Parent Care: Disabled woman assists mother in her dementia

by Marsha_Kay_Seff

Whenever you get so tired and exasperated that you feel you can't look after mom or dad a moment longer, you might want to think about Pam Hoye. Then, take a deep breath and march back into the fray.

I met Pam through the online caregivers support group at SanDiegoEldercare.com. She adds so much to the discussion that I didn't realize she has cerebral palsy; she works very hard to stay in touch with us.

Then one day, she wrote the group:

"What is very interesting and puzzling is seeing how mom forgets I am disabled, when so much of her life was devoted to my care. She can still feed me, for example, and sometimes she'll want to.

"But we cannot count on her doing this. Chances are she'll forget about me and start eating or drinking herself, especially if she's holding my glass or plate."

Intrigued, I asked if I could meet with Pam in her San Diego apartment. She suggested we start with e-mail, as her speech disability is quite severe.

So we chatted on the super highway for a while. It wasn't until I met her in person that I realized what a chore typing was. Sitting in a wheelchair, with little control of her muscles, she hit a single letter at a time with a wooden stick held in her mouth.

Though it also seemed that speaking was torturous for her, Pam assured me it wasn't. And in a few minutes, with the help of her live-in assistant, Alicia, we were all communicating pretty well.

Pam, 59, took in her mom for three months last year, after her younger sister, who works full time, ran out of steam. At 83, mom has dementia. Pam's sister, a three-time cancer survivor living in Sacramento, Calif., had been assisting their mother for seven years, assuming full responsibility the last three.

"Put simply, it was time for me to step up to the plate."

I asked how her sister expected Pam to help when she herself needs assistance with most tasks. Pam lived with her mother half her life before moving out on her own and hiring a team of assistants.

But there's not much Pam shies away from as long as she has the help of the assistants and friends.

So, Pam and Alicia made room for mom until they found a board-and-care home close by.

"It was just something I had to do. My sister would be dead if she continued caregiving," Pam says, adding that their mother was becoming angry and hateful. "I love mom, but I wanted my sister to be alive and well more. ... My sister didn't want to give mom to me; I had to talk her into it. I have all kinds of help, and my sister is all by herself."

Now, Pam, a graduate of Fresno State and former magazine writer, and her assistants take mom to church Sundays and to the park or restaurants Tuesdays and Thursdays. Pam owns a car, which her assistants drive.

She says she's grateful that her sister hung on as long as she did. Not surprisingly, both women still have moments of guilt for not keeping their mother with them. "But she's safe and healthy and sometimes happy."

Pam says, "I can't imagine what it's like not being able to think; I'm so mental. I consider dementia to be one of the worst conditions possible, both for the person affected and for family.

"Sometimes it's like I have stepped into the world of Alice in Wonderland, where nothing is as one would expect."

I feel similarly after meeting this inspirational woman. But not for the same reason.

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