

honorable mention, non-fiction

The Dance of Devotion

by Joyce Ann Tepley

Dodging wheelchairs and avoiding running into slow walkers with their canes and crutches tapping muted rhythms on the carpeted floor of the hotel, my friend Sandy and I maneuvered our way into the dining room. We were attending a conference on Post-Polio Syndrome.

It had been a long morning of sessions on how to preserve one's shoulder muscles from years of strain, the latest research on drug trials to manage fatigue caused by polio's residual effects, and breathing techniques to maintain lung expansion. All that information was necessary to our well-being as polio survivors, but my metal-encased legs and scoliosis-altered spine were screaming in pain. I needed a break and was hungry.

It was only the second day of the conference, held in St. Louis, which Sandy and I attended every few years. We had two more days of lectures and workshops on everything we ever wanted to know about living well with polio by authorities in the field and by exchanging tips with other "old polios" as we liked to call ourselves. The best part, though, was being with Sandy and catching up on our lives.

Sandy turned her wheelchair toward me as we waited in line at the entrance to the hotel dining room. We were eye-to-eye, her seated and me standing leaning on my cane.

"How long have we been friends now?" She asked unexpectedly.

I had to think for a moment trying to conjure up a picture of the first time we met.

"Let's see ... it must have been around 1980 when we were both active in the Disability Rights Movement. You remember. I was president of our local advocacy group and you were working at that rehab center."

"Oh, yea. Man, it's a long way from teaching people how to cook their own meals and rearrange their homes after their spinal cord injuries and strokes. I loved my job in the occupational therapy department but I'm so glad I'm retired. Jim and I have a lot more time now to experiment with new recipes and work in the garden. As husbands go, it hasn't been so bad having him around the house all day." She gave me a wry smile.

Just then, the hostess grabbed two menus and asked us to follow her. She seated us next to the wall of window where we had a great view of St. Louis's landmark arch spanning the Mississippi. Sandy checked where the legs of the table were, and then rolled up to it. As I pulled out my chair and hooked my cane on the back of it, my eye caught sight of two couples seated in a nearby corner. Sandy's back was to them. One of the women was seated in a motorized wheelchair. There was something about her and the others. What was it? I looked away not wanting to stare.

Glancing through the long menu, I looked up at Sandy. "So what looks good to you?"

"I don't know. I should have a salad but I really want a hamburger and fries."

"Go for it. We're on vacation, so to speak. I'm so glad to be away from all that maintenance stuff at home. We had to replace the air-conditioner and the roof was leaking again during that last storm we had."

"Seems like it's always something with an old house," she sympathized, continuing to look through the menu.

The waitress came to take our orders. While Sandy was explaining that she wanted her hamburger medium-well with mustard on the side, I looked again over her shoulder at the two couples in the corner.

This time I noticed that the woman in the motorized chair was to the left of her, I assumed husband, and her hands were resting on top of a Plexiglas platform attached to the arms of her chair. They were not gesturing like her husband's hands were. She was sucking on a tube positioned on a clamp near her face. The tube was connected to a respirator working off the wheelchair battery underneath her seat. The only part of her body that she seemed to be able to move was her head.

The waitress turned to me and asked what I wanted. I gave her my order of turkey club sandwich and hot tea and an image of Phil bringing me a cup of tea, our evening ritual as we cozy into reading or watching TV after supper, popped into my head. I must have smiled from the gratitude I felt at this kind gesture because Sandy asked, "What are you smiling about?"

"Oh, I just thought about Phil and wished he was here at the conference. I know. I know. I told you earlier that I was happy our husbands weren't with us so we could do "girl talk." But some of the information we're getting would be helpful for them to know."

The waitress came back to refill Sandy's ice tea glass. Sandy took a sip and agreed. "Yeah, I was wishing Jim could have heard that session on managing fatigue. They said we should lie down every three hours for a brief nap during the day to conserve energy and preserve our muscles from wearing out even further. Sometimes I think Jim doesn't appreciate how tired I get. It's not like I'm being lazy. I know it's hard for him to understand since there are some days when I can clean house, cook our meals, and go out to a movie that same night, while other days I can hardly get out of bed."

"I know what you mean. Several people at the conference used the term 'hitting the polio wall.' There've been a lot of those days lately when I just couldn't face putting my braces on and getting upright. Horizontal has become my favorite position." We chuckled at my joke while the waitress set down our food in front of us.

I continued. "Phil has never told me that I'm holding him back from being more active like that guy I dated a long time ago who broke up with me for that very reason. He wanted a tennis partner, someone who was into hiking, camping, trekking up mountainsides. That wasn't me! It stung, though. Heck, I was young. Didn't know any better so felt like I wasn't good enough. But I got over it."

Jumping in Sandy said, “What a loser! Him, not you. I’ve been there. Remember, we didn’t have as many opportunities then as we do now to participate in sports stuff. I attended a wheelchair tennis tournament last year at our recreation center and it was just as competitive as the able-bodied matches I watch on TV. The other day I saw some people bowling with a kind of slide you move into position. You place the ball at the top of the thing and let it roll down the incline gaining momentum toward the pins. It was cool.”

Not wanting to let the moment go by I said, “The A B’s have to realize that we disabled do it with devices.” Sandy reached for the mustard and nearly squirted herself in the face.

“Well, there’s that, though it seems the older we get the harder it is to make time for it. Our rhythms are out of sync. I told Jim we needed to have more fun so I suggested we sign up for the wheelchair square dancing class at the center. He said he feared for his ankles.”

Sandy piled the tomato, lettuce, onion and bun on top of the thick hamburger. My mouth began to water as she grasped the dripping contents and brought it to her mouth. I pictured her and Jim swirling around in a blur of wheelchairs their pedals sticking out in front ready to stab and bruise the upright ankles of able-bodied dancers.

I poured the steaming water over my teabag. As I swirled the bag around by its string watching the clear liquid turn to amber I looked up and saw the two couples beginning to eat. My mind started speculating about couples who attended this conference. Usually one spouse is able-bodied while the other is disabled. It was rare to find couples who both had polio. Would they cancel each other out? Was it too difficult to work out the logistics of daily routines?

Our spouses decided to join the world of the disabled and took on the role of helper, using their stronger legs and arms to compensate for our weaker ones. When I walk with Phil and hold his arm, he must slow his pace almost to a crawl. By himself, he could swing his arms and walk with a longer stride.

However, if I use my scooter, it’s another story. He has to try and keep up with me! I am face-in-the-wind full tilt ahead. When I got my scooter it felt good having that much freedom of movement after years of always being the one lagging behind as I tried to keep up with other people walking. So I show no mercy – keep up or catch up.

Sandy gave up walking a long time ago preferring to use a manual wheelchair for getting around. Walking was always more difficult for her than for me since she wore a full corset to hold up her spine, heavy braces locked at the knees on both legs, and used Canadian crutches to swing her legs through. Now she just plunks herself in her wheelchair and does everything from a seated position. Jim, however, has to be watchful of his feet when she’s zipping around the kitchen as they fix supper together.

I picked up my sandwich and took a large bite. Sandy reached for her tea glass.

As I chewed Sandy continued, “You know, Jim has always been restless. Just can’t sit still. I thought when he retired he would settled down some, but that doesn’t seem to be the case. How is it with you and Phil?”

Reaching for my teacup, I thought back to last year. “Well, Phil decided to bite the bullet and had both his knees replaced just before he retired.”

“Really? Wow. Both knees at once?” She shook her head in disbelief.

“Yea, he’d been in such pain for so long from his arthritis and both of them were nothing but bone on bone, so he decided to just get it all over with. Funny thing was, all that time he was having trouble walking, he refused to think of himself as disabled and wouldn’t get a handicapped parking tag even though he had a right to it.”

I went on, “Though we thoroughly planned for the day of the surgery, his time in the hospital, and even hiring help when he got home, it was still really hard on me. I have to admit, one time I got very angry and yelled at him when he called me from his bed to help him put his ice packs on his knees, just as I sat down to rest.”

“Of course you’d feel that way. Anyone would,” she reassured me. “Besides, it’s probably very disorienting to be the main caretaker when you’ve been the one Phil does for all these years.”

I thought that was a profound observation and it made me feel better. “You’re right. Even though I do a lot for Phil, he was the one who went to the grocery store and did most of the cooking. Then, when he first came home from the hospital, he could hardly do anything without help.”

“How in the world did you manage?” she asked, more like a statement than a question.

“Looking back on it now – I truly don’t know. I was exhausted!”

I paused for a moment, took another bite of my sandwich, and thought about how grateful I also felt returning my caring in such a concrete way. Then I thought about how funny it was when Phil first walked after his surgery using a walker. I’ve used one around the house for years that has a tray and basket so I could carry things. It always got in Phil’s way, when I parked it to do something, say at the kitchen sink or I’d forget and leave it blocking a doorway. He usually was patient about it but sometimes would make a snide remark to me.

I continued while Sandy dipped her French fry in catsup and bit off that end. “You know, it was really funny,” I smiled. “Those few weeks right after he got home and couldn’t go outside or drive were a choreographer’s nightmare. It was walker jam! We tried to coordinate our wanderings around the house. You going to the left or right, I’d ask him?”

Sandy nearly spit out her French fry laughing at that image. I knew she knew exactly what I was talking about. “It really is like a dance. Just think, we’ve known our husbands for over thirty years, Joyce, and we’ve created like a tango

Sandy continued talking as I took another bite of my sandwich. Part of the meat slipped out getting mayonnaise on my chin. Reaching for my napkin my eyes wandered back to the woman in the motorized chair and this time I was mesmerized by the cadence of the couple.

Without missing a beat in the conversation with the other couple, her husband cut her food, removed the respirator tube from her mouth, put the food up to her lips, and took a bite from his own meal while she chewed. He seemed to know just when she swallowed. Without looking at her, he reached for the glass of ice tea with the straw in it and held it up to her mouth. She sipped; he put the glass back on the table, reached for her respirator tube, put it into her mouth, and then went back to cutting up more of her food making ready to start another round.

I knew this dance. I marveled at their precision – the choreography of their relationship perfected by this daily act of eating. I mused about my own and Sandy's marriages, the dance of devotion we created over years of familiar routines that eased the ungraceful burden of a crippled life. Yes, my relationship with Phil was sometimes a tangled tango but at other times flowed with a practiced rhythm.

Heroic acts are not necessarily large in scope. They can also be small moments of kindness made all the more heroic by their unfailing repetition. To be able to trust and count on your partner for the continuing existence of your very life is the greatest gift of marriage.