

Sarah Canterbury

### Remembering Sophia Jane

I heard a faint stream of notes carried by piano keys, dusty keys that journeyed upstairs into my bedroom and through my almost closed door. My family's long neglected piano was desperately out of tune, so each note was a little sharp, and a sort of sour sound lingered but I could still make out "Amazing Grace."

The familiar church hymn rose and alarmed me, not because it was music or because the hymn echoed through my home, but because someone was playing our piano, actually playing it, which hadn't happened in a long time.

The hymn filled the hall that opened up below my room and it must have ventured into the rest of the house, the way it had years before when my brother Luke still played.

I don't remember how old I was, or how I ventured down towards it. Maybe I was still a child and ran unafraid of what I didn't know, or maybe I slowly walked to the piano, nervous to find out who crafted the echoing hymn.

I found my grandma Jane, my dad's mom at the piano. She sat oddly far away from the keys and stared at a blank metal music stand. Her feet stretched out to work the pedals and her swollen fingers drifted along the keys, like all she knew how to do in life was play that piano, and that song.

I stared for a while as she played so clearly and looked so lost, "That's really good," I said making her stop and gaze at me.

Her clear blue eyes looked sunken, but she still had that round face and short white hair religiously permed. I couldn't swear on it, but I would bet she was wearing a track suit of sorts,

one that would swish when she walked, and was some shade of pastel blue. She had at least one ring on each finger, trapped below her swollen knuckles. I know she still had on the ornate looking golden shield ring, the one with the small diamond in the center held by six silver prongs; I watched it move across the keys creating its own rhythm.

I always wanted that ring. It reminded me the woman staring blankly at me was still my grandmother. It still reminds me.

“You play well,” I told her, uncomfortable with how she searched to recognize me.

“Can you play something else?” I asked sitting down beside her on the wooden piano bench.

I pressed one of my hands in the center of the piano and pulled it towards the other side, creating a chilling crescendo. Then the house was silent.

“Do you know how to play?” Grandma Jane asked looking at my hands on the keys.

“Just a little, or I did. I took lessons, but I don’t remember much,” I said pressing a few more keys down.

“When did you learn how to play?” I asked.

She said nothing, but stared at my hands on the piano and then looked at me like she was searching for an answer in my face.

“Do you know how to play?” I asked, dangling my hands above the keys and pretending to press down.

She looked at them for a moment and then back to me, “No.”

When she had stopped staring at me, she put her hands back on the keys. Her gold ring bounced up and down a few times and then she played “Amazing Grace” again. There was something beautiful and chilling in the hymn. The out of tune piano, the grandmother who forgot me, the icy blank stares, all blended together with the melody, with the sweet song that sings of amazing grace.

There are worse depictions of Alzheimer’s, worse images I remember, but there is a strange comfort in thinking her gift and love of music never left. I like to pretend that her blank stares weren’t those of a grandmother forgetting, but like a child trying to remember.



There is a picture I love of my dad at the beach, standing in front of the ocean; it was taken years before I was born. He has on green trunks and is squinting a little, and even though I know him by a different hair thickness and color, slightly different build, and age, that picture is what my dad looks like and is to me.

In it he has light brown hair that, like mine, is bleached out because of the sun. I can see his soft blue eyes my brother David and I inherited, and he isn’t smiling in the picture, but I know he is happy. He is tan but not dark, and has what my brothers and I believe is the best mustache humanly possible, the one I have never seen him without. His eyebrows are thick, almost bushy, and his hair is standing up a little maybe because of wind or because he ran his fingers through it.

The way he is standing is important too: slightly pigeon toed with his hands at his hips, as if he is asking “what’s next?” As soon as the picture is over he will begin to chew his lip, a habit

he hates but does, and that's my dad: a man so smart he doesn't know how to get in out of the rain. A man perfectly imperfect, funny, caring, and intense.

My Dad.

My Dad doesn't know I'm writing about him, or at least doesn't really know what I want to say. Part me wants to tell him, but I think I know how he will react before reading it.

If anyone is around he will say, "it's about time," and then make some comical remark about the pressures of being perfect. Or he might act nervous and say, "it was bound to come out."

He might surprise me and genuinely ask what I am writing, but if I get serious at all, brush it off, saying, "that's not true" or "I have you fooled."

I know when he finally reads it he'll cry, fighting not to. His eyes will get barely red and I'll see them start to gloss. If it goes on too long the tears will pool in the corners of his eye and when they start to drip he'll take his glasses off and wipe them away.

I want to tell him what I remember.

I want to write it so I'll never forget.

I want him to know who he will always be if he forgot me.

I want him to know.



Researchers and doctors debate over the possible factors, signs, and main causes of Alzheimer's but share a somewhat cohesive understanding of the disease; that it is progressive,

irreversible, and fatal. Wei Kong and researchers with PLOS ONE note that Alzheimer's disease "is the most common form of dementia," and echo that central understanding of the nature of Alzheimer's being a "progressively fatal neurodegenerative disorder characterized by irreversible cognitive and memory deterioration that inevitably leads to death" (Kong 2). Although there is no known treatment, the progressive disease is highly researched. Elizabeth Rosalind Thomas and Jie Bai<sup>1</sup> in their article "Aerial View of Alzheimer's Disease" say "after the onset of Alzheimer's, the patient usually lives at the cliff hanger of life," (356). The "cliff hanger of life" is a vividly metaphoric way to describe Alzheimer's, also an accurate one.

Once an individual is diagnosed they will likely be told about its "predictable" three stages of degeneration known as the early, middle or moderate, and severe stage. Then they'll live a "cliff hanger" life, waiting for change, for their memory to leave.

I find it amazing how little I knew about Alzheimer's when my grandma Jane had it. When I watched its progressive nature take her away, but I was young, and at first it just seemed like a funny part of who she was.

She joked about it in the beginning. That's what my dad told me, which matches my own memory. We all did it, after a weekend with her we would talk about how many times she asked us the same thing and laugh. But it's not funny, it's just a way to cope so people don't have to cry.

I never thought about what it was like for her to be standing at the threshold of forgetting, at the edge of a cliff just waiting for Alzheimer's to push her off and take away everything she knew about living.



If it hadn't been for the Alzheimer's my Grandma Jane would have told me when she got the golden ring I wear every day, or about who taught her to cook. I would love to talk to her about the best way to get yeast rolls to rise, and I would ask her why she went by *Jane* instead of *Sophia*.

If it hadn't been for Alzheimer's she could have told me about my dad's first haircut, or about when he lost his first tooth. I don't know if my dad screamed in a barber's chair, or sat patiently on a back porch or bathroom while Grandma Jane carefully cut his fine baby hair. I don't know if she saved a lock of his light hair in an envelope tucked away in a long-forgotten baby album, or if the occasion was even special to her. Did he learn to talk and walk quickly or was he nervous to try? I wish I would have listened more; there is so much of her I never knew, and in a way so much of my dad that was lost as well.

Was he like her brothers: Clarence, Jack, and Frank, or did he remind her of Grandpa Canterbury's sisters and parents? Was he always as hard working as he is now? I would love to know.



We were sitting at our treasured kitchen table, the oval relic of my childhood. My dad sat in his seat, the "captain's chair," the only one of six with arm rests and even though we were the only two in the kitchen I left one space between us and sat in my chair to the right of mom's.

The windows were open, letting autumn's chill fill the kitchen. The sun was setting fast, throwing shadows across the yard. I had my used yellow legal pad out ready to write, and I looked at him— my dad. He sat and shook his foot, the way he has my entire life despite my

mother's best attempts to stop him. I looked into his familiar calm, clear, blue eyes—the ones as a child I swore could cast lightning.

“Do you feel like you had to look at Grandma Jane differently to take care of her?” I ask, going right into my list of questions.

“Well I had to do some really hard stuff, but no. Maybe it was because of my background in medicine I just did what she needed, but no,” he said, his eyes starting to water “because I wanted to take care of her no matter how uncomfortable it made me feel. That was my mom and no matter how much every part of me didn't want to see her like that I had to take care of her.”

He took in a deep breath and I scribbled as much as I could.

“But I didn't take care of her. We didn't. We love and respected her so much we let her get too far gone,” he said referring to his siblings, “she stayed in her house alone way too long because we were in denial. Mom never needed help, never let you help but she needed it.”

My hand started to quiver at this point in the interview. I wanted to ask him about other things, maybe funny things, but I also wanted to reflect on what he already said. Wanted to tell him, you did take care of her, but I listened.

He told about things I didn't even ask and I didn't care, it was great to hear about what she was like. I wanted to know Sophia Jane, the poorest girl from Bolt, West Virginia. I learned she taught herself to play the piano, that she was the baby with three older brothers just like me, and took care of everyone but herself. He told me about how, even in a nursing home, forgetting everything, she could figure out how to disconnect the alarm and start walking away, and I wanted to know this woman.

But our conversation started to drag and I knew I had to either explain why I was asking these things, which I couldn't articulate yet, or continue with my list of questions.

“Do you feel seeing her like that, and having to take care of her changed how you saw her?” I said, unhappy with my own question. “Do you feel like you have two memories about your mom—the mom you grew up with and then the mom who forgot?”

My dad took his glasses off.

“When I think of my mom do I think about that?” he said pulling his hand up to his chin.

“Never,” he said which completely shocked me.

“Do I think about the last time I saw her and she just stared at me with this blank expression. When I told her ‘I love you, mom’ and kissed her and she had no clue who I was. No. No, never.” He said, a few tears running down his face.

“Because that wasn't my mom. That wasn't my mom who rang a cow bell at my football games, or canned vegetables. That wasn't my mom who never let me get up a day in my life without fixing me breakfast. So no, that's not who she would want to be remembered as, and that's not what I want” he said as I wrote as fast as I could.

“What would you tell her,” I asked my dad, my voice shaking, “What would you want her to know you remember?”

“Mom, there was never a time in my life that you didn't make it absolutely clear that you loved me. There was never a question about that,” he said, “I would never want to forget she always put me far above herself, that she was sacrificial, selfless. I would thank her for that, thank her and let her know that didn't change.”





Alzheimer's like other diseases affect each individual differently; although Alzheimer's patients will experience three stages of degeneration the nature of the stages, and course of duration is different from patient to patient. In the early stage of Alzheimer's some patients "suffer from frequent recent memory loss, personality changes with functional decline," alarming loved ones and signaling the disease (Thomas and Bail 359). Some patients experience difficulty, "to remember new information" toward the end of the early stage but are still capable to care for themselves (Belt 1).

I liked early stage grandma Jane. The one who I see in pictures holding me, the one who made perfectly set pecan pies, the one who took care of dogs and bunnies, her house and herself. She was forgetful, but she knew and loved me.

Suddenly though I didn't understand why she stopped buying my "doll of the year" birthday presents, or why she began to hoard ketchup, shampoo, and laundry detergent bottles. I don't know which stage I started to lose her, but slowly I knew there was more to the forgetfulness.

The middle or moderate stage of Alzheimer's typically lasts the longest, and has the largest range of degeneration. It is where patients experience "pervasive and persistent memory loss, loss of familiar settings, sleep disturbances, mobility and coordination problem[s], and mood or behavioral symptom[s] accelerate" (Thomas and Bail 359). Somewhere between the early and middle stage of my Grandma Jane's Alzheimer's she lost her best friend and husband of 48 years, Thomas Canterbury. My dad says when he passed away her mind rapidly began to decline, which matches what Thomas and Bail also say about characteristics of the middle stage:

“About 80 per cent of patients at this stage suffer from emotional and behavioral problems which are aggravated by stress and changes” (359). How could my Grandma Jane not be aggravated or stressed about the changes though, she was losing the last pieces of her life she remembered, the last parts she could control.



We were towards the back of the sanctuary, just below where the balcony's overhang ends and the sanctuary opens up; where you can see the baptistery while standing on that light green carpet that covers the floors, pews, and stage. We were in-between the far right and middle section of pews and it was during the evening church service because that's the only reason dad and I would have sung from there instead of the stage.

My dad held one of our church's green hymnals with gold script but didn't need to, we knew the words. I stood beside him clutching his hand and we sang hymn 762, “What A Day That Will Be” made famous by the Gaithers but written years before by Jim Hill.

My dad sang all the verses and when he came to the chorus I joined in, getting a little braver when we came to the line, “When He takes me by the hand, And leads me through the Promised Land”—maybe because that meant there was only one line left in the chorus, but I remember feeling stronger because I was holding my father's hand, and even at six years old I knew that moment was special.

My church still uses the dated green hymnals and every so often I'll hear:

There is coming a day,  
When no heart aches shall come,  
No more clouds in the sky,

No more tears to dim the eye,  
All is peace forever more,  
On that happy golden shore,  
What a day, glorious day that will be (Hill 1955)

When I hear that I'll sit up and think, *that's our song* and I'll sing along, wishing everyone else would stop, remembering the day we sang hand in hand.

It haunts me that "What A Day That Will Be" could become my dad's "Amazing Grace." And I wonder if he were to forget all of me and remember that, like my grandma Jane at the piano, would the memory still be sweet? Would I look at him like I looked at her, or could I be happy to sing along pretending he remembered?

The scary thing about memory is not that it is faulty, but that it is liminal. The scariest thing about who my father is to me could be that he could forget it all.



My whole life I heard about what an amazing cook Grandma Jane was, about how her Sunday dinner rolls would lead neighbors in by their smell. About the gallon sized tub of bacon grease in her refrigerator that replenished itself every weekend and flavored innumerable amounts of green beans. About how she would make stuffing and dressing on Thanksgiving just because my dad liked the extra dry texture of the baked bread pieces outside of the bird.

Donald Duck orange juice, chicken nuggets, butter pecan ice cream, instant mashed potatoes: that's what I remember.

I didn't grow up with Jane the fabulous cook but the Jane who got her stove turned off.

“Well, I would make you mashed potatoes but I have no stove,” Grandma Jane said her eyes locked on my dad, her small frame shaking.

“How am I going to eat without a stove?”

My dad looked tired and a little scared, “Mom, we’ve talked about this...”

“I might as well be dead,” she said, a line she used more and more after my grandpa Canterbury passed.

I was probably too focused on the painful realization that I would not be getting mashed potatoes to pay attention to how the two of them spoke. But at some point she stormed out of the kitchen, and after a while came back.

I don’t know if she asked my brother Joshua and I if we wanted something to eat, or if she came in thinking of her own stomach, but she stood at the stove. Her place of honor as an Appalachian mother, the part of the home that was hers and only hers, the place she loved and showed love; she turned the heat to high and set a pan on the dead burners. After a while she realized nothing was warm and lifted the pan up to search for the familiar heated glow.

“Tim,” she called, “Come here and look at this, something wrong! None of the burners will come on.”

I imagine my dad’s face looking heavy and sad, his lips pressed together hard and eyes glossy, looking in from a doorway or from the dining room hall.

“Mom,” he said and paused, “it’s not broken. It’s turned off.”

“Flip the breaker or something.”

“No mom,” my dad said making me uncomfortable, “we disconnected it. On purpose, we talked about this...”

“Why would you disconnect my stove!” she asked, outraged.

“We disconnected it because you forget, and it’s dangerous. Remember we all discussed it, me, Todd, Tracy and...”

“You have no right! I’m your mother.”

And she relived the moment over again. The humiliation of losing her stove, but worse a reminder she was forgetting. There must have been in the loss some reminder of how much she was losing.

How am I going to eat without a stove? The question stuck with me, but not as much as the question of how much she knew, how much she thought about it? She was losing her memory, the precious, the bad, the hard, her life. And she knew it, but she didn’t.



The Alzheimer’s Association compares brain cells to “little factories” because they “receive supplies, generate energy, construct equipment and get rid of waste” (ALZ.org). Like a factory, brain cells also “process and store information,” “communicate with other cells” and work together to ensure the “factory” goes on, but Alzheimer’s changes everything (ALZ.org). The progression of the disease is “just like a real factory, backups and breakdowns in one system cause problems in other areas. As damage spreads, cells lose their ability to do their jobs,” and the factory has to shut down (ALZ.org).

Before shutdown, the “brain factory” must experience Alzheimer’s final stage, the severe stage. It is when the “patient has confusion about the past and present, total loss of verbal skills, extreme mood swings, behavioral problem, hallucination and delirium” (Thomas Bail 359-60). To extend the factory analogy, in this stage the “brain factory” has lost all access to its databases, employees, and has long been incapable of functioning – it rapidly begins to shut down.

The brain stops doing what it’s designed to do, but not before everything and everyone they love watches them forget: forget where they lived, the people they knew, and their children they loved.



Things I remember about you, Dad:

That time you stuffed maps in my shoes, so I would be tall enough to ride the rock n’ roller-coaster at Disney

When you taught me how to parallel park and made me cry

The lesson on family chains

Pretending not to know each other in Arby’s so we could use two coupons

How much you love to watch *A Christmas Carol*, but just the one with George C. Scott

Getting thrown out of the snowtubing resort for masterminding an “illegal” assembly run

How you close your eyes when you sing

The time you freaked out our waitress over tomatoes

Scream sneezes

Hiding in the trunk to try and scare mom

Handholding contract

How your breathless laugh is funnier than your jokes

How excited you get when you see a barge on the river

That time you thought you read *Moby Dick*

Flipping bacon with your hands

How you think it's funny to say Por favor after any statement to make it "Spanish"

The time you were going to kill my horse but didn't feel like it after you ate dinner

Watching Kim Possible together

How you test the electric fence by touching it

To bed to bed sleepy head



My Mom and Dad's bathtub has leaked for years. It hasn't always leaked though because there are hundreds of bathtub pictures of me and my brothers with that white claw foot beauty in the background. But it was broken that day. That's why they were in my bathroom.

Behind the shut door I could hear the swish of bathwater and my father comforting my Grandma Jane. They needed to use my bathtub, that's what mom told me. I probably tried to argue why they should use the boy's instead, but eventually I listened when I was told to quickly shower and then put clean towels out.

I sat on my bed, with my beloved blue Pottery Barn comforter wrinkled under me. My hair was wet but I hadn't brushed it yet, which really bothered me. My thin hair dries at an unnatural speed, and by the time they were out the tangles would be set.

My room was dim on account of the impractical paper lanterns I had to have, and I could see their light bounce off of the full length mirror that hung on the outside of my bathroom door. I don't know why I stayed up there. No one made me, my dad didn't need me, but I stayed.

He was so calm, gentle, understanding.

"Here we go, let's wash your hair," he said.

I watched my mirror vibrate on the door with his movements. I could hear the pop of my shampoo bottle being opened, could smell bursts of the familiar coconut scent tangled in my own wet hair come and go, but feel none of it. It seemed weird, all of it, which might be why I stayed. I didn't understand.

My father was bathing his mother, and I didn't understand how he could for even a moment.

At some point my mother came into my room to look for sheets to fit the guest bed. She paused by the door and listened as I did.

"You okay honey?" she asked looking at me.

"Yeah, I'm okay, why?" I said.

"I just know it's hard to see your Grandma not remember you," she said, "I think your dad knows she has forgotten him too, but he hasn't said it."



I remember wondering why she was telling me this, and also wondering why I hadn't thought about it before. Did she really—not know me? Maybe I had dealt with that, but for her to not know my dad. It horrified me.

“She wouldn't let him bathe her if she knew who he was,” she said taking the sheets and walking out.

“Alright, let's rinse your hair,” dad said through my shut bathroom door.

When he had dried her off and clothed her, he lead her through my room, he walked behind her holding on to each of her elbows to support her waning frame.

“Look, Mom,” he said, “it's Sarah.”

I watched him force a smile as he lead his mother, a mother unaware she was supported by her son. That wasn't a version of my grandma I wanted to remember, but one I can't forget.



*This is crazy, I tell myself as I watch the curser on my Word document blink. Is this really the only way you can write about your dad, by interviewing yourself?*

*No, but it's the only way to write about all of this, about your fear, about your reasons to write, I answer. Okay, so do it.*

*Why do you want to write about your dad?*

I've always wanted to but I could never figure out what to say. I've tried to write essays about him before but when asked “what's the tension,” “what's the conflict,” I shied away because I didn't want to go there. Really, I've always wanted to write something that would

make him proud, not of me but maybe himself? Write something that preserves a version of who he is to me, one that could make him see how thankful I am for him.

Sometimes for Christmas or holidays I'll write my parents letters, and they'll cry and hug me and tell me what I said is the best present they could get. It makes me wonder how they would feel if I wrote the uncomfortable, if I boldly told them what I feel, what scares me. But I didn't want to go there with my dad, until now.

My dad— I'm afraid he has Alzheimers. Or, that he will eventually. I have no proof, and maybe because of my grandmother everything he forgets stands out, but it scares me. He calls me Tracy, his sister's name, instead of Sarah sometimes. He forgets conversations, important ones we've had and blames it on his hearing. He jokes about the future, about what it might be like when my brothers and I are all married with children and come to see him.

"Hi, grandpa," he pretends to say, "It's me, Daniel."

"Who? I don't know a Daniel, get away from me" he says in his best old man voice.

"I'm Luke's son, I'm your grandson."

He usually finishes it with a joke and we sit around our treasured family table and laugh. It's not funny though. It scares me—I don't want to watch my dad forget and it terrifies me to think about what that moment would be like, knowing I never told him what he means to me, knowing I didn't preserve at least a version of who he is.

I've always felt I had two versions of my Grandma Jane, the early version who loved and knew me but was lost in a way because I was too young to ever really experience her. Then, I

have the grandma who forgot me, and the scenes of that have dominated my remembrance of her.

It scared me. It scares me.

I never want to think of my dad and remember anything less than the person I love and am loved by. I don't want two versions of my dad, therefore I write.

*When you interviewed him you noted everything he admired about his mom you see in him, why do you think he doesn't see it?*

That is typical dad. It reminds me of Sunday school class, which oddly we have together. No matter the topic he'll say how scared he is of the judgment seat, how he falls short, how, like Paul says he considers himself the chief of sinners. I don't want to be mistaken, I don't think my dad is perfect. I don't think he is a god, and I don't worship him, but I don't see a chief of sinners, I see a sinner saved by grace who has been for me the closest picture of what God's love is like.

My dad is always doing, fixing, improving. He doesn't sit, he doesn't stop. So, even though I know he didn't perfectly take care of his mom, he did take care of her. He can't see that though. He sees only miss opportunities and the mistakes. He can't see just how sacrificial he was which I relate to.

*What would you tell him? What would you want him to know you'll never forget?*

Dad, there was never a time in my life that you didn't make it absolutely clear that you loved me. There was never a question about that. I would never want to forget you always put

me far above yourself, that you are sacrificial, selfless. Thank you for that, and I want to let you know that will never change.

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