

2nd Place, Non-Fiction

Too Young to Live at the Terrace

by Stephanie Torreno

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My cousin advised me to think of it as an adventure. Our neighbor told me I could think of it as sharing a dorm room in college. My sister wanted me to give it a try for a year.

All I knew was, at 37, I was far too young to be living in a retirement community.

Throughout my life, my mom and I had always lived together. After my birth and diagnosis of cerebral palsy around the age of one, Mom had always taken care of me. When work prevented her from doing so, she arranged for her mother, Nana Adele, to live with us and help care for me. Mom and I were especially close, and became even closer after my father died before I turned 19. We continued to support each other through life's challenges; Nana's illness and death, my journey to earn a college degree, and my quest to find employment.

Then, on one ordinary morning, as it seemed, Mom had a "minor" stroke. Three months later, she fell in the kitchen and broke her hip. Suddenly, living in our two-story townhouse was no longer an option for Mom.

I never imagined living anywhere other than where Mom lived. So, with Mom in physical rehabilitation, my sister, Cris, started looking for more accessible places for her to live. Everyone, including me, assumed I would go with her. And I did. After all, I had already had months of practice at the role reversal taking place. While Mom had been my primary caregiver after she retired four years earlier, I returned to having an agency provide a personal care attendant to assist me a few hours per day. In between the hours with my attendant, I became more and more independent, and tried harder and harder to become my mom's caregiver.

After Cris took a tour of The Terrace, she brought me to see the one bedroom apartment my mom and I would be sharing. The woman giving us the tour kindly answered all of my questions. She mentioned that a few younger people lived there as well, along with their mothers. I cringed, however, when she said I could easily remain living there for thirty or forty years. Aside from the tremendous expense, I hardly wanted to consider spending the rest of my life at this place.

I moved into The Terrace a few days before Mom was released from rehabilitation. Although the retirement complex was only ten minutes from our townhouse, it seemed worlds away from any familiar environment. Growing up, I had spent many summers in Florida with Nana at her retirement condominium. I was used to being around older people. In addition, my CP had made me comfortable with the equipment of disability – the walker I used on and

off over the years, the wheelchairs used by individuals I knew in high school. Living at The Terrace combined these two factors, and many more, to the extreme.

My former neighbor, and very dear friend, Arnold agreed to come and have breakfast with me that first morning. Getting up and dressing myself, I realized how tight our living space would be once Mom arrived. Arnold knocked on the door and together we walked the short distance to the dining room, where the staff served breakfast and lunch during the week.

Sitting at the “New Residents” table, I looked around at all of the old faces, and the numerous walkers parked around the perimeter of the room. Arnold and I didn’t know which was funnier, us looking at them, or their continuous glances at us. He joked that we should tell my new neighbors that he was my sugar daddy!

At lunchtime, I went to the dining room by myself. Although the executive director knew I was moving in with my mother, he apparently didn’t remember this when he saw me. Preparing to eat alone at the table, I needed help mixing sugar in my iced tea and cutting my food. As a few people joined me at the table, my awkwardness increased. They didn’t understand my speech nor did they understand why someone my age was eating there alone. Frankly, I couldn’t understand the situation either.

A woman with short, white hair came and sat down next to me. We began talking, and she listened carefully as I told her my story. At 87, Adaline would befriend me, help me, and take the time to get to know me - and Mom. Having once had a coworker with CP, and having a granddaughter with a disability, Adaline understood I was more than my disability.

Cris brought Mom to her new home two days later. Seeing the actual, tiny apartment, not the floor plan we had showed her, shocked her. My sister and brother-in-law had done a decent job of arranging our living room furniture and Mom’s accent pieces. Although Mom’s Asian screen divided our couch from my workstation with my computer, our living area was tight. The bedroom, with double beds and one walk-in closet, looked even smaller. If Mom and I were not close now, we sure would be after this arrangement.

Mom’s presence in our new home made me happy because almost two months had gone by since we had been together every day. Her arrival also made me sad and anxious. Always petite, Mom had lost more than ten pounds. She now used a walker to keep her balance, had difficulties with fine motor skills, and was dealing with vascular dementia. We would both have to cope with many new changes and challenges.

When Mom and I lay in our beds those first few nights, she would tell me how she wanted to go home.

“I don’t like it here. I’m too young to live here. We need to go home.”

“You’re too young to live here! What about me? I feel like a kid compared to all of these elderly people. We can’t go home, Mom. You won’t be able to manage the townhouse,

and you'll receive physical therapy here. I don't like it here either, but I agreed to give it a try. You need to do the same."

The role reversal was just beginning. Mom and I would have many more discussions, actually arguments, over weeks and months until we both reached a breaking point.

Breakfast was served too early for Mom to get ready and go to the dining room, so we usually ate in the apartment. Once a week, I would get up and dress myself to go to the dining room alone. I sat with Adaline and her friends, Maxine and Norman. The three of them, plus some women at the next table, would offer assistance and support when I needed it most. Still, walking into the room each day, even with Mom, made me feel more different than I had ever felt. Being asked my name repeatedly by the same individuals, experiencing communication difficulties due to their hearing problems and my speech impairment, and having others tell me I was too young to live at The Terrace grew old quickly!

One convenience I did enjoy at our new home involved taking the shuttle bus. With pick-ups every hour on weekdays and Saturdays, the shuttle could take me many places within a certain distance of The Terrace. Now that I had the responsibility of grocery shopping, I would ask my caregiver to meet and assist me at the store. At least once a week, however, I went somewhere on my own. Increasing my independence and confidence, these trips provided me time to myself away from an extremely cramped environment. The young female driver and I became fast friends. Like Adaline, she saw beyond my disability, and she empathized with me about my situation. I laughed as she would tell me I was one of her only passengers without hearing difficulties. Many times, I would stay on the bus while she picked up other passengers just to have more time to myself.

When Mom felt like going with me, we would go out to lunch or shopping. As much as I wanted these outings to remind me of our former life together, they only highlighted the differences now. I had certainly become accustomed to being as careful as I could be to limit my falls. Now, I needed to watch out for Mom to prevent her from falling. I also had to help her keep track of her walker, purse, or anything else she might leave behind.

If a few incidents really made me laugh, although nervously, throughout these months, they would have to be the ones involving Mom's "stalkers." Mom's first stalker, a former neighbor, followed her from the townhouse complex to rehabilitation, where he visited her once or twice. She complained to me about not wanting him to visit again, especially with old issues of National Geographic! Ray then learned that we were moving to The Terrace. On Valentine's Day, with Mom in physical therapy for an hour, my quiet writing time was interrupted with a knock on the door. One of the first responders was standing at the door with Ray, who was holding a gold bag of chocolates. Never mind that the staff wasn't supposed to allow people who didn't know a resident's apartment number inside the gated complex, let

alone lead them to the actual apartment. After uncomfortably reminding the responder of this policy and telling Ray that I didn't know when Mom would return, I took the gift and said good-bye to Mom's unwanted visitor.

A few months later, Mom's young and attractive appearance caught the eye of a resident. Ted was difficult to miss, with his long-sleeved business shirts and ties in the middle of summer. Mom mentioned him coming up to her a few times when I wasn't around as I often waited until the last minute to walk to the dining room. I didn't think anything of it until she said he grabbed her arm one day to prevent her from leaving. That worried me, and I tried to be with Mom from then on whenever she walked anywhere. At lunch, I watched him out of the corner of my eye. We often waited until Ted left before we walked to our apartment.

One day, though, he stood outside the dining room and called Mom over to talk to him. As she said we needed to go home and we continued walking, Ted began following us! Even in both of our conditions, Mom and I outpaced him. I opened the keyless electronic lock on our door, let Mom in, and waited a few minutes.

"Mom, I'm going to the office. I'll be back soon."

My mom had somewhat lost the ability to stand up for herself. I now had to stand up for both of us. As I approached the receptionist, I saw him sitting in the waiting area. With my back to him and as quietly as possible, I told her my mom was being harassed by a resident. When she asked me if I knew the resident's name, I looked over my shoulder. She sensed that I didn't want to say anything more there, and said she would send someone up to our apartment.

A little while later, Mom and I were speaking to the new executive director and one of the first responders. I gave them more details, and they went to speak to the old coot.

Ted, the resident with the vampire-like eyes (as Mom described him), never bothered her again.

While Mom seemed to grudgingly adjust to our new home, I continued to have difficulties. We both needed more room, and I needed my computer in a private place. Although I had become used to writing online articles in the middle of our living room, often with the TV on, I yearned for my own space again. I became especially angry when Mom would look over my shoulder and read e-mail I was sending. Many times, I would write about her condition and my difficulties in helping her. I tried to choose my words as carefully as possible, but I was telling the truth.

On a particularly horrible day, Mom and I went to the doctor to have my paratransit application renewed. Since we had only met this physician once because our long time family doctor retired, I wanted Mom to go to the office with me. Once we arrived there by shuttle, I asked Mom to take a seat in the waiting room. I went into the examining room alone.

The doctor came in and greeted me. After greeting her, I showed her my application and said she need only answer the few questions about my disability and why I couldn't use the regular bus.

She read it for a couple of minutes and said, "I can't do this."

"What do you mean?"

"I have only met you once and I don't know enough about your disability. You need a neurologist to complete this paperwork."

"Doctor, you know that I have cerebral palsy. I haven't been to a neurologist in years. I don't even have one and don't have time to go to one. I have two weeks to mail this, and I need you to fill it out."

"That's not my fault. I'm an internist, not a neurologist."

I started to go to the door to leave. The doctor stopped me.

"I want my mom to come in here."

After a few minutes, my mom rolled her walker in the room. I quickly told her what was happening. My mom basically had the same discussion with the doctor I had had, though Mom was a little more adamant. I was proud of her.

The physician reluctantly completed the application, asking me questions about how far I could walk. She then said something that stunned my mom and me.

"I don't want to see either one of you again."

"Don't worry, we won't be back."

I was still upset when we went home to The Terrace. When I accompanied Mom back to the apartment, I decided to go get the mail. Mom didn't want to go with me, but I needed to take a walk. I usually asked my caregiver to do this on the days she came since opening the mailbox with a key was extremely difficult for me. Sometimes, someone around the mailboxes offered to help me, or I simply took my time and struggled until I opened the slot.

Approaching the covered mailbox area, I saw a group of people talking with one another after they had picked up their mail. The mailboxes were a popular meeting place at The Terrace, and it meant I had an audience as I struggled to collect our mail. As I still felt upset and shaky from the experience at the doctor's office, my hand flailed uncontrollably as I tried to aim the key toward the lock.

"Why do they send that girl down here to get the mail? She can't do it."

I didn't need to turn around to know who made the comment. The man in the scooter continued to look in my direction. Although I knew he had some form of dementia, his words hurt and unleashed the myriad of emotions I was feeling. I stood against the wall beside the slots and began crying. In between my tears, I tried to give him a message, though I knew he wouldn't understand me.

"I'm not deaf, and if you don't want to watch me struggle, don't look at me."

Jim, who sat at our lunch table, began to walk over to me. He tried to comfort me and offered to open the box for me. I tried to tell him I was having a horrible day. He didn't understand me very well, and I didn't want to stand there any longer than necessary.

"Thanks, Jim, but I want to do it myself. Please just leave me alone."

Several minutes later, I finally opened the mailbox and emptied its contents. I put the letters, magazines, and flyers on a nearby covered trash can and sorted through the junk mail. I closed the box, turned the key, and pulled it out. Picking up the mail and gripping it tightly, I managed to smile slightly at Jim as I turned to walk home.

After breaking down again and telling Mom what had happened, I said what I had just decided.

"I can't live here any longer."

Mom and I had been discussing, and arguing about, moving. She wanted to return to our townhouse, which was now on the market. I knew that wasn't possible, but I also knew I couldn't last a year here. We began talking about other options, and I started picking up real estate magazines at the grocery store. Looking for two-bedroom, first floor apartments or townhomes sounded easy. Since neither one of us could drive, location held the utmost importance because we would be relying on friends and paratransit to take us to the store and on other errands.

My sister and brother-in-law reminded me repeatedly about the conveniences and accessibility we would be abandoning. I didn't need to be reminded. I worried about all of the considerations that we would need to work out to make the move. I certainly understood the difficulties both Mom and I would face living somewhere else. If I continued helping Mom as much as I did each day, though, I needed more space – and a more diversified community.

Remembering a new complex of lofts that had recently been built near our townhouse, I began investigating rental fees for a two-bedroom. Arnold took us to see the complex, and we loved it. Soon after our first visit, my sister saw where we would be living. Cris admitted that we could make it work. Almost nine months after we had moved into The Terrace, Mom and I were moving into a much more spacious place. The "adventure" was over, but as much as I wanted the loft to work out for us, something inside of me knew it wouldn't.

The loft gave both of us personal space. Having my own bedroom and bathroom allowed me to periodically escape from what I witnessed daily - my mom needed more and more assistance. Although I had private, quiet space again to work on my computer, I often felt too tired and too overwhelmed to write. The assistance I received from my caregiver didn't do enough to help me help Mom.

During our third month living at the loft, I did something I had never done in my life: I took a solo trip. I went to San Antonio for Thanksgiving to stay with my cousin Laurie for a few

days. Laurie's brother picked me up on his way to The Alamo City. My mom and I had been talking about my trip for months; she seemed surprised and angry that I was going alone. She continued asking how I would manage taking care of myself, as if I hadn't been doing that for months with minimal assistance. I kept reminding her I was going to be with family and that they would help me when I needed it.

I thought my trip would do all of us some good. Mom would be staying with my sister while I was gone. I wanted my sister to realize how difficult caring for Mom each and every day had become.

After five days with Laurie, her son drove me home. We were running late, so I called Mom and reminded her to have my caregiver stay and be there when I arrived home. I wanted my caregiver to help me unpack and assist both of us with preparing dinner. When I arrived at the loft, however, Mom had allowed the caregiver to go home. I felt shocked back to reality as I watched Mom do her best at making an easy dinner. In the days since I had seen her, Mom had become incredibly weaker and looked shockingly frail.

"Your sister did everything for me while I stayed with her."

"That's great, Mom. My sister doesn't live here, though. Now you can understand why I wanted my caregiver here this afternoon."

The relaxation I had felt during my trip had already disappeared.

The next morning, I had gotten up for a few minutes before going back to bed to watch the news. My bedroom offered a clear view of Mom's bathroom, situated across the living room. I kept noticing the closed door with the light shining beneath it. Knowing Mom now took longer in the bathroom, I didn't think anything of it at first. After ten or more minutes, I began to worry and got up to go check on her. I heard Mom's faint voice after knocking on the door and calling her. As I opened the door, I could see her frail body lying in front of the commode.

"Mom! How long have you been on the floor?"

"Just a little while. I tried to call you. I'm okay; I just can't get up."

"I'm calling 911."

Actually, I called Arnold first. I needed his calm presence with me, and I knew he would come quickly. Then I called the paramedics. Immediately, I worried that the dispatcher would have difficulty understanding my speech. She didn't, but she began asking me to check my mom's airway and to perform other measures I simply couldn't do.

"I have a physical disability and I can't do that. My mom is breathing and appears okay. I just need someone to pick her up."

Trying to control my overwhelming anxiety, I hung up the phone and then called my sister.

The paramedics arrived first and helped Mom up off the floor and had her walk around the living room with her walker. They made sure Mom was safely on the couch, and family was on the way before leaving.

What followed after Cris and Arnold arrived was a discussion among the four of us that would change Mom's and my life forever.

A month later, I made my third move within eleven months. This move may have been the scariest and most difficult, but it was also the most anticipated. I moved back to our townhouse within the community I knew and whose members knew me. Mom couldn't go with me. At 38, and after a few weeks of practice here and there during a very difficult year, I was now going to live independently. Well, semi-independently.

My caregiver comes every day, sometimes in a split shift, to assist me with the tasks I cannot perform independently. On days that I need to run errands or go shopping, I usually get myself ready and take paratransit, or wait for my caregiver to go with me. My neighbors, Judy and Arnold, continue to be extremely supportive and helpful. They consider me a daughter, and I know how very fortunate I am to be able to call them day or night if I need help. Saturdays are usually reserved for visiting Mom, who now resides in a retirement community with different levels of care. After becoming accustomed to assisted living, Mom recently had to go to skilled nursing when her latest fall resulted in a broken elbow and wrist and required surgery. Of all the difficult experiences I have had in my life, watching Mom's decline has truly been the most difficult and painful. I often cry after seeing her, and become sad when I think of her throughout the day.

In between my tears, I continue to try to build my own life. This life is far different from the one I imagined, the one in which Mom and I lived together much longer. My new life can be just as good, or perhaps even better, than the one I thought I would have. I know Mom wants that for me, too.

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I am in the middle of writing the memoir, Keeping my Balance: A Memoir of Disability and Determination, that I have always wanted to write. Although I happened to find the Pen 2 Paper online announcement months ago, I waited until I reached the point where the stories in my essay fit into my book. During the writing process, however, my mom's recent fall resulting in surgery caused me much stress and worry. Concentrating on my writing became difficult, but as I have learned in working on my memoir, writing helps me cope with the difficulties of life. Just as I must continue to face the changes and challenges in my life, I must continue writing.

