Testimony of Delilah Picart

Senate Special Committee on Aging Hearing

From Infancy to Aging: The Effects of Caregiving Across the Lifespan

August 7, 2024

Good morning, Chairman Casey. My name is Delilah Picart. I'm from New York City, yet I've called Pittsburgh, PA my home for twenty years. My professional career as a working local actress has allowed me to appear in films and commercials, but currently I have a job I didn't apply for, and I can't quit. I am a caregiver to my brother and mother. I moved them here from East Harlem in April 2023 when it became glaringly apparent that Mom couldn't take care of herself or my brother anymore.

My brother Eric has Fragile X Syndrome and Severe Autism. He is two years younger than me, and I always anticipated taking care of him. My mother Vivian has moderate dementia, and I didn't think I would be taking care of her. My father Enrique died in 2011 from complications of Alzheimer's disease. He was the parent I was most similar to, and the parent I loved most.

I have a complicated relationship with my mother. She believed in tough love parenting, which I have now come to realize is entry-level emotional abuse and manipulation. From six years old to 12 years old, she would threaten to hit me, and often would chase me to my room with a shoe in her hand. She once poured a pitcher of ice water over my head. I was eight years old. When I was a teenager, I would ask her why Eric was different, why did he get special treatment. She mocked me. As I got older still, and with therapy, I realized I didn't like my mother as a person. She was jealous of me and petty. She would gossip. And she would criticize me in a spiteful way. We are fundamentally different people. Once, I confronted her about chasing me and scaring me when I was a child. "You probably deserved it," was her retort. I have actively and consciously done all I can to parent my daughter with love and affection.

I would go and visit my mother and brother at least three times a year. Never for more than five days. I couldn't stand her tv addiction, the way she ignored me for the sake of some predictable tv drama. She would answer the phone, "Not now, Dr. Phil is on," then hang up on me. I stopped sharing projects I was working on because I didn't want to hear her criticize and judge me.

Before I moved my family here, I had received a phone call from my mother in July 2022. She said she was having a hard time. She could no longer do simple math. She wanted to get a Power of Attorney. I decided to visit my mother and brother once a month, for a weekend. Over the next four months, I saw my mother sit in her armchair and watch tv all day long. She would forget to take Eric to doctor appointments, neglect to trim his nails. Eric would search the kitchen for food, usually molded bread Mom had hidden from Eric. She no longer cooked; all meals were take-out. Her refrigerator was packed with containers of food, most of it weeks old. She had bags of liquified lettuce, molded vegetables, soft green potatoes, old bags of bacon, and numerous jars of parmesan cheese. She complained that her washing machine no longer functioned, she needed a new one. She had piles of clothes on the floor; she had forgotten if they were clean or dirty. Her pill box was mostly full, she had only taken her medication on Tuesday (it was Friday). She neglected to clean Eric's room. I found it dirty; Eric would purge on whatever food he found and then vomit. Since Mom stopped speaking to Eric, he wouldn't tell her he had made a mess. The four-story, single family brownstone I grew up in had become dark, foul-smelling, dusty, and loud. The volume on the television had the ladies from the View arguing and shouting. It hurt my ears. We signed a POA in New York in November 2022.

By January of 2023, I began visiting twice a month. Mom was becoming aggressive. Eric had dark circles under his eyes. Each trip I would empty out the refrigerator of rotten food. The weekly meal service my fiancée Todd purchased for my family would go unopened and rot. She would sit in her chair and mock me. "Lilah thinks I have bad food!" she would proclaim to a visiting neighbor, then throw her head back and laugh. My anger would bubble. I bought fresh fruit and vegetables for my brother. I would prepare dinner in the kitchen and try to salvage a clean plastic container from the closet. Mom would eat a little. She didn't like the vegetarian meals I made. Eric would have seconds. I asked my family members to help pack her up to move, with a target date of August.

I had access to Mom's checking account. One day when I was back home in Pittsburgh, I checked on the accounts, making sure certain bills were paid. There was a debt of $10,000. My stomach knotted. The phone conversation I had with my mother was frustrating and useless. She had no recollection of taking that money out, or where it was. I had visions of a stranger approaching my mother, forcing her to take that money out, or worse, someone mugging her. It was later revealed that she had withdrawn the money from her checking, and quickly deposited it into her Home Equity Loan, which I did not have access to. Within two weeks, I arranged for her and my brother to move out of the brownstone. That was April 2023.

As a caregiver to two individuals with very specific different needs, I am perpetually and eternally exhausted. I am mentally, emotionally, physically, and psychologically tired. I don't have the luxury nor the monetary fluidity to take a break. I had no idea what I was getting myself into when I decided to bring them both here. Yet, I was the only one capable of making a radical change for the betterment of them both. The only one to recognize that my mother had (at the time) undiagnosed dementia, and that my brother was starving and underfed and miserable. Not the nosy neighbors nor her own brother who lived across the street.

As their primary caregiver, I manage their daily care, which includes: pill management (distribution, refill, and pick up); meals (three times a day, seven days a week; five days a week I cook in my house and then pack it and take it over); laundry (once a week, but lately daily [I'll discuss this later]); garbage disposal; transportation (taking Viv to Vintage Senior Center five days a week); dressing (Viv often sleeps in her day clothes); coordination and scheduling of companions; cleaning the apartment (washing dishes, vacuuming, sweeping, bathrooms); grocery shopping as needed (toiletries, paper towels, bath tissue, etc.); scheduling doctors' appointments (quarterly); personal grooming appointments(bimonthly); bathing reminders.

My family lives in a two-bedroom, two-bathroom apartment four blocks away from my house. It was decided very quickly that they could not move in with me and my fiancée Todd. Mom had difficulty going up and down stairs, and the idea of hearing the tv 20 hours a day; not an option. It was one of my first techniques of self-care: boundaries. Mom had a very hard time adjusting for the first six months. Almost every day, I would arrive in the apartment and find all the items from the kitchen or the linen closet on the dining room table. Sometimes there would be carboard boxes in the living room. Many times, she would go on Eric's computer tablet and look up "Man with a Van Pittsberg (sic)". She was getting calls from neighbors asking her when she was coming back, or saying her phone number was disconnected. She accused me of hijacking her, of trying to kill her. She called me sneaky. Many times, she would call my cell repetitively, six or seven calls withing 10 minutes, yelling into the phone, usually after 10pm. I would often power my phone off by 8:30pm, another self-care boundary.

I found a woman companion for Vivian. She spends time with her three days a week. I pay her out of pocket. I learned the term "masking"; a behavior that is practiced by a person with dementia when they are confused by a situation or what is being said to them. They can carry on whole conversations in vague terms because they are cued to react to certain words, tones, mannerisms, and expressions. Vivian gets along beautifully with her companion, and she is well liked at her senior center. I would get the angry Mom, belligerent Mom, mean Mom, usually after 2pm. With the supervision of her Pittsburgh doctor, I got my mother on atypical antipsychotics after she threw a computer tablet at me and missed. It has calmed her down, but it has also given her frequent urination. I threw away all her underwear and she now only wears pull up adult diapers. I say a little mantra before I see my mother now; Grace, Forgiveness, Patience, Acceptance, Compassion, or GFPAC. If I forget a word, I know that's the one I need to focus on with her.

My brother was very happy with the move. He was getting three meals a day and healthy snacks. I introduced him to red peppers and avocado toast and lemonade. He no longer ate whole loaves of bread. He no longer slept in a bed of dried vomit. But I couldn't be with him all day long. Eric was receiving services in NYC, but he was ineligible in Pennsylvania until he had legal residency for six months. Even then, I had to show medical records from over 30 years ago describing and diagnosing his dual disability. By January, he had a very helpful case-worker. His Individualized Support Plan declared him an emergency case because he was living with his mother who was formally diagnosed with moderate dementia.

In the interim, I found a young man to be his companion. Again, I paid out of pocket. They would drive around, listening to music, sometimes going to the museum. When I did have time, we would go to the movies, yet when I brought him home, Mom sometimes had soiled herself, forgetting to get up when she got the urge to use the bathroom. One time I entered the apartment and was met with the smell of something burning. I found two charred eggs in the kitchen trash bin. Mom was hungry, tried to make boiled eggs, forgot the pot on the burner, and had boiled the water to nothing, leaving the eggs to blacken. I removed the pot. Another time, she had made toast only to forget there was a burnt piece already in the slots. I removed the toaster.

Eric and I had a routine. He would greet me in the living room of their sparse apartment. I would apply a nail lacquer to his toenails (he had an untreated nail fungus, something else our mother had neglected) he would wait until "Kelly and Mark" tv show, then he would put on his shoes and go downstairs and sit in the lobby. He would people watch most of the morning and some of the afternoon, until Mom would return from the senior center by 2pm. Then, he would wait for me in the lobby. In the Spring, he would be outside, in the green space or on the corner of the church across the street. One day in June, he was behaving in an aggressive manner, acting belligerent and obnoxious. I had never seen or heard Eric behave this way. He started to wander and refused to go into the apartment. This became a weekly behavior. I consulted his doctor and placed him on the same atypical antipsychotic medication that Vivian is on. His behavior is mostly back to normal. As of July 3rd, he now arrives on my porch by 5am. He is wet, because he unfortunately has soiled himself (thus, the daily laundry). After he has changed into clean clothes (I have a few items because of his frequency) we have tea and coffee in my backyard. We make up stories about the birds. Sometimes, we walk my dog, Mango, and count the rabbits. I love my brother immensely.

Eric's sudden unpredictable behavior has made Todd take lead and contact his supports coordinator/case worker. The emphasis of emergency was mentioned again. We finally toured a few respite places for Eric, with the hope of making it residential. Eric is looking forward to the change.

When I am asked, "How are you?" I give the rote, safe, bland reply, "I'm fine, everything is good." With my close friends and few family members, I'm honest. I'm sad or angry, or good, in this moment. I'm tissue paper thin. I'm spent. I'm struggling. I just can't today. I wish it would end. I need a change. I'm fortunate; I have a therapist, a support group, a weekly session with a trainer at a gym. Todd takes meals over, my college bound daughter pitches in as asked. I've had a very rich full life with highlights and low points. I watched the Towers fall from two miles away, I've had four car accidents, I've had a stalker terrorize me, and I've had my father go missing for 34 days. This is the most challenging event I've ever experienced.

In an ideal world, caregivers would for receive a public recognition, just like military personnel or EMT. A caregiver would be easily identified on a license. A hotline would be available to answer questions and provide urgent support (i.e., cleaning service, laundry service, meal delivery, companionship). A caregiver would be granted a parking pass to go into the disabled parking spots at the grocery store, hospitals, etc. State programs could provide college credit to graduate students in the social services department, and have said students provide hands-on companion care to people with intellectual /developmental disabilities. Supplemental income would be provided to caregivers with more than one individual in their care, and requirements would include people with all forms of dementia, not exclusively for people who are incapacitated and home bound. Chefs would be incentivized to prepare healthy meals for people with disabilities and dementia. Service agencies would receive more money to have more staff and more respite housing, so “emergency” means immediately, not eight months. Finally, the licensed caregiver could go to a hotel and receive a spa treatment, complimentary dinner, and a few nights in the best room. I would love to have a full night’s sleep, and maybe sleep until 7am.

Thank you for your time and attention.