

Letting Go and Learning to Float: A Caregiver's Story

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Abstract: Professional training prepares one for many things, but not necessarily for becoming a caregiver. Although I was trained as a social worker, it was a geriatric care manager who provided the resources and hope that allowed me to adjust to the changes in my life after my mother had a stroke. This narrative discusses some of resistance that initially hindered my professional help-seeking as well as the benefits of finally reaching out for assistance.

Keywords: professional help-seeking; relative caregiving, role conflict, helping, help-seeking

The world changed one day. And, after that day, it seemed as though nothing would ever be the way it was. But this was not the kind of wonderful change, like falling in love or having a baby when the world suddenly seems brighter and better. This was a darker shift. A disaster. Instead of a new piece of the world opening up; it seemed a piece of the world had forever closed. My world changed like this in January 2011.

In one day, the same hand that had sewn an awe-inspiring Easter bunny costume for my school play and then 40 years later had made an equally awesome lion costume for my five-year old, could not move. At all. In one day, a mind that had been renowned for its sharpness, was suddenly struggling to understand a new reality and protesting every new step. In one day, all of my professional social work training seemed to abandon me and I knew nothing except that I needed guidance and help to survive this nightmare.

As our family attempted to adjust to the changes that the stroke had brought, we were also holding steadfast to the vision that they were all temporary, and that eventually, with work, money, and effort, the woman who was our mother would return in full force. Someone I didn't quite recognize had replaced my mother (Boss & Couden, 2002). The mother who was an award-winning children's author; the mother who taught chair yoga in her senior complex; the mother who exercised religiously and paid meticulous attention to her diet; the mom who was ferociously independent; the grandmother who had provided daily nurturing and companionship for my son for the ten years of his life; and, most importantly, (to me), the mom who was my closest friend and confidant. We simply needed to wait for her to return.

After a three-week stint in the hospital initially following the stroke, and a four-month stay in short-term rehab, my mom was discharged. Mom would need 24-hour assistance, as she was no longer able to handle routine activities, like bathing and preparing food alone. We arranged to have a caregiver during the day while I worked, but I decided to take on the evening and overnight care duties. My mother lived just five minutes from my home, and I would be able to easily see my husband and son every day, so I moved in with her to help her adjust to living at home again. I was completely unprepared for the level of caregiving that my mom required and for the multiple impacts on all members of our family (Lutz, Young, Cox, Martz & Creasy, 2011; Ski, Castle, Lautenschlager, Moore & Thompson, 2015). My husband prepared dinner every evening at her home after picking up our son from school. We ate dinner and watched television together and tried to maintain as much normalcy as possible. At my mom's, I slept on the couch in the living room, where my sleep was frequently interrupted by mom's needs during the night.

My brother, husband and I figured that Mom would be back to her former, if slightly altered self, by the time school resumed in August. To make this fantasy come true, I willed myself to see changes and improvements that were perhaps there, but not in the magnitude I declared. I was convinced that she was getting stronger and that if she just tried a bit harder, she would regain her former self-sufficiency. I could not understand why she resisted using the tools we purchased that would help her get dressed, or make going to the restroom easier. Between my denial and her new reality, our relationship teetered on the edge of destruction. I could not accept that she had a brain injury, and that she would often be forgetful or misinterpret what was going on around her (Grant Glandon, Elliot, Giger & Weaver, 2015). These mental lapses I took as personal affronts. At all costs,

I was going to save her from going into the abyss of dementia.

It is as if she is drowning. I reach for her and pull her back to the surface – hard. Sometimes too hard. I don't mean to be rough or to inflict pain, but she is drowning and I can't let her go. I frantically push the water away from her face, and she struggles to be free. Her eyes fill with tears as I drag her back to the shore and insist that she walk on firm, solid ground. Familiar ground. Like she used to. Before. She is weary and so am I. But for a moment, we are stable. She leans on me for support, but I want her to again embrace the stability that she needs and that I crave. We stand together, physically and emotionally spent. I have succeeded and for a moment, she is not drowning. I don't understand why she is fighting against me. I know that she does not want to go under – that she longs for the clarity and safety of terra firma. So whenever I see her slightly drifting, I grab her attention, so that she doesn't get too far away where I can no longer reach her.

In my efforts to save her, I was too often short-tempered. I was more often, exhausted. As spring turned to summer, then to fall, then to winter, my family had lost all semblance of our former routine (Lutz et al, 2011). As school resumed, I checked my son's homework intermittently, and tried to keep up with his daily activities. I was becoming concerned about how he was doing as he seemed generally sad. Each day, when I kissed my guys good-bye, I wondered if they were really doing okay on their own. I felt guilty, and obligated. I felt like I was simultaneously in the right place and the wrong place (Pierce, Thompson, Govoni & Steiner, 2012). I was really tired, but mostly tired of avoiding the fact that mom was not coming back, at least not as I had hoped (Saban & Hogan, 2012).

I put my hand out to touch her hand and can't find it. I feel the same, familiar terror – I am really going to lose her this time. I am reaching, but I can't see her clearly. I feel the water and realize that she is fine, and it is me who is underwater. I am drowning. And she can't save me. But I want her to save me. I am scared and unready for the challenge of being the one in charge. She has always been there for me, and

now the thought of being there for her, without her being there to guide me, literally pulls the breath of me – suddenly and sharply. I am going through the motions, so unsure, so overwhelmed and so scared of making the wrong choice, or a bad decision. I have always leaned on her, probably too much and for too long. I want to tell her – no, I need to tell her – that I am losing my best friend and it makes me cry inside a little every day.

I literally gave out. I had very little left to give, but the relationship I had so treasured was becoming more fractured every day. There were good days, of course, with laughter and conversation. But there were more days that were marked by frustration and sadness. It seemed as if my earnest attempts to love and to be a good daughter, were sometimes being rebuffed and I just could not make things right. I wanted desperately to be a good caregiver, but felt I was falling short (Saban & Hogan, 2012). I was going to hell on the path paved with my good intentions, and taking my loved ones with me.

It was at a point of pure desperation when I finally called a geriatric care management service. I was sure that geriatric care management was a high-priced term for things I already knew how to do. But I was also becoming increasingly sure that I did not know enough. I kept waiting for my professional skills to kick in. As a social worker, I knew how to be positive, supportive and strengths-based. But I felt like I was drawing from an empty well. I am not sure why I was resistant to acknowledging another social worker's expertise and experience. Perhaps it was because I was afraid of being judged, not only for my lack of knowledge, but also, maybe, for not doing such a good job with my mom. In addition, I could not initially justify hiring someone with the same skills and training that I possessed. We were spending lots of money – on physical therapy, medical supplies and aids, and caregivers, but we were not seeing a great return on these investments. I certainly didn't want to "throw money away" on someone who was my professional peer. Despite my training and years of experience, it was becoming increasingly clear, however, that I did not possess the objectivity to engage my professional use of self. I flitted constantly and uncomfortably between my roles as child, parent, caregiver, and advocate. For sure, I did not seem to know enough to keep my mother both comfortable and happy on a predictable basis. So, I put professional

training and pride aside, and once again, my world changed.

The geriatric care manager entered our world just as a social worker should. She met my family where we were, in that moment, with all of our strengths and challenges (Wideman, 2012). She observed the artifacts that had shaped my mother's life prior to the stroke. She saw my mother's artwork and her children's book. She saw the bookshelf full of eclectic titles and topics. She saw that things had changed significantly for my family, and she helped us acknowledge those losses. In my mind, the stroke had left my mom in pieces. What had been a beautiful fabric was now mostly remnants and all I could see was the "hole" that was left.

The geriatric care manager, however, was able to see the "whole" that was still there (Boss, 2010). She helped our family to see that some things were the same. There was still my mom's quick wit and our gentle teasing and laughter. There was still hope. There was still love. Her lack of comparison to what was, helped us all embrace what is. Where I could see only someone who could no longer swim; she could see someone who was now more comfortable floating. She could also see someone whose very adulthood had been diminished by needing assistance with previously private activities, and she validated my mother's concerns and wishes in ways that I had not and could not. She could hear my mother in her current voice, not as a mere echo of her former self. She helped my family regain its collective power. She restored our sense of options and choices, as well as our hope that together we could make a plan that would meet our needs, individually and as a family (Kane, 2011). She helped me relinquish some of the roles that did not fit, and embrace the one true role that still did – daughter.

This experience has helped me identify and understand important implications for social work practice with caregivers. These implications include, the acknowledgment of grief and loss related to sudden and traumatic illness, strategies for coping, particularly with immediate family members and the importance of recognizing the limitations of professional training in personal crises. It is also important that social workers investigate the experiences of caregivers through qualitative research.

For a while, I was able to think about how it used to be – when my mom kept me from drowning in self-doubt, or bad relationships, or questionable self-esteem. Her hands reassured me and had supported me with clarity and strength. I never knew her to be afraid, just strong and sure. But now, she was scared, and needed me to be a safe haven. I realized that she wasn't drowning and didn't want to be rescued. I had been the one screaming for help. With the help of our lifeguard, I began to let go of the struggle and trust the waves that had changed the landscape of our lives. I close my eyes and gently, gently, brush her hair and rub her shoulders. I tell her that she is loved and that she is safe. I return the gift of reassurance. I am letting go and learning to float – prepared to go where the water will take us – together.

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