

WATERS

On some nights, when the house is quiet, and sleep won't come, I close my eyes and walk away. I cross a huge field and come to a bridge that takes me to a beach. On this beach, I allow myself to feel all of the emotions that I can't afford to feel as I muddle through everyday life. The waves of water become a million feelings as I stand and watch them come closer with the tide until eventually, they start to wash over my feet and then back out again. The warm winds are strong and they carry away the sound of my crying. When morning approaches, and the tide has receded, I find my way back home, exhausted but fulfilled. It has been that way hundreds of nights, but recently a change has come. The winds have turned colder and the surf more turbulent. Storms carry the water farther inland, rushing under the bridge and filling the parts of the field that are the lowest. And there it stays, unable to retreat back to the sea. Making my way back home now involves navigating my way around and sometimes through the places where the water has pooled. Some of the puddled water is shallow. There is the water that is the self-consciousness that I feel when people see my son in his wheelchair and realize he is very different from other children. Some of the water is the jealousy that I feel when I see a pregnant woman or a new baby nestled and protected in his mother's arms. Another pool's water is the disgust I feel when I look at the incision scar across my

abdomen -- an incision that had to be made so that my son could live. I was only 32 weeks along and the scar reminds me of the last two precious months that he wasn't given. But these shallow waters are not a threat and with a few days of sun, could evaporate altogether. Another pool, with water more murky is the pool that holds my desire to be a mother that cannot imagine her child any other way, but my dreams forsake me. I cannot count the nights I've watched him run or heard the sweetest words come from his mouth. And even though the dreams usually wake me, I will myself to go back to sleep, yearning for them to come back. They are the kind of dreams that stay with me through wisps and whispers throughout all of my days. More challenging to wade through are the ponds of water that hold my resentment. Resentment toward the doctor that wouldn't listen to me when I told her my baby was not moving the way I knew he needed to be moving inside me. Another doctor told her my baby was in distress, yet she still delayed delivering him for another day. I resent the wall of lawyers that protects her from ever being held accountable for the mistake she made. I resent my husband, who treats our son as a prop when other people are present, and little more than an inconvenience when they aren't. I resent him for taking for granted that nothing exciting happens during my days. He doesn't even ask me about my days anymore, yet I'm expected to be excited when he talks about his hockey games or projects

at work. He doesn't tell me goodbye when he leaves in the morning and he doesn't tell me goodnight when he goes to sleep. On the couch. Every night. The pools that scare me the most are filled with fear and grief. I grieve the child I wanted but will never have. Growing up, my father said, "If you find something that you love doing, and something that you are good at, do it as much as you can." My insecurities kept me from realizing what a good mother I was until my daughter was nine years old, but once I realized it, I wanted to give her the gift of a sibling so much. Her brother will be her responsibility when I am gone and I grieve the freedoms she will not have but deserves. I fear that she will see him as a burden, even if just one moment. I fear that she will not be strong enough to make the right decisions for him when faced with a doctor only looking to make another notch in his surgical mask. These waters are too deep for me to see all of the things they hold, but I know these are the waters that hold the things that are dying or already dead. Things that will make the waters toxic. The ground around these pools is eroding and I fear the whole field will soon become one sea that washes away the bridge I need to cross to get back home.

I know somewhere in the field is clear, clean water, full of pristine shells and unbroken sand dollars...sea glass polished to perfect smoothness and pieces of driftwood twisted into the

shape of a heart...hundreds of pearls waiting to be found. I hope I can find those waters before I drown.

On behalf of all of the parents that are traveling their own journeys, I want to thank you, Elizabeth, for putting your emotions into words. Thank you for sharing your feelings and for not fearing judgement. The journey of being a parent to a child with a disability is often long, hard, and isolating. I believe that once she saw the amount of responses from the other parents in the group, she realized that we too have all experienced these exact emotions, if not similar ones and that the journey does not always have to be one of isolation.

What I would say to any parent asking me how to deal with the endless emotions that accompany being a special needs parent is to embrace the deepest pain and the greatest joy in every heartbeat. I believe that we are emotionally wired to find the balance in between the two. There may be days when you feel very alone. On those days, reach out to someone who is a few steps ahead of you. Don't ever be afraid to ask for the help you need to "find the clear waters", they do exist.