

Saying Goodbye

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My mom was a beautiful, intelligent woman. Soft-spoken and tender, she spent the years before my birth as an elementary school teacher. She taught proficiently, and she nurtured and loved her students well. The other day I was reading her journals from those years. I was brought to tears when she told a story of seeing one of her students—a little girl—with a large bleeding gash on her forehead. She said that she ran to the girl and “swooped her into [her] arms,” and that as she walked to the office she never knew if in the next step her legs would buckle, and I *knew* that feeling. The feeling of hurting, and having her as a young woman run to me, her little boy, and “swoop” me into her arms. It felt so familiar. So familiar, and so distant.

She was the perfect mother for me.

She had the sweetest faith I’ve ever known. So often I would walk in on her praying at her bedside that in my youthful egocentrism, I would get annoyed that I couldn’t ask her what I needed to ask. (Often, it was if I had permission to play Nintendo.) It wasn’t until years later that I contemplated the possibility that in those moments of outpouring she might have been—and probably often was—praying for *me*. And that those prayers had kept me safe at times in my life when I was headstrong and reckless.

I attribute much of what I am today as a human being to that woman, and to her prayers.



My mom is dying.

In her late forties, my mom started having trouble when she went to the grocery store. She would hold two items of similar price and be completely unable to determine which was the better deal. Paralyzed, she would stand there as the minutes passed, silently weeping. Eventually she would either leave without buying anything or call home and seek guidance.

We all thought this was a symptom of her longstanding anxiety. We thought she was getting too panicked at the cost, and hyperfocusing on making the “right” choice. My dad took her to the doctor, and they got her on some new antianxiety meds.

These didn’t help much.

A few years later, when she was fifty-one, my wife, Lolly, and I got pregnant with our first daughter, Anna. My mom was *overjoyed*. “How wonderful! I’m so, so excited!” she said. Anna was to be her first grandchild. She began right away to buy outfits and books and toys. When she found out it was a girl, she would send cards addressed to the “Queen of All Our Hearts.” It’s so strange to look at those cards now—written in her handwriting. Handwriting that is as familiar to me as my own name. Handwriting that will never write another word again.

When Anna was born, she was a tiny little thing. Five pounds. My mom came down to help, and she laughed and cooed as we put tiny little Anna into her miniature clothes, only slightly bigger than doll clothes. My mom was so helpful and cheerful, cleaning for us, giving us breaks, watching as Lolly and I took our first steps into the world of parenting. She was perfect. She stepped in often to let us sleep, and stayed up with our precious daughter in the night.

It was during this visit that we had the first glimpse into what was happening.

Lolly was the one who first noticed it—who first uttered the dreaded word. She and my mom were in one of the bedrooms folding clothes, and my mom saw some fuzzy pink bunny slippers that someone had given Anna at a baby shower. “Oh!” she giggled. “These are the cutest booties I’ve ever seen! I love them! Where did you get these?” Lolly told her. The person who gave them to us was someone my mom knew well—a mutual friend we had all known for many years. My mom smiled and commented on what a nice gift it was, and how thoughtful it was of those friends to send such a cute gift.

Later that day, in the same room, my mom caught sight of the bunny slippers. “Oh! Well aren’t these the cutest shoes I’ve ever seen?” She was giggling again, in delight. “They’re so cute! Where did you get these?”

Lolly kindly explained it to her again.

Who hasn’t had a moment where they forget a detail or a conversation? Who hasn’t had a lapse in memory? These were the things Lolly said to herself, but deep down she knew something was wrong because of that conversation, and because of other small things she’d noticed over the course of the week. She pulled me aside that evening. “Something’s wrong with your mom,” she whispered. “She’s reminding me of my grandma before she died. I know it sounds weird, but it’s almost like she has Alzheimer’s.”

There it was. That word.

I had just done a presentation on Alzheimer’s for a prerequisite class for grad school. I’d just read all the statistics and looked at all the symptoms. Even so, it was too hard to believe. I tried to dismiss it. “That’s *impossible*,” I said. “She’s too young. Your grandma was in her eighties. My mom barely turned fifty. It would have to be early onset, and that’s genetic—there’s no history of it in my family.”

As I look back, that moment reminds me of the times Lolly and I are driving in the car and she senses something wrong—some mechanical malfunction—and says, “Uh oh, something’s wrong with the car.” Then I insist that there’s nothing wrong with the car and that she’s just paranoid. I am *adamant* about how wrong she is—adamant to the point of anger—only to then have the car break down sixty seconds later.

Denial.

My mom’s symptoms were mild. She functioned nearly perfectly the rest of her time there. It was easy to just push that incident aside and assume it was nothing. To assume we were just being paranoid. To sink back into the status quo and let things be—pretend nothing was wrong so that for a few more moments at least we could enjoy things while we didn’t know the truth. At least we could enjoy my mom before we knew, for sure, that something *was* wrong and that she, though so young, was already dying, already being taken from us, piece by piece.

It was not long before our sixty seconds of denial elapsed and the car began to chug to a stop.



The symptoms worsened. Lost items. Missed words. Repeated stories. It all happened more often and with more intensity, and as the next couple of years passed, the problem began to be undeniable. Something was wrong. Something was very, very wrong.

I think Lolly and I accepted the truth before everyone else. There was one terrible night—I remember it clearly because it was the night before I began my clinical practicum for my master’s degree—that Lolly and I stayed up for three or four hours weeping into the night, mourning what this meant. “She has it,” I said. “She has Alzheimer’s. My mom is dying of Alzheimer’s.” We watched the hours pass as we talked. Because Lolly and I had grown up together, we had both known this great woman our whole lives. We cried. We cried for the fact that our children wouldn’t know her for who she was. We cried for the pieces of her that were already gone, that had already been taken, as well as for the pieces that were sure to go. As the reality of it all continued to set in, we wept at the memories—my mom as Lolly’s Mia Maid adviser; how excited she had been for Anna, her very first grandbaby; what a wonderful mother she was to me growing up; what a wonderful person she was. At four in the morning, we finally fell asleep in each other’s arms.



My dad was still hoping, still banking on what the doctors had told him—that my mom was too young to have Alzheimer’s, that the anti-anxiety medication they had put her on was causing the symptoms of dementia, and that once off them, my mom would slowly return to normal. They stopped the medication and then waited. Weeks and weeks passed. Nothing changed.

Finally, during a trip down to see them for Thanksgiving, I had a sobering talk with my dad. Since that heartbreaking night with Lolly, I was coming to terms, as much as one can, with the fact that this was happening. And now that I had broken past the denial, I craved to not be alone there in that place. I craved for the rest of my family to be there, too. There was a part of me that wanted to be abrupt. I wanted say, “She has it, Dad. Just face it.” But you can’t just say that kind of thing to a man who is losing his soul mate. You can’t say that to a man who has woken up next to the afflicted every day for the last thirty years and loved and adored her through raising children and moves and jobs and church callings. Instead the conversation was much more subtle.

“How has mom been doing?” I asked as we stood ringing up some last-minute Thanksgiving groceries at a grocery store.

“Not very good.”

“Still having the memory trouble just as bad?”

“Yeah. Probably worse, actually. The other day she couldn’t even work the remote control.”

“So . . . how long ago did she stop taking the meds?” I said the words softly, like an afterthought.

He paused as his brain did the math. “She stopped them at the beginning of August . . . which means it’s been about four months now.” We stood there in silence, holding our grocery bags filled with pumpkin filling and ice cream. We both teared up. “I think it’s time to start acting on the idea that this is Alzheimer’s,” he said, his voice choking.

“Yeah. Probably so,” I said. There was dread in our words. A dread of watching this actually happen. A dread of knowing for sure, of hearing a neurologist say the word.

By the time the call from my dad came, months later, I was more adjusted in my grief. It was still jarring to hear the word. It had been confirmed: early-onset Alzheimer’s. I took the phone call, the revelations of the diagnosis, well, however.

But soon after, I discovered that grieving someone who is dying of early-onset Alzheimer’s is a strange thing. They haven’t died, you see. But they are also no longer themselves. As several more years have passed, it has become clear to me that watching a young person die of Alzheimer’s is one of the most excruciating types of loss.

The disease goes breathtakingly fast. The grief is vicious. You are grieving the loss of someone you know. That person is gone—dead, disappeared never to return—but then you go home and *there that person is in the flesh*. I can hug my mom. I can hear her voice. I can tell her I love her. I can hear her laughter. And she will never ever be herself again. She is . . . *absent*.

It’s loss and possession at once. It’s being able to say goodbye and never being able to say goodbye at once. It’s needing to grieve and having no death to grieve at once.

It’s torturous.



There are so many strange, horrible things.

I will describe only a few of them—some of the least degrading.

There is an embarrassing impulse—the impulse to avoid. I would never have expected this, but it's real. I've talked about it with some of my siblings. I make myself stay in contact, but a part of me doesn't *want* to see her. Doesn't *want* talk to her. Because every repeated story, every mangled sentence is further proof of her demise. Each visit is filled with signals that say, "The woman you love is gone, and her body is dying. You can't pretend this isn't happening." Knowing she's so vulnerable and then having my brain not want to see her is horrible.

The changes are so different than I expected. In my mind, there was a strict order to things: she would start to repeat things more and more frequently, and then she would forget who we all were, and then she would forget who she was and where she was, and *then* she would lose motor function. How much more excruciating to watch her lose her motor function—the ability to use the bathroom, the ability to put on a seat belt, the ability to write—while she still remembers who we all are and who she is and what is happening to her. She is there, but she is so far gone, like a person fallen down a deep well. A kernel of her real self remains, watching her own deterioration. I didn't think it was supposed to happen this way.

My father's suffering is heart wrenching. I hate watching my dad suffer through all of this. He is doing an amazing job, and his pain is more than I can even imagine. So many shattered dreams: no twilight years serving missions; no celebrations; no fiftieth anniversary bash; no golden years together. Just illness and loss and cleaning and helping the dying body of the woman he loves.

These are just a few of the hard things.

Laced in the pain and trauma are sweet moments. I treasure those.

Occasionally, there are conversations where the real her comes through, if but for a moment.

I'll close with one of these treasured moments.



At one point, I wrote a friend of mine who had lost her father to the same disease. I asked if she had any advice for me. After an email filled with good advice, she warned, "You never technically get to say goodbye. Its not like you can do it when they're lucid one day over a cup of coffee."

Not long after this, she wrote again in a panic: "After I wrote that email I was like . . . I SHOULD'VE SAID GOODBYE WHILE HE WAS

LUCID OVER A CUP OF COFFEE!! Of course you can do that! . . . So to amend my previous email, in the immortal words of John Stamos, only not John Stamos, the other John who's a singer who I can't think of right now because I'm so tired, 'say what you need to say.'"

One evening when I was visiting my parents, my mom and I were chatting. She was repeating the same stories and the same phrases and forgetting basic words, and the sun was setting, and it was getting dark, and we were alone, and I realized *now* was the time.

I started crying, and I got down on my knees in front of her and held her hands, and I said, "Mom, I need to tell you something. I need to tell you how much I love you, and how much you have meant to me. I want you to know that you were the best mom I could have ever asked for, and you were so perfect for me, and that you saved me with your prayers—you *saved my life*. Thank you, Mommy. Thank you for all you have done for me, and for being the perfect mom for me. I'm so sorry this is happening to you. I want you to know how much I will miss you, and how much I already miss you." I was bawling, and speaking quickly, and she was crying too, and then she had a flash of lucidity. Her mind focused, and she hugged me, and through her tears she called me by name and said, "I know. I know. I love you! It's okay. You don't need to be sad. It's okay. I'll be *fine*. You're such a good boy, and you've done such good things with your life. Don't *worry* about me. I'm so proud of you! I know. I know . . ."

In a perfect display of motherly altruism, she, the one riddled with disease, hugged and comforted *me* as I said goodbye. She will never remember we had that conversation. And I will remember it until the day I die.

And now it is I—following her pattern—who finds himself kneeling at the foot of my own bed, pouring out my soul in prayer for her. It's my turn. It's my turn to ask God to take care of her while she suffers, and to take care of my dad. To ask him to bless them and be with them as they are in agony, and to thank him. To thank him for the sweet memories of my youth, and to thank him for sending me to that wonderful, wonderful woman.

The time to speak is now, I've learned. And that is the lesson. Perhaps you and your loved one have struggled. Perhaps you live far, far away and don't get to see him or her often. Perhaps your parent is still young, and the thought of death seems distant and vague—nearly *impossible*. Don't wait. Don't hesitate. Take the chance to look your mom—or any other loved one—lovingly in the eyes and *speak*. Ask for forgiveness and grant

forgiveness. Share love and share your memories. Tell him or her the things you've always meant to say but haven't. Lay it bare. Take the chance while you have it, and if you have it again next week or next month or next year, do it again. You won't regret it. Not for one minute.

Don't miss your chance to say goodbye.

Just say what you need to say.