leaving me with this mess, this story, this pettiness, the hurt I see in my father who did nothing to deserve it. I work through it one day at a time, and look for others who show me a better way.

When it comes time for you to die, tell your loved ones that you love them before you are too ill to speak. Have those "big" conversations when you are still well enough to finish them. Your open expressions of love and affection will be a shield for those you leave behind, a good memory of what your lives meant together. Take the time to say, "I love you" and "good-bye."

Life helps us prepare for death by creating opportunities to face difficult change. Face them. Every one you cross will offer you lessons that will help you live and die. If you can die openly and honestly you can teach your family and friends how to die with more love and flexibility. People like Jim Percival, Esther Muhlberger, John Daniels, and Frank Homan have taught me how to die. I will always remember them and always be grateful to them.

For now, enjoy your life, learn and see new things, tell and show people close to you that you love them (don't keep it a secret), experience gratitude, try something new, explore a dream, step outside and feel the air, do something for someone else, particularly a stranger. Have a wonderful time. I hope you all live like you were dying.

Shirley Schmalz told me that when she was growing up ninety years ago, her family had a summer home on a beach in Mattapoisett, Massachusetts that had been built by her grandfather. If you don't know about summer beach houses, they are powerfully sentimental locations where the same group of folks gather for generations, as was the case with Shirley's family. A terrific hurricane blew onto shore one day after the summer season was over and everyone had gone home. It wiped out the entire beach and all the homes on it, all those familiar pathways, family mementos, and favorite ocean spots, gone. When Shirley returned to the beach the only thing left standing on her family lot was a toilet. That was it, a big beach and one toilet. She says that the toilet was sitting there alone as if to say "The heck with you." Shirley always laughs when she tells this story. I asked her if she laughed even then. She said "Oh, yes. It was funny." A lot of people would have cried. Many would have been angry. Shirley laughed. Everyone was safe, and the toilet was the only thing standing. It is funny, very funny, if you know how to live like you are dying.