

Caring for a Loved One with a Disability

It's 6:30 A.M. Reaching over to the night table, I take my phone from the charger and cancel the alarm. Although I almost always wake up on my own before the alarm goes off, I always set it. If I oversleep, it's not I who might suffer; it's my father.

After I rise and pull on the clothes I left piled next to the floor last night, I see to some basic functions and then go to his room. He's awake already-- he usually is-- and he greets me with the smile he does every day, a smile somehow signaling both his gladness to see me and a chronic sadness.

This is the man I always thought was invincible. The football star, the officer who led his devoted soldiers into combat and loved each one as the son he never had, the man who ran beside me as I learned to ride a bike, who carried me in his arms more than two miles the time I slipped in Yosemite and badly sprained my ankle, who modeled strength and dignity and sacrificed so much to raise me after disease robbed me of a mother and him of the love of his life.

I recall the time he took me rock climbing. How terrified I was at first! But there he was, always calm and measured, always talking me through every move and every procedure, explaining the systems and assuring me I was safe and he had me. Watching him move so fluidly and confidently was inspiring. By the time we reached the top, I felt as if I had been climbing all my life.

But one night, an improbable series of coincidences culminated in the permanent loss of the function of his legs, and with me as his primary caregiver.

And so we begin our daily routine. His wheelchair is beside the bed. I lift him into a seated position, and then I awkwardly position myself behind him the best I can, wrap my arms beneath his armpits, and then lift and pivot him into his wheelchair. He is still a large man, still powerfully built, and he helps by pushing up off his palms, but with the softness of the mattress, it doesn't help that much.

Now I accompany him as he wheels himself to the bathroom-- there is much he can still do for himself and insists on doing-- and then we repeat the process so he can use the bathroom. Because of the bars we installed, it's a little easier this time, but it's still much exertion on both our parts. I step out to afford him privacy. When he's done, he raps twice on the wall, and I return to help him back into his chair so that he can brush his teeth and shave. Then we go to have breakfast. We still have bathing, changing, and dressing to go, but he knows I'm exhausted by this point, and so he always wants to have breakfast first in order to give me a break. Fortunately, we have no stairs to negotiate; I can't imagine how much harder it is for people who do have them.

It's something we don't talk about much and something I try not to show-- the exhaustion and the back pain-- but he knows and he feels bad about it. After all, I weigh less than half what he does, so he knows. I don't hold it against him at all, though. I love him and will do anything for him, but it still does take a toll on me.

He tries to help in other ways, such as limiting the amounts of fluids he drinks so he needs to use the bathroom less often. We sometimes good-naturedly argue about this because I don't want him depriving his body of basic needs for my comfort.

We will go through this lifting and transferring several times today. Bathroom breaks, a nap, a trip to the park or a store, getting ready for bed, going to bed. And then we will start all over again tomorrow. Most of the time, all goes smoothly even though it is difficult. Always, he is gracious. Occasionally, he will look at me with sadness in his eyes and murmur "I'm sorry."

"There's nothing to be sorry for," I respond. "You're my father. I love you. I just wish I could make this easier for both of us."

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SOURCES USED:

<https://californiahealthline.org/news/college-students-disabilities-caregiver-coverage/>