

# Lessons from the Lake

By Regina Kaufman, PT, EdD, MS, NCS

I was with my family at a lake not far from my home. She and her family were at the same lake, near too to their homes. For me, this was a lovely and unremarkable outing; for them, lovelier by far, and nothing commonplace about it. It was important to us both, but in very different ways.

She'd been ill for some time when she had a stroke. She had intractable seizures attended by depression and anxiety. She was a wife and a mom, now struggling with her health. Her son was in the 6<sup>th</sup> grade when the stroke happened: intra-operative, as surgeons tried to silence the source of the seizures. The impact was devastating. Her motor, cognitive, communicative, and behavioral systems were all broken. The burden of care was too much for her family to manage. She lived for a long time in a nursing home a full 90 minutes from her husband and son.

In the pre-stroke part of her life, my spouse and I knew her as casual friends. We shared parenting tales, school festivals, and moments of concern about her health and the jagged terrain of the health care system. We knew of the pending surgery and were stunned by its outcome. We had meals and kind words for her family, but as time passed we floated to the periphery of her life, engaged as we were with our

own family and the friends who were not an interstate ride away.

Two years after the stroke she moved to a group home near her family. She traveled daily by van to a day program - a day program where I worked, for the hours I was there, as the only physical therapist present. Whoever appeared at the door of the gym could work with me in therapy. She appeared on her first day there.

I'd had a heads-up, by a chance encounter with her husband. "I heard you were the PT at the center. She'll be visiting there tomorrow. She's moving into the group home on Saturday." Pleased to learn she was coming home, that heads-up also gave me pause. I believe in professional boundaries. There had always been someone to step in when my professional role encroached on my personal life; but not this time. My head spun in two directions: "I'm mature, I'm professional, I can handle this," then pulled to the other side by a strong sense of association formed from our time together as moms. I was deeply sad for her, and a little remorseful, too, about my failure to help more in the wake of her stroke. I thought, "This is too close; this is too hard; I don't want to do this."

A period of reflection and my head settled down. I knew I'd be good with it. After a time, I was. But for

the first few sessions it did feel too close. Her efforts to hold together her fractured life were messy and loud. Easily overwhelmed by the sights and sounds of the center, and with little ability to communicate or cope, she cried and screamed and struck out at staff. As I helped her reorganize her chaotic self, the depth of her loss connected to this stroke could not have been clearer. My heart ached for her as I witnessed her emotional turmoil.

My heart ached for me too. Our history together as moms and our intense work together at the center brought my own vulnerability clearly into focus. I was more shaken than I like to admit by how impaired I perceived her to be and how much that threatened me. I would see her in the PT gym and hours later see her son from the carpool lane as my own daughter hopped into my car. The loss of her role in the life of her son was exemplified then. In those moments I could not deny my own defenselessness: what happened to her could happen to me too. When I cried on those occasions, the tears were for her, and for her family, and for the fragility of all of our lives.

Then came the encounter at the beach. It was a glorious summer day. We were there first, settled and conversing with friends while our kids created games and chattered in the water. The movement of a wheelchair across the sand caught my eye. Recognition dawned as I watched her husband and son lower her into the water. My first inclination was to dart over, to be part of the moment; but my second sense knew better. I left her alone with her people and enjoyed watching from the shore as they swam. Her husband stayed close at first, holding her carefully, but after a time, he let her go. She swam without him. She has a trademark laugh, and it rang out over the beach, catching the attention of the beachgoers. Pure delight was reflected in that laugh.

Apart, together, apart, together – they swam and played for a long time.

Finally, they were cold. As they made their way back through the water to the wheelchair, her son caught sight of us and waved. It felt like an invitation, so my spouse and I scurried across the sand, calling our congratulations at what they told us was a last-minute, first-of-its-kind decision. This beach was a common destination for her family in their pre-stroke life. They had not considered until that day that perhaps it was within their reach again. Her husband described an ease in the water that they had not felt since well before the stroke. Appearing relaxed and self-satisfied, he smiled and said “That was good.” She, who struggles most of all to talk, echoed softly, “That was good.” They were triumphant. They’d reclaimed a part of their long-ago lives.

She began to shiver while we talked. It was time to go. Because it was easier down than up, we helped with the transfer and with pushing the wheelchair back across the sand. Then we left them; he to dry her, dress her and bring her home, and we to gather our kids and make our way home as well. Our beach-leaving was ineffably simpler than theirs. We remarked on that as we shook the sand from the blankets.

That encounter stuck with me. It pushed at something I’ve been thinking about for some time. As physical therapists, our evidence-based training pushes us toward a traditional biomedically-oriented focus on physical deficits that we catalogue using standardized, decontextualized measures.<sup>1</sup> We direct a large proportion of therapeutic time toward remediation of basic function. This is useful, no doubt, to a subset of people. But when injury is severe and the likelihood of restoring typical function

is small, a tight focus on function means we neglect to sufficiently explore alternative means for re-engagement with desired worlds.<sup>2,3</sup> I work frequently with people with serious injuries who are displaced from their usual contexts of engagement. Tasks, relationships, responsibilities and joys that once filled their days are replaced by struggles to restore lost abilities, often with limited success. I'm becoming certain that unless I broaden and deepen my focus, I'll keep missing opportunities to help people re-engage in preferred milieus with the full power of their remaining capacity.

I think I missed those opportunities with her.

What if, instead of worrying about my typical professional distance, I'd embraced our history and grieved with her when I first encountered her at the center? What if, having confronted one of her lost roles from the carpool lane, I'd spent more time talking with her: exploring important priorities for re-engagement? What if, after witnessing an agitated outburst, instead of returning to our standard therapy, we'd traveled through the center together, seeking spaces and activities that would match, protect and nurture her emotional and physical self? What if, instead of a chance encounter at the beach, I'd helped enable reconnection to some of the times and spaces she'd lost – if I'd helped her to see that the beach was a space she could re-inhabit to begin with? Those actions might have compounded her progress toward

re-embodiment of her familiar world with little cost to functional restoration.

I continue to see her at the center. Calm is still disrupted by emotional tumult. I'm accepting of the heartache I feel. I see her fully as my contemporary and am reminded that any day, without warning, I could be her. I hope that never happens. I am grateful I saw her at the beach. It assured me that despite their years of hardship, her family still embraced pleasure and joy. That day also brought my underlying unease with my practice into sharper relief. Thanks to our shared experiences, I've shed some dispassionate professionalism in favor of more genuine connection. I'm committed to asking better questions, listening more carefully, and digging toward a deeper understanding of the individual's once-familiar worlds. I plan to be better at facilitating living even as I foster function. To those ends, she has been an important teacher.

## References

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