

Finalist, Non-Fiction

Help Wanted
By Stephanie Torreno

Copyright © 2015 Stephanie Torreno. All rights reserved.

Most people look forward to weekends. I don't. Going to the mall or to the movies on a Saturday or Sunday means navigating crowds. This can pose danger to me because I walk with impaired balance. When friends ask me to join them in activities or go out to eat on the weekend, I appreciate these outings rather than keeping busy alone on these two days. One difficulty remains on Saturdays and Sundays during the past three years I have been living independently.

To manage daily life, I am allotted a number of weekly home health care hours from the state. I use most of this vital support Monday through Friday when Candace, who has worked with me for nearly three years, comes each week day and sometimes twice a day. Candace helps me with household and personal tasks I cannot handle myself. She showers me, prepares meals, cleans, and grocery shops. When I have an appointment or errands to run, Candace often meets me after I take a cab to my destination. Candace and I form a good team. We accomplish most of what I need during our hours together.

On Saturdays and Sundays, I dress myself and eat breakfast and lunch that Candace prepared and left in the refrigerator. My self-sufficiency ends, though, when I would like to eat a hot dinner. Someone must come late Saturday afternoon and cook my dinner, plus prepare breakfast and lunch for Sunday. Weekend assistance may also include washing a load of laundry, taking out trash, or helping with any other minor task that cerebral palsy doesn't allow me to do on my own. This caregiving requires one to two hours at most each weekend day.

My home health care agency kept sending potential weekend workers for me to meet. Many times, I hired a woman after only talking to her a few minutes. If a caregiver didn't live too far away and seemed to take the responsibility seriously, I hoped my new hire would work

out. More often than not, a new caregiver would come one weekend, and not the next, never to show up again. Believe me, I am not a difficult person to get along with! Not knowing who would provide my much needed assistance left me vulnerable and anxious.

Rather than relying on the agency to find someone to work on weekends, Candace and I began searching for possible candidates. One of Candace's cousins helped me for several months, but quit when she realized I expected her to work rather than play on her cell phone. With no weekend help, I began asking everyone I knew to help me locate a new caregiver.

My good friend, Lynne, who cooked Sunday dinners for me when I didn't have help, recommended a woman at her church who needed a job. Debra, a plump woman whose lack of height made my petite stature feel tall, revealed quirks that became quirkier weekend after weekend. She failed to grasp the simple routine of brewing coffee from my K-cup machine. This involved pouring a cup of water and pushing a button. She had problems simply filling cups with drinks and securing lids on them. After instructing Debra each week and reminding her of the way I needed my food and beverages left in the refrigerator, I typed a list of tasks to prompt her on what to do. This list grew longer as Candace arrived every Monday morning and found messes left from my weekend care with Debra.

"What happened this weekend? The countertops are sticky. How many pots, pans, and utensils did she use to cook you dinner? Can't Debra hand wash a few things? I know you have a dishwasher, but you're only one person."

"She needs a lot of guidance. I wanted cereal for breakfast yesterday morning, and she asked me if I ate it with milk. I told her to fill up my milk cup so that I had enough to pour in my cereal."

"Did she think you eat your cereal dry? You're not a toddler!" Candace remarked.

“She started to put the baggie of my Cheerios in a two-inch bowl.”

Candace just shook her head and wiped the counters.

I had patiently explained to Debra that, due to my CP, I would probably knock such a small bowl over while trying to eat. I showed her the cereal bowls. The funny thing is, Debra told me she once owned a restaurant.

Debra did not see food she continually dropped on the floor, and when she did, she had difficulty picking it up. To retrieve grapes that rolled off the counter, Debra lay on her stomach in the narrow galley of my kitchen to grasp them. I feared she would be unable to pick herself up after she finally gathered the wasted fruit.

One Sunday, an hour before she was supposed to arrive, Debra called to ask me if it was okay if she didn't come. It seemed she wanted to attend a church picnic that afternoon.

“No! You have to come. Who do you think is going to make my dinner?”

“Oh. I forgot to ask you sooner. Okay, I'll see you in a little while.” said Debra, a guilt trip dripping from her voice.

As I grew increasingly frustrated with Debra, she did try to help me in unique ways. Once, she brought a bottle of hand soap with an oversized pump for me to try. She thought the large plastic pump would be easier to use. While I appreciated her thoughtfulness, I had figured out how to manage simple tasks in my own way. After all, Debra held a master's degree in education, not occupational therapy, and I had lived with CP for forty years. That master's degree was getting harder for me to believe every weekend she came.

Although I was reluctant to let go of the help I needed, I realized Debra made my life more complicated. She sometimes required more assistance than I did. When I had to call her to remind her to come on a Saturday, I knew I had to dismiss Debra.

I turned to the home health care agency again to find my next weekend caregiver, Linda. After asking her my usual interview questions, I agreed to hire Linda, a woman in her forties who seemed to possess a sense of responsibility and commitment. She worked hard, mopping my kitchen floor one Saturday evening after I ate the dinner she prepared. I didn't think anything of the fresh pine fragrance that scented the first floor of my townhome until I hobbled into the kitchen Sunday morning. My feet barely touched the tile before both legs splayed in opposite directions. I struggled to scoot over to the counter to pull myself into a standing position. Leaning against the countertop, breathing heavily, I dialed Linda's number.

"Hi, Linda. Did you use Pine Sol on the floor?"

"Yes, I did. I wanted to get it really clean for you."

"I should have told you not to use Pine Sol. It makes the floor too slippery. I've already fallen once, and I don't know how I'm going to maneuver through breakfast and lunch. Can you come over any sooner today to wash this floor again? I'm scared that I'm going to hurt myself."

"I'm on my way."

Linda impressed me with her willingness to come that morning. An hour later, she mopped the floor several times to rinse away the slick residue left by the Pine Sol. She made sure I could walk in the kitchen without an increased fear of falling, and she returned that evening to prepare a hot meal for me.

The following weekend, Linda came Saturday afternoon. Everything went well, and I expected to see her Sunday. When she called the next morning, my frustration began building as I listened to Linda's explanation as to why she couldn't make it that day.

"My boyfriend took me to Galveston last night. I don't think I can come today."

“It’s 10:00 in the morning. You have six hours to drive to Houston. Why can’t you come later this afternoon?”

“I’m not coming.”

“You have a job to do. I’m depending on you. I won’t be able to eat dinner if I don’t have help. Why didn’t you have the decency to tell me this yesterday?”

I don’t remember who hung up the phone first. My lividness mixed with sadness as I coped with the recent death of my mom. *How I wished my mom was here and we continued to spend weekends together. Why can’t I be in Galveston, staring at the ocean and forgetting all of my worries?*

Those thoughts became a Facebook posting as I sat feeling desperate. I actually called Linda again. She didn’t answer her phone. I wasn’t surprised. Fortunately, my sister saw my Facebook post and called to invite me to have hamburgers with her family. They picked me up on their way back from out of town.

So much for Linda’s sense of responsibility.

In the following weeks, I relied on two young women already employed by the agency. Both lived quite a distance from my home. Sadie, the first one, turned 21 over one of the weekends she worked with me. I understood her wanting her birthday off to celebrate the milestone, but asking for both days seemed excessive.

A mother to a one year-old son, Sadie shared her struggles of living with her overbearing mother, trying to support herself and her child by working an overnight job, and wanting to have fun in between her responsibilities.

“My mom is controlling my life. I know you just lost your mom and would give anything to have her back. But, I need my freedom and space.”

“Didn’t you tell me your mom cares for your son while you’re at work?” I responded.

“Yes, but she wants to know where I am every minute of the day. I can’t live like that. I want my own apartment.”

“Don’t be in such a hurry to live on you own. It’s hard.”

Sadly, Sadie’s life included too many difficulties, and she quit caregiving for me after a few months.

Terry worked for me next. Again, she lived quite a distance from me, and her car didn’t look or sound dependable. In fact, I knew when Terry arrived before she rang the doorbell because I heard her vehicle’s transmission gargling as she approached my carport. Terry did everything she could to come and provide assistance. When she couldn’t find a babysitter for her toddler son, she began bringing him to sit in his car seat in my living room. I felt sorry for Terry and didn’t want to say anything to her or the agency, but her divided attention affected her ability to perform my essential tasks. Her little fellow remained content, eating snacks and watching television from his car seat. After a half an hour, though, the child wanted out of his confinement.

Candace began filling in for Terry when she experienced car trouble. Terry and I discussed her situation, and we agreed that I should look for someone else. She promised to stay until I found another caregiver. Two weeks later, Terry called both me and Candace to say she couldn’t work for me anymore.

I don't know who felt more frustrated with not finding a reliable weekend caregiver – me or Candace.

“It's not like you're running these people off!” Candace said one day.

While she knew I needed to eat, and she didn't want me to fret about my weekend care, Candace had a husband and children to care for, too. She deserved her weekends, and I wanted her to have them. Candace continued to come, though, when I could not make other arrangements.

Since the agency failed in providing assistance seven days a week, I decided to take more control over my services. I felt that Candace earned a pay raise, and when the agency did not give her one, I wanted to make that happen. The Consumer Directed Services option gave me greater freedom in managing those who worked with me and in coordinating their schedules. The agency would continue to handle paperwork involving my care budget and employees' payroll and taxes. After receiving assistance with setting and adjusting my care budget, CDS enabled me to determine my employees' pay rates. My responsibilities would include supervising my employees, specifically hiring, training, and dismissing them. This change frightened me. I had been dealing with many of these aspects for years, however, and wanted to try the option. If it didn't work out for me, I could always return to the agency-managed service.

My tactics for recruiting caregivers have included advertising in my townhome complex and networking with friends and neighbors. One of my Facebook friends, a patient advocate, informed me of a website that prescreens home health care workers. I decided to broaden my search and register on the site in hopes of finding a caregiver. By posting a description of the type of care I required, caregivers could apply for the position. I could review a candidate's profile and decide whether I wanted to contact her or not. In a matter of three days, I started

receiving emails notifying me of applicants. I began responding to these messages through the website's system. My first question asked what part of the city the applicant was traveling from since I learned one of the biggest hurdles for part-time caregivers was owning a dependable car and staying off expensive toll roads.

Candace and I met Paula, who lived about fifteen minutes from my townhouse. I liked her, but Paula immediately asked for more hours per week or weekend, which was a common request from other potential helpers. We explained that I really couldn't offer Paula more hours. She agreed to work the weekends, though, and I hired her through the site's system on a Thursday. By Friday afternoon, Paula called to tell me that she had forgotten about a funeral she was attending on Saturday. She tried to negotiate the time to come and help me. I would have been flexible any other time, but I didn't think flexibility was a good start, particularly with a new employee on her first day of work. I also trusted Candace's doubts about Paula.

Another applicant, Emma, didn't live too far away and came one morning to meet me and Candace. Emma worked full-time during the week and wanted to earn extra money on the weekends. She and I talked easily, and Candace showed her my basic routine in the kitchen. I hired Emma and looked forward to having her assist me that Saturday.

My cell phone rang Saturday morning. Candace was calling to tell me that Emma's neighbor called her. Emma was going out to run errands before coming to work for me when her apartment ceiling caved in on her. She was being taken to the emergency room. Emma could not come that day. Candace came to make my dinner.

Oh no. Not again. While this misfortune was a legitimate reason not to show up, I couldn't stop thinking that my never-ending search for a caregiver may never end.

I continue to wait and see if Emma will be okay.

Candace and I remain flexible with one another, making sure I receive the care I need while giving her well-deserved time off on weekends. Friends keep recruiting potential caregivers, and Lynne recently shared another contact interested in working for me. Kim lives less than five minutes away. After meeting Kim, I decided to give her a chance. That Sunday, believe it or not, Kim, who agreed to be my new helper, twisted her ankle on her way to church. I began to worry about both of us, but Kim came and used my stair chair to assist me with chores in my bedroom. She prepared a salmon dinner and left me with everything I needed until Monday morning. Hopefully, Kim's a keeper!

Some people use weekends to take adventures and escape from the hum-drum of the week. I've begun to consider my weekends as unique adventures. And in the past few months, adventures I really wouldn't choose to take.