

Helping Mom Die: An Auto-ethnographic Account of Preparing for Death

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Abstract

This article is about a journey that I took with my mother as she left us. It is an article using an autoethnographic approach which allows me, the writer, to use both my personal pain and thoughts as a way to give peace, understanding, and perspective of the time before my mom's death. This article is also about giving a framework for those who will also go through the same experience with an aging parent, to both take away the stigma of death and to help the reader be present in a tough situation. For me, it was an honor to be with the woman who brought me into this world and to be able to be alone with her as she left.

Keywords

autoethnography, death, grief, relationships, dying

Where you used to be, there is a hole in the world, which I find myself constantly walking around in the daytime, and falling in at night. I miss you like hell.

—Edna St. Vincent Millay

Mom died on December 25, 2017, at about 9 pm. She was not alone. I was there. It wasn't easy for her. She didn't want to leave. I had to talk her into

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going. It was the most difficult week of all of our lives. But mom prepared us for it. We knew what she wanted. She had planned it. She had shared it. The only way I can make sense of a situation is to research it and write about it as a way to cope. And because I am trained as a feminist sociologist, I feel the need to share this experience with the hopes it will help someone else as they go through a similar situation.

Autoethnography

Traditional research has been shown to be narrow and limiting because it does not account for the various ways the researcher views the world. Autoethnography uses the personal experience of the author as a way to understand the cultural experience of the event. This method allows the researcher to be more self-reflexive. I see the importance of placing myself right in the middle of whatever I am studying and being open about my own worldviews to help the reader understand my thinking around the subject (Custer 2022). This type of method uses the personal experiences of the researcher as a way to understand what is being studied and addresses it in writing. Scholars use this method as a way “to produce meaningful, accessible and evocative research grounded in personal experience” (Ellis, Adams, and Bochner 2011).

According to Denzin (1999, 568) “writing is not an innocent practice. . . the authors of autoethnography. . . use personal experience and memory as the point of departure for writing things that matter.” Denison goes on to say that “the writer strips away the veneer of self-protection that is given by professional title and position. With nothing any longer to hide, the writer is now free to excavate the personal in the name of the political.” Ellis et al. (2011) suggest that it starts with an individual’s personal life trauma, but pays attention to the physical feelings, thoughts, and emotions, to try to understand the experience that is lived through. Writing in this way is cathartic for me, it allows me to think and write about my own experiences which in this case is death of a loved one. My experience is mine alone. It is different for my brothers and my sons. It allows me to cry while typing and be raw about very personal and emotional parts of my life that I hope to share with my readers. I have done this in previous articles I have written. When something happens in my life, it becomes my goal to research it, make sense of it, and then write about it (Wysocki, 2000; Wysocki, 1998).

Autoethnography has come a long way since researchers began using this method of study. Much has been written using autoethnography as a method, such as those writing about death due to an airplane accident (Ellis 1993), September 11 (Ellis 2002), severe sexual abuse (Ronai 1996), stillbirth of a baby (Weaver-Hightower 2011) and being victimized while wearing a

Muslim veil in public (Zempi 2017). For instance, Custer (2022) writes of his own father's death and describes it as storytelling that allows the writer to be vulnerable and reflexive about the trauma he has experienced. What they all have in common is that the reader is able to see and feel the experience of the author. In this article, I talk about the death of my dad, my husband, and my mother. Each of them is a different experience for me. However, this article is mainly about my mom and how she prepared us for her death and what it was like, as her medical power of attorney, to be with her until the end. Retelling this experience with my mom is allowing me to connect with the memories of her while reflecting on topics such as family, death, grief, and loss and with the hopes of healing,

Sociology of Death and Dying

Much of the literature on death and dying is found within the discipline of psychology. There is often no reference to the sociological factors associated with death. In this article, I am using the sociological perspective to take account of the wider social context, which is likely to produce an incomplete and distorted understanding of the human experience of illness and loss. Emotions are sociological phenomena that are conceptualized, experienced, and responded to dependent on the larger social situation.

According to Thompson (2012), everyone is a unique individual, but unique within a social context. Durkheim (1983) believes that each human being is born into a preexisting society that differs based on class, sex, and ethnicity. Society, and where we are born into it, will have a huge bearing on our life experience. Therefore, death is a social construct that is shaped by social factors, so it is important to situate myself from the beginning. I come to this experience as a sociologist, feminist, White, Jewish, heterosexual, woman, whose views on life and death might be different from someone of a different background. For instance, since I am Jewish, I don't believe in cremation. Jews believe that the soul doesn't immediately leave the body and that the process of decay allows a gradual separation from the body. Therefore, burning the body would be immediate and painful. I believe that no one should suffer unnecessarily. It doesn't matter if it is my dog or my mother. Years ago I went to the funeral of a friend from graduate school. She was African American and Seventh Day Adventist. The funeral was so powerful and uplifting. It was a true celebration of life where everyone was on their feet singing and dancing in the aisles. It was a wonderful experience and something I had never seen before. As a Jewish, White woman, we cry and are very subdued at a funeral. If the family is more religious, they would "sit shiva" by staying at home and receiving

condolence calls. Those who visit bring food for the grieving family so they are allowed time to grieve. Furthermore, Jews don't believe in donating their body after death. While many do nowadays because we understand how important it is, it is prohibited by Jewish law because deriving any benefit from a dead body is considered mutilation. These are all very different traditions, which shows how using autoethnography and the sociology of death and dying together is a good way to show how my experiences with death and dying are interpreted.

Mom

Mom was born in 1933 in Jersey City, New Jersey. She was the oldest of three siblings, my Aunt Evelyn and Uncle Arnie. My grandfather immigrated from Russia in 1904 and after settling in New York, moved to Jersey City where he married my Grandmother, Belle. Growing up, mom was surrounded by family and friends, which consisted of mainly religious Jews. She was very sick as a child, had rheumatic fever growing up, and then developed severe asthma. Her parents decided that she would go to the University of Arizona for college, where the air was supposed to be better for asthmatics. Once in Tucson, Mom received her degree in elementary education, started teaching, met and married a young Jewish man in the Air Force, our father. Shortly after that, I was born in Tucson on Davis Monthan Air Force base.

I am very much an Air Force brat. After Tucson, we moved to Riverside, CA, then to Columbus, OH where my brother Craig was born seven years later, on to Tampa, FL, back to Tucson, where my brother Barry was born three years later and in 1965 we were transferred to Denver, CO. Lowry Air Force Base in Denver was the last place we were stationed. Dad was then sent to DaNang Vietnam from 1970 to 1971 and after that he retired from the Air Force. For me, moving around contributed to my ability to meet and talk to anyone I came close to. I had to always meet new people. Mom said that she "loved her military life." I think things would have been easier if Dad had not been gone so much, but she always said "it was just the hardest part of the military."

In the late 1970s, Mom developed an acoustic neuroma (MedlinePlus 2020). This is a benign tumor that forms cells on the eighth cranial nerve. I was a young adult, working in the operating room in South Miami at the time, where I very much enjoyed my single life. Mom went to Massachusetts Eye and Ear, where there were specialists, to have the surgery and she wanted me with her. At the time, I was around 22. I remember it being a really long surgery and when she came out of the OR, we could barely recognize her. Her face was black and blue and swollen. The surgery paralyzed one side of her

face. It was frightening. Dad was still in Denver taking care of my young brothers, so it was up to me to stay with mom and help her get better. She was not, and has never been, great at rehabilitation. I remember once actually standing in the shower with her, while she complained about everything she was being asked to do and saying over and over “I can’t do it.” I had to be firm and told her she had to get better because I had to go back to my life and she had to go back and raise my brothers. This must have worked. She did it.

After all of this, I got married to my first husband George. We moved around a lot because he was an engineer who did troubleshooting on big nuclear power plants. We had two kids; somehow, I got a PhD and began a teaching career in 1996 at the age of 40. Dad went into civil service and was stationed at Edwards Air Force base in California. It was during this time that mom started having joint replacements due to severe arthritis. This is when she started having terrible pain. The pain was everywhere it seemed. Unrelenting pain that just got worse over the years. Ultimately, dad retired and they both returned to Denver where it was only a five hour drive from where I was teaching in Kearney, Nebraska. This enabled me to go back and forth and I saw my parents frequently,

Delving into Death 2009–2012

Years ago, mom started talking to me about her death wishes. I think what made her begin thinking about it was our father’s death. Mom and Dad had been married almost 54 years when he died. I remember the day well. It was my first day of the spring semester in 2009. Something showed up in my email that I thought Mom would like so I forwarded it to Dad, who was always sitting in his computer room, listening to Rush Limbaugh (he never was sure how he failed so badly to have a Democrat for a daughter), and doing the finances for the many organizations he belonged to. It could have been Mended Hearts or Jewish American War Veterans. But on that particular morning, he was working on the finances for Civil Air Patrol. Dad’s idea of retirement was to volunteer.

On January 9, 2009, after I sent something to Dad via email, he printed it out and placed it in Mom’s chair since she was taking a nap. Dad proceeded to grab a book and go into the bathroom. The phone rang later, waking up Mom, who then went to get Dad. According to Mom, she knocked on the bathroom door and when there was no response, she opened the door. Dad was dead. The doctors say it was quick. Mom said there was no struggle. But, I think the experience made us all, especially mom, start thinking about death and the importance of planning for it. Mom had always done the planning. She handled the money. She knew where everything was. And by the time I

got to Denver which was a few hours later, she was already handling everything. There was no emotion, she just handled things. She admitted to me later that she never cried. I told her I was sad for her.

By this time, George and I had divorced and I married Bill in 2003. He was a Vietnam Vet with severe post-traumatic stress disorder (PTSD) that was very difficult to live with. He threatened suicide frequently and in 2010 I came home to a note on the door that said "Don't come in call the cops." So I did. I figured he had taken pills. But no. He was in our house with a gun that I didn't know we had, threatening to commit suicide. The cops took my neighbors out of their homes and ultimately SWAT took Bill to the hospital in handcuffs. I was really angry. I was really tired of dealing with him. I had the locks changed the next day. After living with someone who has uncontrolled Post Traumatic Stress Disorder for so many years, sleeping by myself in peace and quiet is something I value to this day.

On April 1, 2012, two days before Bill died, he told me he had bronchitis and asked me to bring him cough medicine and leave it on his porch. He wouldn't let me in his house nor could I see our dogs who were living with him. I had no idea why. The next day I talked to Bill and told him that I didn't believe it was bronchitis, but that it was his heart. Bill had 16 stents in his heart, so I could read his symptoms pretty well. Bill said no and then proceeded to tell me he had been to urgent care and they had put him on a z pack of antibiotics. I told him there are no *do-overs*. If it was his heart it could be dangerous.

On April 3, I was teaching and when I finally turned on my phone, the police were calling me and asking me to come to the hospital. I thought Bill had a heart attack. By the time I arrived, he was gone. It is so difficult to be told to go into a little room where they had a nun waiting to talk to me. I refused to go in until I had my own support system there. Luckily, Bill had told a number of his friends what he wanted after his death, so I had them there to help. While Bill and I had talked about donating his body when he died, we both figured Bill would not be a candidate because of his heart issues. Little did I know, I would receive a call that night from *Live on Nebraska* asking me if I would donate Bill's body. It turns out that while Bill's heart and lungs were no longer viable, his corneas, skin, veins, bones, and tendons were. Bill had the chance to help over 100 people who needed those parts. I said yes. Bill would have wanted me to say yes. He loved helping others, especially vets, and did a great job. The only one he couldn't help was himself. Dealing with the donation team right after a death was very difficult. They ask a huge amount of questions. I understood the reasons, but it took all night and the questions kept on coming. Once they had his body they

called with more questions about scars on his body where he had cancer removed. So they woke up his dermatologist to ask her questions.

Bill was very specific about what he didn't want when he died. We had talked about it numerous times. He had also talked to his friends about it. He did not want anyone looking at him in an open casket. Every time he went to a funeral where there was an open casket he would say he didn't want that. Bill was not Jewish, so the death rituals for him were much different from mine. For me, losing a spouse, even with a troubled marriage is difficult. There was so much to do immediately and in the days to follow. I now understood how my mom was dealing with everything when my dad died. I did cry, but there was a lot to do and a lot to be planned, and I went into *auto-pilot*. I just kept moving. I had to deal with the medical issues of our three dogs who were living with Bill and who had not been taken care of. I was unaware of that. I worked with the priest who was a friend of mine, and who had just moved into a new beautiful church to come up with a service. I designed the funeral program. I took it to the printer. I called the Patriot Guards Riders and requested they be at the funeral. The mission of the Patriot Guards is to attend the funeral services of fallen heroes in order to show respect. When I pulled up to the church on the day of the funeral, there were over 40 Patriot Guards holding the American Flag lining the walkways for the guests. As soon as I saw them, I stopped the car and was crying so hard one of my students walked me into the church, while another one parked my car. Now that I think about it, I was doing exactly what my Mom did after Dad died. I was numb and just needed to keep on moving. A few nights after everyone left and I was alone the emotions hit me hard. I managed to call a former student, who came into the house and took me to the emergency room. I couldn't stop crying and shaking. When we walked in, the same nurse who was on duty the night Bill died, took one look at me and told me this feeling was common. She put me in a room, they gave me drugs to calm me down and I don't really remember much after that.

Figuring Out the Details

Starting in 2011, I was dealing with my own health issues. Bill had been taking me to another city to the doctor prior to his death. The medicines I was being given were making it difficult to teach. The pain and fatigue were unrelenting. So in 2013, I went on disability, retired, and moved back to Denver to be close to mom and help her out as she moved out of her home and into independent living.

A lot of thought by my youngest brother went into which facility mom should go to (Gillick 2008). One of the requirements was that the facility

have not only independent living but also assisted living and rehab in case she became very ill. The facility we chose was close to where we all grew up in Denver. In fact, it was within a mile of the high school my brother's and I went to. It wasn't uncommon to meet friends from high school as we all were visiting our parents. The first few weeks that Mom was there, we received phone calls from her asking if she could go back home because no one would talk to her. We said no. Before too long she had "her ladies" and they actually formed little cliques. They all cared for each other deeply and I loved going there for dinner and chatting with them. Because many of her friends were dying, talking about death was a frequent event around the dinner tables with *her ladies*.

But talking about death isn't enough. One has to prepare for it. Our mother was a planner. Her first order of business was financial. Mom made sure her will was in order. Her three children were beneficiaries on all her accounts, which included savings accounts, life insurance, and Individual Retirement Fund (IRA's). She wanted it very simple for all of us. Because she didn't want any potential fights among siblings, she went one step farther and put my oldest son, Eric, as her executor and had his name placed on her checking account. This allowed him the ability to write checks for her funeral and other expenses that would come up at the end. It also meant that there were no probate costs or court. Thank you, mom. Thank you, Eric, for doing an amazing job.

I also suggested to Mom that she fill out a *Do Not Resuscitate (DNR)* form and put it on her refrigerator. Every state has a different form, which must be signed by the individual and the doctor. This form tells everyone, in the case of an emergency that Cardiopulmonary resuscitation, CPR should not be started. Without this form being visible, if paramedics were to arrive and find her unconscious, the law states they must administer CPR. Even if this had not been Mom's decision, the outcome for elderly patients is very low (Inamasu and Mayatake 2013). Fernando et al. (2019) found in a review of studies on CPR results, that in those patients over 70 years, the number of patients who had a return of spontaneous circulation was minimal. More than half of those patients who initially survived resuscitation, died in the hospital before discharge. Furthermore, survival to discharge after in-hospital CPR was 18.7% for patients between 70 and 79 years old, 15.4% for patients between 80 and 89 years old, and 11.6% for patients of 90 years and older. There was little data on social and functional outcomes after surviving CPR. Moas 82, and in the hospital for an illness, when a nurse told her the survival rate wasn't great with CPR for someone her age, and the damage they did to the body was usually extensive. Ribs tended to be broken. Mom wanted a

DNR. She had one on her refrigerator, with her will, and in her chart with the hospital. Mom was making sure she had all bases covered.

Over the years mom and I had many conversations about her death and what she wanted, and more specifically what she didn't want. She was determined she didn't want to suffer. She had seen her mom be tied down after a stroke and fed through a feeding tube. She was terrified of something like that happening and made me promise that wouldn't happen. Mom asked me how to commit suicide if she needed to. Like the dutiful daughter and researcher that I am, I looked it up. What I found was that it isn't easy to commit suicide with pills. In most cases, the person would just vomit, and not succeed. So I handed mom all the information and told her I didn't think that was a good plan. While we never talked about suicide again, but when we cleaned out her apartment later, we found her stash of pills in her nightstand with the papers I had given her about committing suicide. I guess they made her feel like she had some power and control over her own destiny. Finding them made me smile. I didn't blame her one bit and it made me happy that she was once again planning.

But mom put me in charge of "pulling the plug" as her medical power of attorney. She told me that she believed I would do whatever was needed and make sure she didn't suffer. Mom did not believe my brothers would be able to make the decisions. I assured her I would do what was needed to take care of her. Like everything else, I said yes. I actually had no idea what it really involved at that point. Little did I know that where death is concerned, nothing is black and white, and there are many shades of gray. But the thing about planning is that we all knew exactly what mom wanted.

Medical Problems Increase

The pain mom was in got progressively worse. She couldn't lift her arms. She hated pills and wouldn't take them to control her pain. Pain very much became part of her life. In December 2016, mom had a transcatheter aortic valve replacement (TAVR). According to the American Heart Association (2017), TAVR is a minimally invasive surgical procedure that repairs the heart valve without removing the old, damaged valve. It wedges a replacement valve into the aortic valve's place. The University of Colorado was the first hospital in the country to do this type of surgery. The way mom's doctor did the surgery was with a catheter going up her groin, but he also had a chest surgeon in the room in case something went wrong and the chest had to be opened up (Casteel 2016). My son Eric and I were with Mom for this appointment. We met both the cardiologist and the chest surgeon. Mom looked at the doctor and said she would not allow the surgeon to open her chest and then

asked “will I know it if I die?” Her cardiologist appeared to be startled and said “No, you will be asleep anyway, so you would just slip away.” This discussion made me feel like my heart was going to stop on the spot. Once again, mom was planning and she had control. Whether I liked it or not, I had to respect her wishes and understood her desire to end the pain. I believe the only reason she went through with the TAVR was for us. But that was her limit. So if that was what mom wanted, that was the way it would be. I didn’t like it and hated the thought of not having my mom around. But I believe that everyone should have the ability to make their own decisions. So everyone was in agreement with mom’s wishes.

I went with mom on the day of her surgery. We sat in the waiting room before they called her back for surgery. She was nervous. I was nervous but kept talking to her to keep her busy. Eric met me in the waiting room. Mom was taken in and the waiting began. I was really nervous. I don’t get that way for most surgeries, but this was her heart and it was different for me. In a very short time, we were asked to go sit in a small room and wait for the doctors to talk to us. I panicked. On April 3, 2012, after the police called my cell phone to tell me my husband was at the hospital, I went flying into the hospital and was told to go to a small room. I refused to go. I knew what they were going to tell me. That my husband was dead. So sitting in this small room waiting for the doctors was a terrible experience for me. I felt like I couldn’t breathe. I expected the worse. Eventually, the doctors came in smiling. They said everything went great. She did great. Okay good.

That is until we got to her hospital room and discovered her heart was going crazy and they were trying to save her. It was pretty terrible watching all the tubes and the staff running around trying to get her heart to cooperate. Once that settled down, Mom was moved to another room. I walked in one night to find the Heart Failure doctor working on mom. At one point mom looks at me and states “how do you feel knowing I’m dying.” I told her she wasn’t. But if I would have known then, what her next year would be like, I might have told the doctor to quit working on her at that point and let her go. I still regret that.

There are many risks after TAVR surgery and the patient must be on aspirin and blood thinners to keep from having a stroke. In March 2017, I was in Dallas with my youngest brother Barry. I received a call from mom saying she didn’t feel good and didn’t know what was wrong. I told her to go to the ER. She said, “no I hate the ER.” And that was that. The next morning, a nurse where mom lived in assisted living, realized mom was bleeding internally and called an ambulance. My brother and I got in the car and started to drive to Denver. Our other brother, Craig, and his wife, Kristin, met mom in the ER and she was admitted. She had an upper GI scope to see where the

blood was coming from and they started to treat her. By the time Barry and I arrived at the hospital, mom was delusional from the drugs and being in the hospital. While my son, Eric, was sitting with her she told him that she wanted to go to *Star Wars*. She has never seen a *Star Wars* movie in her life. She kept trying to get out of bed. I assume this was very tough for my son to see his Grandma this way. We didn't really talk about it. Eric is not the emotional type. I suppose I could ask him how he really felt about it, but didn't. He knew he needed to be there until I could take over and he held on until I got there. It truly was a family affair with mom.

When we finally arrived, we took turns being with mom. I got there early in the morning so I could talk to her doctor. I started hearing about a program called palliative care, which the medical staff said was the most "underutilized service around." Palliative Care is specialized medical care for people with serious illnesses (Livne 2019). This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve the quality of life for both the patient and the family.

One day, prior to this hospitalization, I was reading Facebook posts and came across one from my high school friend about her mom's death. The death was brutal. Hospice never showed up. She lived in assisted living, where no drugs were available to relieve her mom's stress and struggles. Since we knew each other when we were teenagers, I contacted her because I wanted to know how to protect my mom from such a terrible death. My friend said "be prepared, get everything lined up." So I called a Palliative Care that was connected to Hospice. My hope was that we would already be in the system and that we would have them when we needed them.

Palliative care sent us a wonderful male nurse practitioner for mom. He was well trained, listened to his mom, us, and connected with mom's doctor to make changes, if changes needed to be made. My hope was that she would not have to go back to the hospital. The best part of it was when he met with the entire family to make sure everyone understood what mom wanted concerning her death. We had a huge family meeting, with the nurse to deal with this.

Mom said it was a waste of her time to have the palliative care nurse come to see her and that she didn't need it. By this time, my youngest brother had moved into mom's extra bedroom in assisted living. He did it to be with mom and because, while I lived only a mile from her, I couldn't do it all. I was running on empty after five years. According to the Cleveland Clinic, *caregiver burnout* is when the caregiver is in a state of physical, emotional, and mental exhaustion. This can lead to fatigue, anxiety, and depression. I was already burned out after doing this for years with mom and while I didn't know what it was called at the time, I knew I was feeling stressed and exhausted. I really

wanted to be everything mom needed, but somehow knew I needed to take care of myself too. So when mom decided she didn't need palliative care anymore, we both told her it was absolutely not an option. It was for our peace and serenity. Not hers. Little did I know how much having them in our lives and being prepared would help at the end (Renz, Kyburz, and Peck 2015).

“Grief is like the ocean; it comes on waves ebbing and flowing. Sometimes the water is calm, and sometimes it is overwhelming. All we can do is learn to swim.”

—Vicki Harrison

For the entire month of November 2017, my dog Lola and I were on a cruise ship sailing around the Caribbean. For the last five years, I didn't give up travel, but always made sure I could get back home to mom if she needed me. I knew I could get off a cruise ship and fly back to Denver at any point. I arrived home on December 3 and left again on December 6 to go help my youngest son, Jonathan, who was working in Las Vegas for a few weeks. He rented a home and my job was to take care of his dogs while he was at work for two weeks. However, I got sick and ended up in the hospital with both flu and pneumonia for five days. Therefore, I extended my stay and didn't get back to Denver until the night of December 19. On December 18, while in assisted living, mom apparently fell and banged up her body. She was bruised all over and we assume she hit her head as well. We were not notified at all about the fall for some reason by the nursing staff. My brother, who had been working all day, found out that she had fallen when he got home about nine that night. He had a good conversation with mom. She told him she didn't have her walker and that she had just fallen. On December 19, my brother texted me to say she wasn't acting right. Something was wrong. Somehow the decision was made that she could go to bed and they would reassess her when she got up. By the time I got off the plane that evening in Denver, I was receiving texts from my brother saying mom was in the ER and “you need to get here, I can't do this by myself.” So my dog Lola and I went directly from the airplane to mom and the emergency room at the University of Colorado Medical Center in Denver, Colorado.

Mom passed all of her physical examinations that night in the ER. She had a neurology resident asking her all kinds of questions and having her do various tasks. At first, mom wasn't sure who the president was. She said it was Kirby the dog. Then later on when asked the same question she said “I'm not mentioning that man's name now.” We knew she passed the test and was referring to Trump. I was still coughing and exhausted from being as sick

when I was in Vegas so I went home for a bit. They were going to transfer mom to a room. A few hours later I called the nurses station and was told mom was combative. *Who is being combative?* I said. *My mom? No way!!!* So Lola and I rushed back to the hospital and mom didn't even know who I was. That began our whirlwind ride from the ER to hospice over the next six days. Facebook post by Diane (12/20/17) "Update: not good Mom isn't making any sense. They think she is having seizures because of a brain bleed. She knows my brother, but she hasn't a clue who I am, This is tough shit, Two days ago she was talking to me."

I spent the night in moms' room for the next few nights while she was in the hospital. Mom didn't know me. It was really heartbreaking to watch. Facebook post by Diane (12/21/17) "mom isn't really responsive. Agitated. The EEG isn't showing seizures, but rather just her brain is running slow. Trying to get my brain wrapped around all this. I feel so powerless." I felt like we had switched roles. I was now the mother. Every time the hospital staff came in to take blood, clean her up, or take her blood pressure, mom would cry out in pain. Mom was anxious and struggling so she was given Ativan every four hours to keep her calm. Mom didn't know who I was and was calling me mommy by that time. She had numerous CT scans of her head that just said something was wrong with her brain. Her brain just wasn't functioning correctly. But the doctors couldn't tell us why. They would need to do more tests. The problem was that mom hated being in an MRI machine and the night we were in the ER clearly said she did not want an MRI. It was her decision and it was up to me to follow her wishes and say no MRI. Facebook post by Diane (12/21/17) "tough day with mom. No improvement. She is not able to eat or drink or communicate. Just trying to keep her comfortable."

We had a very young neurology resident with us who was very, very optimistic. Sickeningly so. He thought mom could get somewhat back to normal with months of rehab. On Thursday, two days after we arrived at the hospital, we had a big meeting in the hallway with the young resident, his attending, and many other people who were taking care of mom. They still didn't know what was wrong with her brain. My brothers and boys were always around to offer support to me. I wasn't sure how they would do with everything that was happening, but they were around for anything I needed. My oldest son said to them "if my mom (me) and I needed this kind of service we would want you to do everything in your power to get us to 100%. But grandma's not like that. She misses her husband, we know something is wrong with her brain and she can't go through months of rehab." I told them to stop all the tests, no more blood work or blood pressure. We were sending her to hospice. And "no you cannot cause anymore pain to her, it's over."

Because we had palliative care already, I only had to call mom's palliative care nurse. He took care of the calls to begin the hospice process, and by that evening I found myself sitting alone in the hospital room with Lola in my lap while the hospice nurse evaluated mom to see if she was really ready for hospice. The evaluation to see if mom was ready for hospice took very little time. Signing all the papers was quick. It was obvious it was time and following mom's wishes, there was nothing else to do. The hospice nurse spent about three hours talking me through the process of what to expect. She was taking care of me. I was exhausted by this time. I had not left the hospital. I was sleeping with my dog on a terrible couch. The cushions kept falling on the floor with us on them. I was still having breathing issues from pneumonia and using the oxygen in mom's room to take a breathing treatment. I remember feeling numb as I was talking to the hospice nurse. She was going to handle the doctors and getting Mom transferred. I just had to decide where Mom would go. I could take her back to assisted living but didn't feel that staff would provide great support since there was only one nurse on duty. I was told about a new rehabilitation center that was taking hospice patients. Upon the recommendation of the hospice nurse, and after talking to my brothers about it, I decided on the new facility. I was told what to expect over the next few days and the nurse helped me understand I was making the correct decisions for my mom. Mom was still calling me "mommy" which was unbearable. Facebook post by Diane (12/21/17) "Tonight I signed the papers for hospice and mom will be moved in the am. Following Moms [*sic*] wishes is a real tough job, but she has always known what she wanted."

The next morning, it took quite a while to get all the university doctors to sign off and discharge Mom. Once that happened, I insisted she be given both morphine and ataman to keep her calm, and she was moved by ambulance to the new rehab facility where we were met by the hospice nurse.

I wonder if my first breath was as soul-stirring to my mother as her last breath was to me.

—Lisa Goich-Andreadis, *14 Days:
A Mother, A Daughter, A Two-Week Goodbye*

Hospice December 2017

I made the decision that mom would go to a rehab facility for hospice with full-time nurses who would administer the drugs every two hours. I included my son's and brothers in this decision. They agreed. This facility gave me the room right next to mom for sleeping and showers. I was really grateful they provided this for me and of course, my dog was there as well. While mom

didn't really know who we were, she asked for toast and coke. She could have anything she wanted. She really didn't eat much and then it became apparent that swallowing her regular medicine was getting more and more difficult. After a long discussion with the hospice nurse, we (the family with me at the helm) decided to stop all her regular meds.

Putting updates on Facebook and baring my soul about what was happening with mom was both good and bad. Most people were great and so supportive. One friend said, "hold on, it's quite a wild ride." He was so correct. Others said, "You know what your mom wants, now do it." But some of my relatives, including mom's siblings, decided I was killing mom and made it known to everyone. While Bochner (2000) and Richardson (2001) suggest that autoethnographers be considerate of others while reliving our experience, to leave this part out, would be leaving out a difficult part of my story. Facebook post (12/21/17) "As if I'm not stressed enough I have relatives doubting my version of what is going on here. I've had it and have decided to cut off all communication with whoever pulls this bullshit now." One thing they reacted badly to was their belief that I shouldn't take mom off her blood pressure medicine. I never quite understood this because with morphine every two hours her blood pressure was already low. I found out later both my brothers received calls from these relatives asking them to stop me from *kill-ing our mother*. I later found out that both of them told them that I was only following mom's wishes and they were fully supporting me. Still, it was an awful thing to have said about me during a really tough time. It hurts to this day. And we have not really talked much since. I think the moral of that story is to be careful what you post on social media during this kind of situation. Everyone has an opinion. Facebook post from me (12/22/17) "the only thing I can say is holy fuck this is brutal" and a friend replied "and it gets worse. Fasten your seatbelt. Sometimes all you can do is lay in the floor and cry from your soul."

On December 24, mom got a second wind. She clearly said to me "Diane, I love you." I told her I loved her back. Then she told my son, "honey seeing boobies won't hurt you, you have seen them before." My son joked with her and said "yea grandma, but not yours." She hated wearing clothes. They were too constraining in bed. So I went to sleep that night, in the room right next to hers, that the facility had given to me so I could stay close, thinking, we had made a turn! Great!

Not so great. This is what is called terminal lucidity and it is quite common. It is where the dying person has a period of increased mental clarity. I certainly didn't expect this. I thought it meant she was possibly getting better. That feeling was short-lived. I went to bed in the next room and the next morning mom had what is commonly referred to as the death rattle. She was

really dying. And it was explained to us that all of her organs were shutting down. She could hear us. We told her that my brother and his family were trying to get home from Florida where they had been vacationing. All day long, my sons, my brother Barry and I sat with her talking among ourselves and to her. One of my girlfriends came to talk to her and told mom I would be OK. Mom was still receiving morphine every two hours and Ativan every four hours to keep her comfortable. The sound of that rattle was the worst thing I have ever heard. To this day, I can still hear it. I did tape it. But haven't listened to it since. I also took pictures on the last day. I have been a scrap-booker for years and to me, it made sense to document death as much as life. My favorite photo is of my youngest son Jonathan, sitting on her bed quietly talking to her and holding her hand. Sometime during the day, I texted my aunt and uncle (mom's siblings who thought I was killing her) and told them if they wanted to say goodbye I would hold the phone to her ear. My aunt called. I let her say goodbye. I know mom heard my aunt because I had to wipe away tears. Hearing really is the last thing to go. Her brother, probably still mad at my choices never called her. His loss. And I will admit I am still angry and sad about his decision. And they still think I killed her.

At about seven, my brother Craig and his family finally arrived from Florida. Mom waited for them. I wasn't in the room, but I've been told he held her hand and told her she didn't need to hang on anymore. My nieces said goodbye. My sister-in-law said everyone needed to leave except me. She said if there was a lot going on in the room she wouldn't die. I am not sure how she knew this, shortly after everyone left and it was just mom and me again. Alone. I think it was just inferred that she needed me. She had spent her life calling me when she needed something. I had already been there every night for over a week.

I hated seeing mom struggle. The hospice nurse had ordered a suction machine for mom to help with all the secretions that made it sound like mom was drowning. I had watched the nurse do it so I figured out I could do it. I am not sure if I put much thought into whether or not I should do it. I just did it because mom needed it. I was using the suction on her because it literally sounded like she was drowning in her own secretions. I was rubbing her chest and talking to her. I remember looking at the pillow in her lap and wondering if I could end it for her. I felt so desperate at the time, I would have done anything to make the end come quickly for her. I have never had that feeling of taking someone's life. It's a desperate feeling wanting to stop her suffering. So instead I talked to her. I told her I didn't know what else to do for her. Then I realized what she wanted me to say. I said "mom we are all going to be ok. I'll make sure Barry (my youngest brother) is ok (she has always worried about him), dad is holding out his hand for you. All you have to do is grab it."

I put my hand in hers and she slipped away. It was almost at the same time I reached for her hand. At that same moment, her nurse walked in and I told her she was gone. With tears in her eyes, the nurses listened for mom's heart and shook her head yes.

I sent texts to everyone saying that it was all over. I was able to sit with mom until everyone came back. She had her huge comforter on the bed and I put my legs under it with her and just sat with her. I'm so grateful for that time with my mom. She brought me into the world. I helped her leave it. I can't reread this part without crying:

When someone you love dies, and you're not expecting it, you don't lose her all at once; you lose her in pieces over a long time—the way the mail stops coming, and her scent fades from the pillows and even from the clothes in her closet and drawers. Gradually, you accumulate the parts of her that are gone. Just when the day comes—when there's a particular missing part that overwhelms you with the feeling that she's gone, forever—there comes another day, and another specifically missing part.

—John Irving, *A Prayer for Owen Meany*

Afterward

After living through this experience, I had to make sense of it in order to reconstruct my life as Ellis (2002) suggested. I had to make sense of the experience so I could somehow give meaning to my life now without both of my parents in it. Writing about it gives me the opportunity to figure this out. Ellis describes the need we have as researchers to be able to harness and order an event, therefore “pushing chaos into the background so that a linear coherent plot can unfold” (Ellis 2002, 377). I couldn't have done this writing while I was going through this experience with mom. I know that I am certainly not the only one to go through helping a parent die. My brothers and my sons went through it as well and they rarely talk about it, much less have a need to write about it. However, what is different for me is that I feel the need to both frame it and make sense out of it in order to tell my story and also to help others as they are going through it.

During mom's eulogy, my brother Craig said that mom and I had a love-hate relationship and that she always came to me first. I was there for her no matter what. I did what she asked me to do and while I miss her so much I am so glad that she brought me into the world and I was the one who saw her out.

March 2018. As I am writing about my mom's death, my brother calls. Aunt Evelyn, Mom's sister is dying of cancer and has a very short time to live. Shortly after Mom died, Aunt Evelyn asked about mom's death. I told her it

was very peaceful. Actually, it was beautiful. My cousins were taking turns laying with Aunt Evelyn. I can't quit crying. It is less than three months since we did this with Mom. These two sisters talked every Sunday for their entire adult life. They were our grapevine. The only way we knew what was going on with our relatives in Florida was because Mom would tell us what her sister told her. For the last few months, it has been up to the kids, my generation to make phone calls. Today, March 24, 2018, my cousin called to say my aunt had died.

Because of the emotions, I feel every time I reread this, it has taken me longer than usual to get it published. The process of reliving this as I am writing feels excruciating (Matthews 2019). Mom has been gone since December 25, 2017. More recently, on December 24, 2021, my ex-husband George, father to our boys and grandpa to our grandkids died. He was visiting Eric's house in Denver to celebrate his birthday. He had a heart attack in the dining room and died in front of our grandkids (ages, 7, 9, and 11). Our daughter-in-law did CPR until rescue arrived. I have asked and she has told me, she believes he was dead when he hit the floor. Because Mom taught us so well how to prepare for death, and because George and I got along, I had encouraged George to write everything about his finances so it would be easier on Eric, who was the executor. I told him exactly how I did it. Everything should be in a spreadsheet. George, the consistent procrastinator, didn't do it. Fortunately, Eric made him do a small will. It was a very simple will that said everything goes to our boys. There wasn't much more. Except when he talked about his funeral. He said he didn't care, but that "Trump was not invited." He was still sarcastic even after death. Because George didn't prepare for his death, it made dealing with his property so much more difficult. Eric had to figure out probate. He had to deal with two properties. It's been emotional for all of us. We not only lost another person who we loved, but we learned how difficult it is when death is not prepared for. It is a painful reminder of why planning is important.

Writing and telling this story has been difficult. It has taken me a while to get through it. I feel the emotions every time I work on it. My hope is the readers feel it as well. I believe once I see it published it will provide some closure for me. I can not only share what the experience was like for me, but I can honor my mom and the gifts she gave us. I write it in the hopes it will heal me and help others.

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References

- American Heart Association “What is TAVR.” <https://www.heart.org/-/media/Files/Health-Topics/Answers-by-Heart/What-is-TAVR.pdf>
- Bochner, Arthur. 2000. “Criteria Against Ourselves.” *Qualitative Inquiry* 6 (2): 266–72.
- Casteel, Beth. 2016. “Rates of Death and Stroke Equivalent for Surgery and TAVR at Two Years.” ACC, April 4, 2012. <http://www.acc.org/about-acc/press-releases/2016/04/02/10/12/rates-of-death-and-stroke-equivalent-for-surgery-and-tavr-at-two-years>
- Custer, Dwayne. 2022. “A Father’s Death: The Therapeutic Power of Autoethnography.” *The Qualitative Report* 27 (2): 340–7. https://link.gale.com/apps/doc/A697122406/AONE?u=unl_kenarney&sid=bookmark-AONE&xid=185add72
- Denzin, Norman K. 1999. “Two-Stepping in the ‘90s.” *Qualitative Inquiry* 5 (4): 568–72.
- Durkheim, E. (1983). *The Rules of Sociological Method: Selected Texts on Sociology and Its Methods*. New York, NY: The Free Press. Original work published 1895.
- Ellis, Carolyn. 1993. “‘There Are Survivors’: Telling a Story of Sudden Death.” *The Sociological Quarterly* 34 (4): 711–30.
- Ellis, Carolyn. 2002. “Shattered Lives; Making Sense of September 11th and Its Aftermath.” *Journal of Contemporary Ethnography* 31 (4): 375–410.
- Ellis, Carolyn, Tony E. Adams, and Arthur P. Bochner. 2011. “Autoethnography: An Overview.” *Historical Social Research / Historische Sozialforschung* 36 (4[138]): 273–90.
- Fernando, Shannon M., Alexandre Tran, Wei Cheng, Bram Rochweg, Monica Taljaard, Christian Vaillancourt, Kathryn M. Rowan, David A. Harrison, Jerry P. Nolan, Kwadwo Kyeremanteng, Daniel Mclsaac, Gordon H. Guyatt, and Jeffrey J. Perry. 2019. “Pre-Arrest and Intra-Arrest Prognostic Factors Associated with Survival after in-Hospital Cardiac Arrest: Systematic Review and Meta-Analysis. *BMJ: British Medical Journal (Online)* 367. <https://doi.org/10.1136/bmj.l6373>
- Gillick, Muriel. 2006. “Assisted Living: Boon or Boondoggle?” In *The Denial of Aging: Perpetual Youth, Eternal Life, and Other Dangerous Fantasies*, 159–94. Cambridge, Massachusetts; London, England: Harvard University Press.
- Inamasu, Joji, and Satoru Miyatake. 2013. “Cardiac Arrest in the Toilet: Clinical Characteristics and Resuscitation Profiles.” *Environmental Health and Preventive Medicine* 18 (2): 130–5. <https://doi.org/10.1007/s12199-012-0301-y>

- Livne, Roi. 2019. "The Palliative Care Gaze." In *Values at the End of Life: The Logic of Palliative Care*, 26–79. Cambridge, Massachusetts, London, England: Harvard University Press.
- Matthews, Angela. 2019. "Writing through Grief: Using Autoethnography to Help Process Grief after the Death of a Loved One." *Methodological Innovations* 12 (3): 1–10. <https://journals.sagepub.com/doi/pdf/10.1177/2059799119889569>
- MedlinePlus. 2020. "Acoustic Neuroma." <https://medlineplus.gov/acousticneuroma.html>
- Renz, Monica, Mark Kyburz, and John Peck. 2015. "Dying with Dignity: Indication-Oriented End-of-Life Care." In *Dying: A Transition*, 107–28. New York: Columbia University Press
- Richardson, Laurel. 2001. "Getting Personal: Writing-Stories." *Qualitative Studies in Education* 14: 33–8.
- Ronai, Carol R. 1996. "My Mother is Mentally Retarded." In *Composing Ethnography: Alternative forms of Qualitative Writing*, edited by Carolyn Ellis and Arthur P. Bochner, 109–31. Walnut Creek, CA: AltaMira.
- Thompson, Neil. 2012. *Anti-Discriminatory Practice: Equality, Diversity and Social Justice* (5th ed.). Basingstoke, UK: Palgrave Macmillan.
- Weaver-Hightower, Marcus B. 2012. "Waltzing Matilda: An Autoethnography of a Father's Stillbirth." *Journal of Contemporary Ethnography* 41 (4): 462–91.
- Wysocki, D. K. 2000. "A Feminist Relocates to the Midwest." *Culture and Sexuality* 4 (3): 59–66.
- Wysocki, D. K. 1998. "But Women Can't Have Hemophilia!": An investigation into the lives of women with bleeding disorders." *Sociological Research Online*, 3(4).
- Zempi, Irene. 2017. "Researching Victimisation Using Auto-Ethnography: Wearing the Muslim Veil in Public." *Methodological Innovations* 10 (1): 1–10.

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