Feeling the Weight of An Impossible Situation

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By Sarah Kilch Gaffney

Like nearly all parents, I sometimes yell. I don't like it, but it happens. Usually it's close to the end of a particularly long or challenging day when the button-pushing preschooler in my daughter overtakes the exhausted mother in me, and for a split second I lose my cool. I yell, then I breathe, then I apologize.

I am grateful that these times are infrequent. I am grateful that I know I am not the only parent this happens to and that I just need to forgive myself and move on. I am also grateful because I know from experience just how much worse it can be.

There was a time in my life when I was stretched incomprehensibly thin, with no hope for recovery in sight, and it felt like all I did was yell or cry.

My daughter was barely three and my husband Steve was dying; one afternoon remains vivid in my

memory.

I was trying to transfer Steve from his hospital bed to his wheelchair. His hospital bed was pushed against our bed, which was pushed against the opposite wall, and there was just enough space on the near side to maneuver the wheelchair.

He had not walked in nearly two weeks. The week before, I had signed the DNR order his hospice nurse had slid over the coffee table before she moved across the living room to listen to his heart and lungs. The prior day he had suffered a massive bloody nose and nine seizures, including one that lasted for seven full minutes. We were both exhausted and at our wit's end.

During the last months of his life, Steve took high doses of dexamethasone, a corticoid steroid, to help control his persistent and insidious brain swelling. At six feet tall, he quickly ballooned from a slim 165 pounds to over 240 pounds.

Always fond of humor, we joked about our matching stretch marks, but it was truly a terrible transformation for him. People who didn't know Steve before the steroid treatment did not recognize him in the photographs in our home. Though he had never been one to care much about looks, the uncontrollable weight gain and disfiguring side effects pained him, and he especially hated that it made it more difficult for me to take care of him.

I had transferred him hundreds of times. Sometimes the transfers were challenging, but I was strong, he helped as best he could, and most of the time they went fine. I knew from my brief stint in nursing school that no one in their right mind would ever transfer a patient of his size without multiple assists or a mechanical lift, but I also knew that he very badly wanted to stay at home and that I was going to make it work.

The transfer went terribly. He had almost completely lost his ability to use his right side in the preceding hours, a fact that neither of us was aware of until it was too late. I was not strong enough to bear all of his weight as we pivoted and he ended up half in the wheelchair with his right arm pinned beneath his body.

Every time something went wrong—a transfer, a medication complication, an infection, a functional decline—I felt somehow responsible, whether I had any actual control over the event or not. I knew, logically, I was not to blame, but I felt so guilty that I could not seem to manage it all, and all those months of challenges, complications, and of things going wrong had piled up.

In the midst of wrestling him upright and eventually back into the bed, our daughter came into the room. I have no recollection of her action—whether she was in danger of getting hurt as I struggled to move her father or she simply tried to speak to me at that moment—but I screamed at her at the top of my lungs. I bellowed. She burst into tears and ran out of the bedroom.

At that point, I felt the weight of everything, unbearably. I so desperately wanted to do everything right: to give Steve the life and death he wanted and deserved, one with as much dignity and as little discomfort as possible; to love and support our daughter through that process; to keep all the little pieces of our quickly crumbling life together for just a little bit longer.

I wanted just a small slice of grace and peace in the throes of my chaos and grief. Instead, my life imploded in a matter of seconds and I unleashed all that fury, loss, and disbelief on my daughter. I felt like the absolute worst mother in the world.

I managed to get Steve back into bed. We were both exhausted and in tears. I called our daughter back into the bedroom. I apologized and told her that I shouldn't have yelled, that I had been scared and that I was sorry. She hugged me and nodded and climbed into my lap. I kissed her forehead and wiped her cheeks.

On the wall above Steve's hospital bed was a framed picture of our daughter taken the previous summer on White Head, the island in the Bay of Fundy where we visit family every year. The photograph was the epitome of light and joy: her grin haloed by wispy toddler hair, green fields, and blooming fireweed.

She pointed at the picture and asked if we could go to White Head when the snow melted. Yes, I nodded, of course. She paused and then asked if Daddy could come with us. I knew what was coming, but I couldn't, just yet. Maybe, I said, maybe.

Steve died almost exactly three weeks later, on the second day of spring.

I still sometimes feel guilty about those days, wondering if I could have somehow handled the stress better. I cringe when I think of the times I was frustrated or short-tempered, but I also recognize it was the weight of an impossible situation, exactly where no one ever wants to be: watching one's life, love, and family disintegrate piece by piece.

I also remind myself that it wasn't all burning rage and pain, though those memories are sometimes the ones that surface first, especially when guilt is at play. We had a lot of moments of love and light, of

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sacred time together as a family, and of beauty breaking through the suffering.

Those horrific months that I often wasn't sure I would survive are now some of the most valued of my life. I was a disaster of a person and a thoroughly imperfect mother and wife, but I was there and I gave it everything I had.

It will always be one of my greatest honors that I was able to take care of Steve until the end, that he trusted and loved me enough to grant me that esteem. Despite everything we were facing, I never for one second considered not accepting that offering.

Sarah Kilch Gaffney is a writer, brain injury advocate, and homemade-caramel aficionado living in Maine. You can find her work at www.sarahkilchgaffney.com.

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luvmy4GRANDS • 4 years ago

Sarah, what a beautiful story you have told. I was my mother's primary care provider for the last 6 months of her life. I came with all the plans in the world to 'make it work' with NONE of the knowledge of why it wouldn't 'work perfectly' as I was used to having in my profession! I had no 3 year old, but I did have a 45 year old sister who was diagnosed with Acute Leukemia 6 weeks before our 74 year old mom died. I was literally on duty 24/7, as I'm sure you were. On a really bad day, I would lose control and scream every obscenity I could think of to her and my dear step-dad to make them say they 'didn't like me'. I think Norm was not sure he did, but my mom always finished with 'OK! I don't like what you are saying or how you are acting, but I WILL ALWAYS LOVE YOU.' Those are the words I am so thankfully left with . . . and your sentence . . .'Those horrific months that I often wasn't sure I would survive are now some of the most valued of my life. I was a disaster of a person and a thoroughly imperfect mother and wife, but I was there and I gave it everything I had . . .' absolutely hit it on the mark. My mom died over 35 years ago, but these are, perhaps, the most comforting words I've ever read about what I did - and you did, of course. Thank you for taking the time to tell your story. Blessings,

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