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## Getting the Mail: The power in the little things; Navigating cancer with the help of caregivers

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Getting the Mail: The power in the little things Navigating cancer with the help of caregivers Liz Anastasiadis

*Ring, ring.* I picked up my phone to see my Thea (Greek for Aunt) Fedra Anastasiadis' name buzzing, with a photo of us both smiling back at me. "Honey, it's me," said Thea. "Could you please come over and get my mail for me? We could also sit and talk for a while."

"Sure, I can come in around 30 minutes," I said. "Love you and see you soon, bye." I hung up and slid the phone into my back pocket.

My Godmother and Thea Fedra, who I call exclusively by "Thea," is my Dad's older sister. She lived down the street from my house, and we would visit her often. At Thea's condominium, the PO boxes aren't connected to the building you live in, and you have to walk to a different building to get the mail. Kind of like college, but not as fun.

Sometimes, I would get the mail for her when she wasn't up for it. I had my own set of keys to her apartment and mailbox. It was a routine for the last few years of her life. I didn't ever admit it at the time, but I was frustrated with her that day. She wasn't able to do what she used to, and it was a bad sign. It wasn't her fault, but soon, the mail became a nuisance to me, and a reminder. It became a recurring argument: if she didn't get the mail every once and awhile, then she would never get better.

Her chemotherapy treatments would make her so incapacitated that she felt nauseated and was oftentimes unable to walk for longer than a few minutes.

On top of her treatments, Thea always struggled with her weight. Her love of food was an addiction; she would cook lavish meals, bake cookies and spanakopita, tiropita, and baklava. All traditional Greek recipes, all with lots and lots of butter. Cooking and baking gave her joy, and it was one of her many hobbies. Every holiday season, she would bake for her neighbors, friends, and extended family. Some of my favorite memories with her have been in the kitchen.

After parking my car near her condo, I walked to the mailbox. The neighbor who lived across the street from her building waved at me. I smiled and nodded and fidgeted with my hands.

I always knew which mailbox was hers because it had a faded Cleveland Indians sticker on it with the now retired mascot from the previous tenant. I chuckled at its ridiculousness before using my set of keys to unlock the box.

It was completely full to the brim with mail. I struggled to get everything out of it, pulling it almost violently until it finally breached. I sighed and slammed the mailbox shut before walking back to her condo.

I let myself into Theas condo with my set of keys and her Maltese, Lola, licked my toes through my Chaco's, her tiny paws scratched at my legs. It was unseasonably warm in her condo – Thea doesn't like the cold, and her window sheers were always open. It was the first thing she did every day.

"Come here honey and give me a hug," she said.

She sat in her usual spot: the center of her couch, with her bad leg propped up. The TV was turned onto the Food Network: Paula Deen showed her how to properly create a home cooked meal. Her once jet-black curly hair had hints of grey, and some of her hair clumps had scattered around the couch. She still wore her black eyeliner and red lipstick – her signature look.

I walked over and crouched down to give her a proper squeeze. She smelled of lavender and sugar cookies.

Next week she called. The week after, and the week after that. Every week, the mailbox was full. Soon, I started to get her groceries, and ran errands for her when I was in town. There was an unspoken friction between us when I went off to college during the school year, only coming back for holidays and sometimes during the summer. I tended to avoid being home at times, since it was easier to be away.

Once the day-to-day things started getting further out of reach, I started to get an uneasy feeling in my chest. Cancer isn't just something you can pretend you don't see. It eats people from the inside-out. Internally, you are struggling – the body just stops working one day, and all that's left is the fear of when it'll finally take them.

Some people are left to fight cancer alone. The American Cancer Society estimates that 606,520 Americans will die of cancer in 2020. Having to go through treatment for anyone is a struggle, but when you don't have a support system, it makes everything excruciatingly worse.

Thea, who was busy helping our family after my parents divorced, neglected her health. She skipped appointments, waved off concerns, and for the most part, thought she was healthy. Then, she discovered her colon cancer during its fourth stage in 2013. Colon cancer is more treatable in its early stages, being one of the most curable types of cancer.

When colon cancer is found at an early stage before it has spread, the 5-year relative survival rate is about 90%. But only about 4 out of 10 colon cancers are found at this early stage. When cancer has spread outside the colon or rectum, survival rates are lower.

Unfortunately, about 1 in 3 people in the US who should get tested for colon cancer have never been screened. This may be because they don't know that regular testing could save their lives from this disease, or due to things like cost and health insurance coverage issues.

End of life care isn't something broadly discussed. Those who are put into hospice centers are put there when there aren't any other options for them: it's a waiting room for death.

The role of the caregiver, in this instance, is crucial.

Thea was consistently a caregiver during her life. She moved to New York to pursue her opera career before returning to Warren to care of my Papou (Grandpa). He was sick with Alzheimer's and Parkinson's disease, and YiaYia (Grandma) took care of him alone. Upon Thea's return, she was a

secretary at St. Demetrios Greek Orthodox Church for 10 years and then worked at Trumbull County Job and Family Services for five years. Shortly thereafter, she became a caregiver for my three siblings and I after my parents divorced. The care that she gave to others was given back to her during the moments she needed it most.

Thea was born in Rhodes, Greece, in 1963. When our family moved to the United States from the island of Rhodes in 1965 to flee the country's downscaling economy, my YiaYia Theano was the only one who spoke English. The family was sponsored to come into the States by my Papou Vasili's brother Nick, who lived in Warren.

Warren, Ohio is a city with a population of over 41,000 residents located in Northeast Ohio, 50 miles southeast of Cleveland and 15 miles northwest of Youngstown.

My Papou worked at the General Motors (GM) in Lordstown, and my YiaYia worked at a bridal shop in downtown Warren. The rest of our extended family in Greece soon started to migrate to the States, and we created a community for ourselves. The Youngstown/Warren area is part of the rust belt, and used to have several factories, attracting immigrants such as my family to live there. The Lordstown GM shut down on March 6, 2019, ending 4,500 jobs. Today, the Lordstown GM location is a ghost town. Our family has always struggled financially, and the downscaling economic situation in Warren contributed to this.

A beacon of life in Warren was the Greek community. Thea came alive in this environment, and always volunteered at the church, sang, and was generally loved by everyone. It was a central part of her life. Family, friendship, love, and community – this, and music, is what drove her. She would sacrifice anything for them. Thea dedicated her life to creativity and music, and people knew her distinctive voice wherever she went.

One particular relationship that was specifically unbreakable was the relationship between Thea Fedra and Danielle Swann, her best friend, or as they would call each other, "soul sisters."

Thea met Danielle around 1992. Danielle is a short, powerful blonde woman with uncontrollable curls. 20 years old at the time, Danielle was a student at YSU.

They met through a mutual friend, Ray. He lived in Ohio, and Thea Fedra had been friends with Ray during college. They would go to Mr. P's restaurant in Boardman every Friday night with the theatre students, and one Friday evening, Ray told Danielle that he was going to move down to Florida.

He said to Danielle, "I care a lot about you and Fedra, and I think you would get along really well... I want you to take care of each other."

Ray created the connection. After he left, Thea and Danielle went to Cherry Pickers, a restaurant out on the edge of town. They sat at a table across from each other, and it felt like they had known each other forever. The conversation flowed easily; The powerful connection that they had thrived from the very beginning. They talked about theatre, family, education, and their experiences would click. They always had a fun time together.

Danielle was still living with her mom on the north side of Youngstown. Danielle and her mom had a great relationship, but what Thea gave her was a family that filled the void of her separated family dynamic. She fell in love with the traditions of Thea Fedra's family, faith, and community that our household represented.

Soon, Thea and Danielle were inseparable. When Thea left to go to NYC in 1994, they weren't in touch as often, but the friendship didn't change. When Papou got sick, it was getting more difficult to stay away, so Thea made the decision to come back to Ohio and take care of him. In 1997 when he died, Danielle was a sales rep.

Now, Danielle works for Lifetime Financial Growth of Michigan. She travels often for her career and is never in one place for long. She mostly frequents between her homes in Port St. Lucie, Florida and Detroit, Michigan.

Danielle calls herself a self-made woman. She's always been intuitive to how others feel and act around her. She was born in California and raised in Jamaica and fulfills the traits of an avid Virgo. However, although Danielle said that "No one has given me a dollar toward college, a car, or anything in my life," she wouldn't be where she is without her mom. As an adult, she now has a great understanding of the devastation her mother faced in Jamaica. If she doesn't work hard, Danielle feels like she might fail. There's a perspective that she always has to be the one that keeps on working harder than everyone else.

Out of pure generosity, she offered to provide for Thea. To Danielle, Thea saved her in ways that money never could fill her pockets, head, or memories. That, to her, is what's most important about her connection with Thea.

"Fedra was one of the most emotionally mature people I've ever met. You could tell that she cared by the way that she spoke, how she was never judgmental," Danielle said to me over the phone. Her voice cracked, and it sounded like she was moving around – she likes to be busy. Sometimes, staying busy is the only thing that keeps you moving forward.

Thea dedicated her life to family. During her treatment, this didn't change. Her commitment to family and friends led her to have a system of support.

Years later, whenever Danielle would visit Warren, it felt like a vacation. My family would mark our calendars that weekend and dedicate those days to spending as much time together as possible.

When Thea was healthier, Danielle, Thea and I would go on adventures together around the city. From going to the grocery store, to grabbing lunch at Panera, visiting Thea Evangelia, and just sitting down to watch bad romantic comedies together, it was always filled with small gatherings with relatives around town, wine, and inside jokes. As time went by, the visits and adventures would still be fun, but more strained around the complications of Thea living with her condition. Thea, who lived alone, would have multiple caretakers in town, but when Danielle came, she wouldn't let Thea lift a finger to do anything. She became, in conjunction, her best friend, caretaker, and one of the people Thea turned to for financial support. When all else failed, Thea would contact her social worker in Warren for assistance.

Those who live alone often don't even have access to any caretaker, since their children, friends, or other extended family members don't live nearby. However, social workers can't offer the same kinds of attention—and affection—that family and friends can.

This isn't the only struggle that those who live alone with cancer face. Most over the age of 60 are distanced from relatives and have no one to take care of them. The role of an aid is the hardest one to fill, especially for those who are low income, my Thea being one of them. From medical bills to staying on top of your health, it's difficult to also balance work in the mix. For those who have to hire someone, it's around \$25 per hour.

Thea was fortunate enough to have a support system in her family and community. Danielle and I would take the brunt of it when we were in town, trying to make her as comfortable as possible while also wanting to spend precious time with her.

The hardest part, Danielle recalls, was no longer being able to do the little things together. Theas treatment went on for years, with pockets of hope mixed in. In 2018, there were a few months where she believed she was cancer free and she halted her chemotherapy treatments. However, a pet scan unearthed cancerous tumors in her lungs by the end of the year. By the time 2019 rolled around, her doctors told her that chemo was no longer working. She had two options: to sit in despair, or to try two experimental clinical trials at the beginning of 2020.

There's a trope in the cancer community called "the last good day," wherein the victim of cancer finds themselves with some unexpected hours when it seems like the decline has suddenly plateaued, when the pain is bearable. Thea, over time, wasn't able to go anywhere: to do those errands, go on short adventures to the mall or the graveyard to visit Papou with a bouquet of flowers. December 31, 2016 would be one of Thea's last good days.

Every year, our family had a New Years' Eve party, where we would invite extended family to our house and host them until well after midnight.

For at least a week before the event, our Dad would yell at us to clean the entire house from top to bottom. Our family likes to be tidy, and you absolutely cannot have dust, trash, or clothes strewn about when relatives come over. Keeping up appearances is important: our business is ours, and we don't trouble everyone else with it.

On December 31, 2016, Thea was more healthy, able to walk around, laugh loudly – the life of the party – and Danielle was her partner in crime. The night didn't truly begin until those two arrived together.

Thea, dressed in a black sparkly button up shirt, plain black slacks, her hair, still short with ringlet curls, was dyed a dark indigo that was only seen when the light hit her head, and to top off her look, red sequin slippers covered her feet.

Her first request upon arrival: to have some wine and ouzo together.

The next morning, the sun came up and uncovered a remnant of the night before: a lone, red sequin slipper forgotten in the parking lot of her condominium.

The earth continued to rotate into another year, and Thea was still alive. The days were difficult, but I was always happy to spend time with her.

Soon, we found that her clinical trials weren't working. I was studying abroad in, Prague, Czech Republic during Spring 2020, when I got a Face Time from her. She was beside herself with tears, and she apologized. I asked her, "Why are you sorry? You did everything that you could do. I'm so proud of you," I said as I sat in the kitchen of my apartment half a world away. Then, I asked her if she wanted me to come home. Before studying abroad, I had concerns about leaving because of her condition, but she told me to take the once in a lifetime opportunity. She still reassured me that she wanted me to stay. A month later, the coronavirus pandemic sent me home. I was sad but also relieved that I could see her again, even after weeks of quarantine.

One of the last days we spent lying together in her bed talking and listening to Moonlight Sonata (third movement), the Phantom of the Opera soundtrack, and creating one of the last memories I have with her. The day was bittersweet, and a feeling of apprehension hovered over us for its entirety. There is such a stigma that if something is not good, it is not worthy of experiencing. I wouldn't change that experience for the world.

One of the final days was a random Sunday in July 2020.

The sun was shining, the sky clear and gullible: the perfect day for driving. I got a call from Danielle; she said to come quickly, that Thea's waiting.

After that, I broke some traffic rules, and almost hit a pedestrian on the way to Thea's parking lot. My car had barely turned off before I slung my seatbelt off so harshly that it got stuck in my door when I slammed it shut. Danielle was waiting outside, pacing and staring at her phone. I could almost see the time Thea had left ticking in her head. The timer didn't have too many seconds.

Thea was lying on a hospital bed that invaded her room, unable to have full conversations anymore. She barely even recognized me before passing out from the pain. Her eyes were glossed over when I said goodbye between the shots of morphine they injected into her mouth. It dripped slowly down her esophagus, but she could only gag at the taste without being able to swallow any water to wash it down.

Her breaths pumped by the ventilator were harsh; they sounded wet and dry at the same time. Like someone was rubbing broken glass on the inside of her throat, and all she could breathe was blood. Two days later, on the morning of Tuesday, July 14, 2020, Thea passed away at the Hospice House in Poland, Ohio. At that point, cancer had metastasized to her lungs, and her entire body. She was with Danielle and her brother, Graham. Fedra was 56 years old.

In November 2020, around the four-month anniversary of Thea's passing, my roommate at college, Bella Ponader, was nervous for her upcoming surgery in December.

During Bella's freshman year at Denison, she was diagnosed with thyroid cancer. In the same year, she had to get her thyroid removed, and now, she has to take hormonal medicine daily. In Summer 2020, Bella was told that her cancer had metastasized to a different part of her throat and that to remove the cancerous cells, she had to undergo surgery. After Fedra's passing, Bella and I bonded over stories of Fedra's resilience and optimistic attitude despite the odds stacked against her.

Fedra loved jewelry. Once she passed, I inherited a lot of her old necklaces, rings, earrings, broaches, and headbands. Almost all silver, I wear them often to remind myself of her presence. One ring in particular doesn't fit, but I took it with me to college anyway.

Before Bella went back home for the semester, I gifted her the small, circular ring. I told her that it was for her protection, and that Thea's spirit will protect her during this difficult time. I wanted to stress the importance of small acts of kindness – and how far of a reach they have. That is Thea's true legacy.

During Thea's funeral, Father Kosta said that "you could feel her presence when she walked into a room. She touched the hearts of people she never met, and never let her struggle make her bitter. She was beloved by all." Amidst the echoes of the COVID-19 pandemic, these words felt truer than ever. The need for empathy during the hardest moments are what keeps people alive.

She indeed was beloved, and by Danielle and me are no different. I try not to focus on the past, but I would give anything to be able to complain about getting her mail again. In that moment, as Father finished his speech, Danielle and I were next to each other in the church pew, near the front of the casket. Although her mask hid half of her face, we looked into each other's eyes and came to a mutual understanding: we would take care of each other and call each other often. Caregivers, although exhausted after providing, feel the loss the most deeply.

At the small reception, I recited a speech in 'Thea's honor, and shared a video slideshow I created with her best photos. During the speech, I challenged everyone in the room to, every day, do one good act in the name of Thea. Whether that was holding the door open for some random stranger, carrying groceries for an elder, or donating to a charity. It could even be as small as asking someone in your life to live fully. I urged my relatives to have meaningful conversations. If we all do one thing, I said, think about the amount of impact that will have. If we continue to do this, her story will never die.

Before they lowered her into the ground, I placed peacock feathers onto her casket. It was Thea's favorite bird. In Greek mythology, the peacock tail means "the eye of the stars."

Later that night, my brother Chris and I went on top of the parking garage in downtown Warren, and we played music on my cell phone. One of the songs that Thea could sing well was "Sweet and Simple" by Journey. The piano crescendo was accompanied by a slow, rhythmic guitar.

The lyrics moved us from beginning to end: *Try and keep it simple / Not too far away / Moving slow, so simple / Never felt this way...* When the song broke into the chorus, Thea would belt the notes out loudly. *Don't be lonely / No, no, no, forget the past / Sweet as sugar / When you're moving slow.* 

As the clock tower of town hall glowed down on us, we looked to the stars on that clear summer evening, and we knew that Thea looked back at us, not too far away.

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