

Writing Alzheimer's:

A creative Writing Exercise

By Eva Soares

Slipping Away

"Mona! Where is my coat? I need my wallet and I think I left it in one of the pockets."

"Oh dear, come on and sit down by the fire. No need to go rummaging in the closet like a boar looking for truffles. Please sit down, it's time for your pills."

"My pills? You don't understand, I need my wallet. You see, I dared Jeremy to ask the first woman he met in the hallway on a date. Turns out, he stumbled upon an associate professor from the philosophy department. You know the tall one that looks like she cat-walked out of a fashion magazine, that lucky bastard. So now I owe him sixty bucks."

"You're mistaken dear. You haven't taught alongside Jeremy in over five years. Now come sit by the fire, you'll feel much better."

"Nonsense! I just taught a History of the Middle Ages class yesterday. What are you talking about?"

Mona sighed. Her husband was already lost in his past, and didn't seem to be waiting for an answer to his question. She didn't want to break the news to him, not again. He would just forget about it all the next day, it was useless. Yet, when faced with his creased forehead, pursed lips and confused expression, she couldn't deny him that truth. Lying to him would mean that whatever she told him wouldn't help or heal his head. If she lied, then it would mean that all hope was lost. Mona couldn't accept that. After all, her husband had been diagnosed early, the doctors had said. He had been an excellent professor. His colleagues had praised him for his countless publications in *The Journal of American History*. He had even been invited by Harvard's History department to speak about medieval liturgy. Now, he was the shadow of his former self, still holding onto gleams of the past. He lost his closest ally, leaving him greying and haggard, sometimes wandering as if he were searching for his thoughts. She began rearranging a pile of her husband's old papers which had been catching dust on the mahogany desk. A student's essay fell and glided to the ground. As she crouched to retrieve it, Mona read:

"He who has hope, has everything; an Arabian Proverb well known in..."

That's it! She needs to hold on to hope, for the sake of her husband and herself. The thought had somewhat lifted her spirits and she began humming "The Girl from Ipanema", the song he would always hum in her ear as they were swaying in the living room. She continued humming while she took his hand and guided him towards the sofa. As she walked, she sang words here and there:

"Tall and tan and young and lovely..."

"The Girl from Ipanema goes walking"

Had she heard that correctly? Mona gazed at her husband in awe. He had serenaded with her, he remembered their song. Yet, he didn't seem to realize the importance of the tune since he slumped back into the old leather armchair. He had been lucid enough to sing with her. It had been only a moment, but she would cherish it. When she placed the plastic cup with three different colored pills, he became confused again.

"What's this? I'm not sick! You always worry, you always think I'm sick."

Mona couldn't refuse her loving husband an answer. It would be too cruel, she just couldn't. Mona took a deep breath. She stood up, firmly facing her husband while squeezing his hand in her soft plump palms.

"You have Alzheimer's dear."

Reflections of a Former Professor

Notebook n°26

467th day with Alzheimer's:

Today, I have a doctor's appointment. Mona told me she was going to wash the dishes before driving me there. She is in the kitchen washing the dishes. I am in the living room writing in my notebook. It's always been my favorite part of the day, writing all morning until Mona has finished her house chores. The sound of the pencil scratching on the lined paper soothes me. It urges me to go on, before my mind forgets, erases, deletes everything. I want to leave something of myself, my thoughts, my feelings, my terrible humour, all of it to Mona. She used to whistle when she was busy in the kitchen. Sometimes, she would whistle the melody of "My Favorite Things" as if she were Julie Andrews prancing around the house. I can't hear her whistle now. Maybe she forgot the lyrics. What was it, strudels and poodles?

I am back from the doctor's appointment. I asked Mona if she remembered the song. She said yes. I said I did too, a little. Then, she said I should make a list of my favorite things "that way you wouldn't forget, Edward". So here it is, a few of my favorite things:

1. A crackling fire on a Sunday morning, perhaps a Saturday. Which day is it that there is no post?
2. Voltaire's Treatise on Tolerance. It is such an insightful collection of essays. The man was brilliant! My students would always butcher his quotes in their essays, it was painful to read.
3. Kissing the cappuccino foam off of my wife's lips.
4. The tonkotsu ramen from the Japanese restaurant next to the University.
5. The smell of rain on tar. It's always raining when I have to hand in a manuscript to my editor. I must remember to continue the piece I promised to finish before the winter. I really don't know where I'm going with this new piece. I just think I want to talk about myself for once. I don't want to talk about some cocky Frankian King who collected mistresses. (insert footnote). My editor has been waiting for a long time, and I still haven't written more than a chapter. She is confident that whatever I write about will be fascinating, "even if it's just about Edward Keathe's dreary life". She likes teasing me, it's her own way of socializing. I guess it works with other people, but I've never liked it. I think she wants to feel superior, as if to confirm that fact with every jest. Mona calls me.

474th day with Alzheimer's:

Mona is in the garden trimming the thorns off of the roses. I am writing in the living room. It's sunny today, like yesterday. Or was it the day before that? What day are we? Mona tells me it's a Friday today. That's right, I watched an episode of House M.D yesterday, and I always watch it on Thursdays.

475th day with Alzheimer's:

Mona is making some coffee. I am writing in the living room. We went to the park this afternoon. It was so sunny again today, I told my wife I just had to be outside. She asked if the garden was enough, but of course it wasn't. I have to prepare for the marathon with Jeremy! She always forgets about the marathon. I'm representing the History department of the university. This year, I'm going to beat my record of 4h12min. I've been training for months, and I feel so vigorous I could start the race immediately¹. The coffee is here. I will drink it and then eat a small speculoos biscuit. I must remember to drink my coffee, or it'll turn cold like last time. Mona tells me that was yesterday but I'm sure it happened this morning. She tells me my mind isn't what it was. Yes, I forgot to put my shoes on to go to the park. Yes, I forgot it was Friday. But that happens to everyone, Mona is just being paranoid.

480th day with Alzheimer's:

Mona is...in the bathroom, I think². I am writing in the living room. My wife tells me Eliza is coming home this afternoon. She must be one of Mona's nurse friends from work. I hope they'll blabber for hours without including me in the discussion. That way, I'll be left alone to continue writing. I feel like this notebook is helping me. My mind seems to be an empty space, a blank page. Yet, as soon as I pick up my pencil, I can physically fill that blank page. As I do, the mist in my head dissipates. Eliza? My daughter Eliza! Yes, of course. She wants to become a nurse, just like her mother. My little Eliza, only ten years old and she already knows what she wants. She always has. My Lizzie is so bullheaded that I'm certain she'll reach any objective she sets herself. What she lacks is the capacity to take a step back. I'll be there to help her do that. I'll always be there if she needs a hug, to rock her to sleep, to say comforting words³. Where is Mona? Where is Lizzie? She's supposed to be in school, but I don't remember Mona driving her there. And I'm going to be late for work!

¹ Edward used to run the Marathon with Jeremy every year. Of course, he hasn't done so since his Alzheimer's diagnosis - Mona.

² I was in the upstairs bathroom, did he remember?

³ Eliza is our 40 year old daughter. She is a nurse at the local hospital and lives in the same neighborhood. She said she couldn't imagine raising her children somewhere other than where she was raised. She came to visit Ed that day. He thought she was my colleague. Eliza knows not to react to his delusions. It's hard for her too.

490th day with Alzheimer's:

Mona is somewhere. I am writing in the living room. My name is Edward Keathe⁴. I live in NewYork. My name is Edward Keathe. I live in NewYork. I need to keep writing. I can't forget. My name is Edward Keathe. I live in NewYork. My wife is Mona. She has a friend called Eliza. She came for coffee last week. It's funny because she has the same name as my daughter. My daughter is in school now, but I'll see her tonight. Maybe she'll need help with her homework⁵. I can't forget. My name is Edward Keathe. I live in NewYork. My wife is...

501st day with Alzheimer's:

The woman living with me is sitting next to my chair. I am writing in the living room. She says I need to continue writing. She says it's good for my mind, the doctor said the same thing. I haven't seen Mona yet, but I'm sure she's just sleeping in. I wanted to bring her some breakfast in bed, but the other woman wouldn't let me. She calls me Ed, like my wife does. I wonder where she is. I haven't seen her all morning. She's probably sleeping in. She loves having a lazy morning on a Saturday. Maybe I'll make her some breakfast and take it to her later.

510th day with Alzheimer's:

Dear Notebook,

Edward is in residential care. I am his wife, writing in his notebook. I guess this is the only way I could find closure. He spent so many days scribbling nervously with his pencil. I was concerned at first. I thought maybe he was writing things which were delusions, and I couldn't intervene to correct them. I thought that surrounding him with the truth was the solution. If he was compelled with the truth continuously maybe his mind would be convinced somehow. Maybe his mind would be redirected down the right path. I found a way to prevent his memories from taking my Ed away. They would often pop up in his head. Suddenly, he was gone, lost in his labyrinth. I couldn't take care of him anymore. It was too much, everyday too much. The housework wasn't the problem, I could handle that, like I've done so since our wedding. It was more of a mental toll. I had to be a companion to him. That meant telling him everyday that he had Alzheimer's. Each day, Ed would react differently. I was lucky when he

⁴ Ed started writing that after a woman at the supermarket recognized him. She was a former assistant of his whom he had helped with her PhD. He told her she was mistaken.

⁵ I had to explain to him so many times that day who Eliza really was. She is our Lizzie, our angel, our daughter. When I thought he had finally understood, he began raving about taking her to school. I don't know if I can continue. I'm getting old too. I should have done what Lizzie told me weeks ago, take him to a nursing home. Maybe he'll be happier there.

simply didn't understand what it meant to have Alzheimer's. Instead, he would just sigh and sit down to write. It was hurting me more than it hurt Edward. He could forget the pain that comes with the realization, with the truth. I couldn't. I just couldn't forget the truth, for his sake. He needed me to tell him when he was wrong and when he was right. I think I know what Prometheus might have felt, tied to his pillar with his chest wound healing each night only for an eagle to open it again in the morning. Now, Edward is in a nursing home being taken care of by people who know exactly what to do. That's it, he is happier there. He has more people to talk to, a nurse who will always be there for him, as many notebooks as he wants, if he has the energy to write. I visit him often, but he doesn't seem to recognize me. He talks to me in the same way, but it's like he didn't notice I was gone. At least, I know I'm still in his mind. That's all that counts.

Exegesis

For this piece, I decided to follow up on one of the course's assignments in which I developed the character of a former professor who had been diagnosed with Alzheimer's. In the assignment, his wife's perspective informed the reader about the character. Here, I wanted to have Edward express himself. Through this, there are textual changes and anomalies that also reflect his mental state. His writing deteriorates at the same rate his mind does. In order to have a realistic kind of writing for someone with Alzheimer's, I read through blogs written by caregivers and people with the disease, like Enomwoyi Damali's blog "Mom seems afraid that if she doesn't write things down, she will forget". Furthermore, I took inspiration from the novel *House of Leaves* which makes extensive use of footnotes to include different perspectives without altering the original text. This method was particularly useful to have Edward's writing exist in parallel with his wife's corrections, without polluting his train of thought. I chose the theme of dementia in order to participate in a discussion about fiction and truth. Truth is a crucial aspect for people with Alzheimer's and their family. Yet, fiction also plays an important role when it comes to memories and the delusions derived from them. Our memories are after all a fiction that tells us about ourselves and our lives. Furthermore, the act of writing is pushed to its limits when it comes to writing with a broken mind. In addition, feedback from my peers urged me to pursue this idea. One of my peers brought up interesting questions and comments, when referring to having Mona's perspective and her telling the truth to her husband:

"How would the piece be if she didn't break the news to him? That we only see the sad truth of Alzheimer's from Mona's perspective since the man keeps forgetting anyways? By having Mona go along with whatever he's saying, or listening to the same story three times in a row only to give the same reactions."

In this exchange between peers, I enjoyed feeling part of the creative process of fiction. The most useful piece of feedback I gave was an answer to my peer's uncertainty regarding textual style emulating text messages:

"To answer your question, I would use a special or particularly different font like a robotic one, or something that references technology. Maybe you can look up the font Apple uses for their text messages. You use time codes and incorporate the difference in tone between the thoughts and the text message really well, which gives more realism."