

When Trying to Go Quietly Creates a Commotion

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At what point do our loved ones' quality of life and final wishes take precedence over painful invasive treatments that we authorize because we want to keep them alive?

“This is going to be the year you grow up,” my grandmother said to me. Jokingly, I replied, “I may be seventeen, but I’ve been a grownup for some time; I’m here taking care of you as usual.” She laughed as she fiddled with some papers in her purse, but somehow I could detect that she wasn’t joking. “Being a grownup means making decisions with your head and not with your heart. That time is going to come, and I need you to be ready. I want to go over some things with you.” I sat frozen in silence for a minute, and, as I was about to reply to her comments, my uncle Thomas and Dr. C. walked into the exam room. Dr. C. said my grandma was showing signs that her kidneys may fail and she needed to have a graft inserted so she could begin dialysis to offset potentially severe symptoms that may arise. Grandma smiled while putting the papers back in her bag and said, “Well, I don’t see the point of doing this now. I’m about to be eighty years old and I’ve had a good life. If my demise is going to be from kidney failure as the Good Lord sees fit, then so be it. Come on, y’all, I’m ready to go home.” Thomas became very emotional as if she had already received a death sentence, stating “Mommy, you have to do this surgery. We need you healthy and here. How will that happen if you don’t take care of yourself?” “Because I’m old, Thomas, and there’s no point. I feel fine and I want to go home,” she replied. Thomas turned and looked at me and said, “Tell her she’s doing this.” I sat staring at my grandma and all I could think about was she may die because she’s hardheaded. What would we do without her? I said, “Grandma, you have to do this one.” Previously, I had always been on my grandmother’s side with however she wanted to handle medical situations. I felt it was her body, her call. This is the same woman who survived two strokes, had high blood pressure and was a mild diabetic—but this time around the pressure of my uncle even made me side with him. She said, “I don’t want to do this, but if you want me to, Eve, then I will.”

The surgery was scheduled for the first week of October and initially everything went well; she healed and was able to begin her dialysis in early November. However, shortly after the graft was inserted in her arm, it became infected and another one was going to have to be inserted. My uncle pushed her to sign off on a second surgery and for the next graft to be inserted in her groin. “I feel like a pin cushion, and I don’t like this at all,” Grandma said to me. “I don’t

either and if this one doesn't work, I'm wheeling you out of this room myself and I'm going to kick the butt of whoever gets in my way," I replied. She said, smiling, "You promise, Eve?" as she suddenly handed me her Bible out of her purse. "Why are you giving me this? Don't you want to have it with you?" I asked. She said, "Just keep it for me, but read it while I'm here," as they wheeled her away from me, once more, for another procedure that I know she didn't want.

Again, everything was okay initially, but now Grandma was using a wheelchair as she began to have issues with circulation in her legs. We were in the house getting ready for Thanksgiving, and it was the first time I had to cook, and she was my assistant because she didn't have the energy. She wheeled over to me and asked, "Have you been reading my Bible yet?" "No Grandma, but I will; I've just been working really hard and now I'm just trying to get this dinner together." Disappointed, she said, "Eve I need you to read it..." but family began to arrive and she was cut off. I wish I could say we were going to have many more nights like that one because it truly was perfect, but a few days after, my uncle found my grandmother somewhat incoherent and complaining about her legs, so back to the hospital she went.

I arrived at the Long Island College Hospital at the end of my shift, exhausted and emotionally overwhelmed that December night. I had been so busy with work that I was only making it to the hospital a few times a week instead of daily. I was walking to her room thinking— *she wasn't home for my birthday and I'm going to give her a piece of my mind for being sick for my 18th*. When I walked into her room, I was completely caught off guard to find her hooked up to several humming and vibrating machines. A nurse was also there changing bloody bandages on the nubs where my grandma's feet had once been. I WAS FURIOUS!! "Who let them take her feet and why is she on these machines?" Frightened by my tone and body language, the nurse said she'd go get the doctor. When the doctor arrived, he explained to me that my uncle authorized the amputation as the nerves in her legs weren't circulating blood, but there were some complications. "What is an eighty-year-old woman going to do without her feet?" I asked. She would have never wanted this and now she was on a ventilator as well. Again, the doctor expressed that Thomas automatically had power of attorney as the elder; no other healthcare directive on file suggested otherwise. My uncle once again signed off on another torturous procedure I know Grandma didn't want. Thomas and I argued that night because he claimed the doctors are professionals and are making recommendations to keep her alive, but my position was: at what cost are we letting them do this to her? He called me a "stupid kid" and felt he knew more because he was older, and then he left. I stood there, holding her hand with tears falling from my face. She opened her eyes and looked at me with the most exhausted look in her face as a single tear fell from each eye. She tried to move her legs and then she closed her eyes as if it was a signal to me she was ready to let go. In that moment, I didn't know what I was going to do, but I knew I had to do something. After all, I made her a promise and I planned on keeping it....

Far too often these initial tests that are ordered tend to spark numerous costly, fretful, and investigative procedures that are extremely invasive, for

problems that may not ever be able to be fixed in what remains in a senior citizen's life. These procedures tend to leave them in a condition worse than if they had never been tested in the first place. Their bodies are not capable of recovering from such physical trauma. If it is the patient's wish, why not let the aging leave this life of their own accord, instead of making them feel they have to be subjected to procedure after procedure, just because we love them and want them here? Most doctors are not having these conversations with their patients. The doctors should make sure the patient's last wishes are noted in their healthcare proxy or living will, so when a medical emergency does arrive out of the blue, families aren't left making emotional decisions with doctors just to save their loved one's life. Instead, the loved one is doing what they want even if it means leaving us.

Medical professionals have an agenda to operate on the elderly "regardless of the patient's preferences or goals," because Medicare is guaranteed to pay for the procedures, argues Amy Kelley, an assistant professor of Geriatrics and Palliative Medicine at Mount Sinai School of Medicine in New York (Peterson). And why not? As stated in the article, "Elderly Americans Unlikely to Benefit from End-of-Life Surgeries," the medical field is a business, and making profits will always be its driving force. Harvard's School of Public Health reports that 1.8 million Medicare beneficiaries age sixty-five and older died in 2008, and over 34% were operated on during their last year, 25% in their last month, and 10% in their last week of life (Peterson). These are high numbers when you think about it: that's 1.8 million Grandpas and Grandmas who could have been enjoying retirement or the company of grandchildren, gone because they chose surgery in the hopes of extending their lives, and it resulted in their losing their lives anyway. "Policymakers must align incentives for insurance plans, healthcare institutions, and providers with individual patients' goals," Kelley says in a commentary that accompanies the Harvard study (Peterson). It is so important for families to have these tough discussions and uphold personal wishes by documenting them and submitting them to medical administrators so that the focus is always on the patient and not the hospital's revenue. As much as medical professions pledge to be there to save our families, the goal is always financial gain and procedures will always be pushed to play on our emotional desire to save or have more time with our loved one.

If so many seniors are succumbing to lack of vitality to recover from these procedures, then why are so many such procedures still being done? Geriatrician Robert Jayes, an associate professor of medicine at George Washington University School of Medicine, says, "An ounce of prevention can be a ton of trouble. Screening can label someone with a disease they were blissfully unaware of" (Boodman). I agree with this statement wholeheartedly. Prior to the initial doctor's appointment, my grandmother was of sound mind and mobile. Sure she had aches and ailments, but she was able to do things and lived very comfortably on her own. I'm sure it wasn't the first time she had been told she had kidney issues, but, in hindsight, I understand now why she drank so much water and consumed so many green vegetables. My grandmother hated hospitals and always went for the alternative to the extremes. She offset her conditions naturally so she could be at

ease. As stated in an article published by the Alliance of Natural Health, doctors are not supposed to mention natural remedies to patients as they can put their licenses on the line, because most alternative health practices have not been blessed by the FDA. The FDA governs the drugs the doctors distribute as well as their professional licenses, thus leaving doctors to side with conventional medical practices, and therefore they tend to promote surgeries and painstaking procedures as the only option of treatment. That keeps them safe professionally, and the hospitals generate income. At seventeen, I didn't understand that system.

I went home that night, ate what was left of my 18th birthday cake, and sat in deep thought wishing I could have a real conversation with Grandma, or, at the very least, have her tell my uncle to stop because she's had enough and she's ready to let go. Although I wasn't the religious type, I prayed that night and finally took a moment to open up my grandmother's Bible in hopes of coming across a passage that would comfort my mind. Inside I found a bunch of random papers clipped on a page with highlighted text that read, "When I was a child, I spoke as a child, I understood as a child, I thought as a child: but when I became a man, I put away childish things." I opened the clipped pages and there was a signed healthcare proxy, her will, and some insurance papers. All of her wishes were written out and they did not include being operated on, ventilators, and feeding tubes; but, most importantly, they empowered me, once I became eighteen, to make all medical decisions on her behalf. All I had to do was sign it and submit it to the hospital administrators, as she had had it signed and notarized. I had absolute power now to stop my uncle, whose childish heart couldn't make an adult decision. In that moment, I knew what that highlighted text in her Bible meant.

Dr. Atul Gawande, a noted surgeon and renowned public health researcher, writes in his article, "Overkill" published in *The New Yorker* in 2011, that:

The medical system had done what it so often does: performed tests, unnecessarily, to reveal problems that aren't quite problems to then be fixed, unnecessarily, at great expense and no little risk. Meanwhile, we avoid taking adequate care of the biggest problems that people face—problems like diabetes, high blood pressure, or any number of less technologically intensive conditions (53).

That statement strikes a nerve in me, because my grandmother had high blood pressure and diabetes for years and Dr. C. was very comfortable with leaving her on daily medication. Between both ailments, she consumed at least four pills a day, and that seemed fine over the course of ten years. I remember him very clearly saying "her kidneys may fail." That didn't mean they would have, but, caught in the moment, all we heard was "kidneys fail" and we reacted. Dr. Gawande's statement makes sense in my mind, because, as long as Medicare was paying and my uncle was agreeing, then the cycle of hospital life would continue. That's not saying Dr. C. was a bad doctor or that a malpractice suit was in order, but it wasn't the best decision for her frail system.

In the end, I never want anyone to watch a loved one suffer by way of poking and prodding, especially if it's not what he or she wants. Instead of creating

false hopes, enjoying the time together is worth so much more, especially when a person is able to live as he or she wishes. Taking time to make sure all end-of-life wishes are documented and on file so everyone is on the same page will save so many headaches and avert family quarrels. There are countless medical professionals who would rather set up some type of palliative care regimen than an operation on a weak body. At the time, I hated my uncle; I looked at him as some form of Norman Bates who couldn't be without his mother. I have since forgiven him and I understand his position, as love makes us do weird things. My grandma knew I would follow her wishes, no matter how much she meant to me, even if it meant letting her go.

Some days after delivering the proxy and having it accepted by the hospital administrators, I walked into my grandmother's room. She looked as though she knew I had finally opened her Bible and found what she had been trying to give me for some time. There was silent calm in the air, the machines were off, and she looked so beautiful and relieved as if she hadn't been that pin cushion for the past couple of months. I kissed her forehead and told her I understood what she meant when she said I was going to grow up this year. Just then the nurse walked in and said, "Sorry, I didn't know anyone was here. I'll come back." "No," I replied. "It's fine." She said, "Oh, okay," very hesitantly. "Most family members don't like to stay for this part," she said as she pulled the sheet over Grandma's face and began to unlock the bed's wheels. "WAIT," I said, caught totally off-guard by what I was witnessing. It hit the nurse at that moment that I didn't know. "Oh my God, I'm so sorry!" she cried. "I was under the impression you knew she passed away." I always thought that when I lost her I would collapse into an inconsolable grief, but at that moment I felt so much joy because she wasn't hurting anymore. Even though tears welled up in my eyes and began to stream down my cheeks, I mustered the strength to say, "It's okay, you can take her now, she's been ready for some time. But do you mind if I help you wheel her out, please?"

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