The Other Side of the Bedrail

By Mary Pugh Alligood, PT

Why listen to me? I have unique insight as I have practiced for 18 years as a physical therapist (PT) before being diagnosed with inoperable brain cancer. My surgical history reads like the kind you had in PT school; that seemed impossible and was obviously made up by a professor with intentions to construct a really difficult exam.

Surgical history:

age 16: Vastus Medialis Obliquus advance lateral release

age 36: C-section

age 37: hysterectomy

age 43: craniotomy to confirm cancer

age 49: sepsis before colostomy

So begins my trip to a new body part. June 16th, I could not get out of bed even with "maximum assist" and all my therapy tricks from log rolling to breathing with movement. Emergency medical service was dispatched. With 6 people I was moved to a back board and carried down 16 stairs to waiting ambulance. I do not remember much after arriving at the emergency room. I am told that my amazing 19-year-old son had conversations with the surgeon - discussions where my youth was a determining factor and surgery chosen to be temporary solution.

The next independent memory was being in acute care after 5 days in ICU - where I am told I did not sleep. I looked down and there was the first of many appliances I would see on my left lower quadrant. I remember thinking I was hallucinating. All the powers of denial went to work: *This can't be me! I don't have a* ***colostomy***.

Next memory: a PT and her student coming in all smiles proclaiming "We have to get you out of bed." *Really, I thought, have you seen me, do you realize I have a new body part? I wear poop on my abdomen?*

Suggestion #1: Please validate feelings of a patient with a new colostomy bag by saying something like "I know this must be frightening, but if you say stop, we stop." Taking the time and giving a little control, a little empathy makes a huge difference. The therapist said: "There are 3 of us [PTs] - we can do this." Somehow it was reassuring and validating knowing the third PT was me. Another simple but powerful example, one fantastic nurse just said: "If you have questions please ask. If I don't know the answer I will get it."

Eventually I progressed to inpatient rehabilitation – a whole new world even though, ironically, I had

previously been supervisor on that unit. The required 3 hours sure seemed like a lot! I had speech therapy due to lack of executive skills noted while in the ICU and occupational therapy (OT) due to functional loss. *The first OT session, a shower – are you kidding?? I am just learning how to take off pouch, clean, and replace. I don't care how my hair looks!* Finally though, good hygiene mattered again and I starting with brushing my teeth. Since both PT and OT helped with this task I decided my breath must really be horrid!

Suggestion #2: Starting with small tasks can actually translate into big goals for your patient. For me, just brushing my own hair was empowering and made a shower actually seem possible.

Suggestion #3: Colostomy is a rough surgery. With so many changes, the other side of the bedrail is terrifying, so be a pillar of strength as well as compassionate caregiver. Please do not discount how scary this tiny opening on the belly can be. Rehabilitation is so vital to seeing the bright side of remaining abilities of your patients – us "colostomites" need you.

Thank you for all you do.

About the Author

Mary Pugh Alligood, PT

Mary Pugh Alligood has been a physical therapist since 1992, practicing in multiple settings including inpatient SCI rehabilitation and most recently home health care. She is deeply dedicated to her work, recognized by her patients and co-workers as a joyful and compassionate soul who radiates sunshine and hope. In October, 2010 she experienced a massive life threatening seizure, and was found to have brain cancer. She continues to remain loving and optimistic through her struggles and values the opportunity to share the challenges of her journey to help others. She resides in Naples, Florida with her two incredible sons.