

## **Chapter 1**

### **The Journey: October 2015**

"It is good to have an end to journey towards, but it is the journey that matters in the end." Ursula LuGuin

Stars glimmered in the dark of the very early morning when Andy's voice whispered in my ear, "Let's get up and row." His excitement was palpable. Rolling off our air filled camping mattress, I felt my knees grind into some stones under the tent floor. I moved gingerly, as I dressed in shorts, t shirt, and sweatshirt to ward off the California morning chill. We walked, with our \$600.00 carbon fiber oars over our shoulders and life vests on, down the steep dirt hill to the beach, only fifty yards away. It was not fully light. The sand felt cold to my feet and the ocean waves lapped gently up my ankles, waking me up. High tide made it easier to push our eighteen foot blue rowing boat from the sand into the water.

Oars were secured in the oarlocks and I climbed into my seat and held the boat steady with my long powerful oars. Andy stood in the water holding the stern and when the moment came, he put one foot into the boat, pushed offshore with his other foot and twirled his body, in a balletic move, that landed him on his seat. The first few strokes with the oars were mine alone, while he got his feet into the straps and situated. I felt the fluid beauty of the oars penetrating the water, and then my own muscle power pulling them through, which resulted in our boat gliding forward, towards the open ocean. Shortly, Andy began rowing too and I'd match his rhythm and with double power we'd shoot across the bay and into the wild waters.

"Breathe in and breathe out. Legs, back, arms, legs, back, arms" was our repeating mantra of movement in our rowing boat.

We passed natural caves that burrowed into the island, and glided over a reef in our craft that rode high enough in the water so as not to worry about hitting anything. We saw blue and golden colored fish weaving through the tall elegant kelp forest and then passed into deeper waters. Pelicans joined our early morning forays and flew above us. Sea lions draped over the last buoy lounging and barking their mournful cries. Water splashed as one of them rolled off the buoy and into the sea.

Now we were in the open ocean, a half mile out, gliding along and following Catalina Island's undulating topography. On a lucky day, a seal might pop up and swim alongside for awhile. Occasionally, we'd ship the oars and float together, taking in the extraordinary reality of the moment.

Was this a dream? No, Andy was eleven years into his Parkinson's disease experience. His seven years of being entirely disabled were over.

Motor boats loved to come zipping up to us and inquire, "Is that as fun as it looks?" A giant double decker yacht came close, its engine purring and its owner standing on deck. "I used to row like that in the mornings and it was the very best part of my life." We smiled at him and Andy gave a thumbs up sign. "I got old, though." He went on. "You are lucky you are young and healthy enough to still do that."

Andy was seventy years old and I was fifty eight.

I was forty seven when Andy showed the first symptoms. Our kids were ages twenty one and seventeen. The early stages of the disease were relatively mild physically. I learned that the really early stages included depression and lack of motivation and had been presenting in Andy for years. We had struggled financially for awhile. My life spiraled into a busy and difficult path when I was responsible for Andy's care, which increased each week, and juggled that with being the breadwinner as well as making time to be Mom to fledgling adult children. My over busy life kept me a step or two ahead of my fear and removed me from fully feeling the losses I was experiencing. The strategy of not looking too far ahead, worked very well for surviving difficult pieces of our life. It protected me. Being an optimistic person, and having the ability to tap into joys amidst the suffering in a situation, it was an easy leap for me to pass over the depths of my own pain and despair. If I was able to live in a way that kept me from feeling that pain, then did it ever really truly happen?

I think it did.

We had not been able to afford health insurance for twenty years. Ever since health care, in our country, had been taken over by private, for profit insurance companies, around the 1970s, our income did not allow us that luxury. When Andy was diagnosed, we were completely shut out of that system because he had a preexisting condition. I faced the reality of my life, which included loss of equal partnership with my sick husband. I recognized that my days working were going to have to become longer and more intense. Our children, who were beginning to strike out into the world on their own, and our daughter, who was beginning her first year of college, were going to have to live their lives without the support we craved giving them. Since Andy's disease was incurable, I faced the fact that we would never be able to afford medical care. There was no one to ask for help. My family did not offer. Friends did not know.

I felt alone.

I focused on what we could do rather than what we couldn't. This way, my fears became manageable and my life became simply, and metaphorically, putting one foot in front of the other and repeating the process. As the years went by, my fears changed when different losses and challenges presented themselves. Repeatedly, I was facing a life I had no idea how to navigate. Sometimes I'd be overtaken by fear, and I would break down.

Once, while standing in front of the bulk section of sweet treats, at Whole Foods Market, I was considering buying some carob chips for a snack. For years I had eaten carob instead of chocolate as a healthy alternative choice. In one instant I felt that everything was falling apart anyway and filled my bag with chocolate almonds! Chocolate seemed to calm me down and so my healthy choice was not made anymore.

One of the first losses was when Andy told me he could no longer safely work with the torch, making his share of the bronze jewelry we sold. I realized that now I was solely responsible for making all of it.

I laugh at myself, writing this now, because that was nothing compared with what was to come.

I became a researcher about therapies and cures for Parkinson's. Some things helped and others did not. After Andy stopped all torch work, he became a man who could only use his right arm. We adapted. Andy was able to maintain our home and car, he could finish our jewelry, and do some repairs and maintenance on our friend's vacation home. He could get around alright and do all this because of his ingenuity and willingness to adapt, but everything he did was a lot slower. We went out to dinner occasionally. Andy would sit on his left hand to appear more normal.

We were hoping this disease would go away and we lived the first couple of years trying to keep our life before Parkinson's alive. I had anxiety about the possibility of his right side tremoring. I would surreptitiously check him daily, because if that ever happened I knew our life before Parkinson's would be gone completely.

Parkinson's sufferers stop shaking when they are asleep. One night, I awakened and realized I was tremoring. I could feel it in my body. I was slightly shaking and could not control it. My mind perked up and I thought, "My God I have Parkinson's too." As my state of being awake grew, I realized it wasn't me. Andy was shaking because he had awakened and the vibration of it reached through the mattress to me. We gave away our queen sized bed and bought two singles and placed them side by side with a small space between. This resolved the sleep problem, but we missed touching each other.

When his right hand, arm and side started tremoring, Andy heroically tried and failed to adapt again. He'd eat standing up at our counter so no body part would touch the plate or bowl, and he'd brace his arm against the wall, trying to quiet it enough to bring food to his mouth. Walking became difficult, and then dangerous.

Andy was a lifetime runner and a gorgeous National Forest trail began steps from our home. We had run there together for many years. One day Andy took a walk on that trail and returned

limping and accompanied by a neighbor who had found him. He had broken his scapula, after falling down, and had not been able to get up.

Andy stopped brushing his teeth altogether because he often hurt his mouth with his toothbrush.

He stopped driving.

These activities of daily living, and his inability to do them, were losses we absorbed. The rate of loss seemed to be at about one thing per week for a very long time. The life we had built together was dismantled piece by piece.

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I turned fifty and I didn't want to be in this situation. The symptom progression was excruciating and relentless. The amount of care that fell to me felt incomprehensible and became that one foot in front of the other experience, as the only way I knew of coping. Each morning I took care of my own needs as well as Andy's. I didn't enjoy shaving him or cutting his nails, but helping him dress, preparing his mouthwash gargle and swish and brushing his hair were more enjoyable to me. I did prefer one job over the other. Was I engaging in preferences as the only way I could have any say about something that was not optional in my life?

I missed everything about our life before Parkinson's.

I missed having an independent husband who could make his own choices.

I missed our runs and hikes together.

I missed being more equal in our life.

I missed going out together for dinner or a movie.

I missed working together.

Andy taught me the process he had developed for finishing the jewelry we made, because that was getting harder for him to do, and I added that to my list of responsibilities. I longed for my husband, best friend and father of our kids to be well.

My longing sometimes showed up in unattractive ways, such as jealousy. In an unguarded moment, driving with a friend and their spouse, I said, "It has been devastating to no longer be able to be a team with Andy." The spouse replied, "Really. Well, Beverly and I are a team in every aspect of our life together, aren't we?" He looked at her, smiling happily. Fortunately, I

was in the back seat of the car and they couldn't see my tears. I was jealous. I was also ashamed to feel that way. I learned not to have unguarded moments.

There just wasn't anybody to share my pain with. So, I didn't share it with anybody. Except Andy.

Our saving grace, at the time, was Andy's voice. His voice was my teacher when I had to learn to do the things he used to do. It was the primary way he expressed himself and was one of the only ways we could access our previous life. We talked together and remembered our long history and adventurous lives. We laughed as I shared stories about my daily activities. One morning while he was sitting in his chair shaking like crazy instead of going for a run like he did most mornings of his life before Parkinson's, he said. "Honestly, this is the worst aerobic workout ever. I never stop shaking and burn calories like mad but there is no benefit!" His courage and strength existed in his voice. It was a balm to my spirit, a joy to my heart and connected us in our love.

Living this way for six and a half years, takes a toll. In our culture we don't have a natural way to express the pain we suffer and so usually it stays silent. It is not a peaceful silence, though, and that is the danger. I recently learned, that after Andy had received back much of his ability to live independently, my own deepest life force was somewhat hidden and hard to find. It made sense. During those hard years, I barely had time to take care of all I was responsible for doing, much less express my own suffering.

I didn't have a welcome place to go and express these difficult feelings. It never felt right to intrude on my parent's or sibling's lovely lives with my own messy, unattractive pain. I don't know what would have happened had I felt able to do that. This is not a judgment against them. I know I am not alone in keeping hard times to myself and now I've learned that all that inward containment can become poison, over time, if not expressed.

During this period, there were several instances of people unexpectedly stepping forward and standing with me in the gates of sorrow where I was stuck. My friend since childhood, Nubia, began to give us money. It was such a needed gift that each time it made me cry because she really saw us and cared enough to help. We'd met as babies and apparently weren't immediately taken with each other. Later, we became best friends in elementary school. During those hard years, she deposited significant funds into our account, that allowed us to try new treatments, help our kids, and live more securely. I felt seen, recognized and loved.

Our younger friends, and neighbors, also stepped up and helped. Marianne and Chris, and Day and Iris, were two young couples who lived in our neighborhood. All four of them helped us in uncountable ways. I called Marianne and asked, "Are you and Chris available to come over and feed Andy two times a day all next week? I have work and need help but I will have premade all of the food. It will need to be warmed up, though, and I'm hoping \$13.00 an hour is enough?" Mar replied, "We can definitely do that, Michelle, but we don't want to be paid. We love Andy and don't consider spending time with him to be work." I cried for the pure friendship offered.

My dad relentlessly pushed us towards trying to get benefits from the VA. It took years. Without his encouragement I would not have persisted. I interpreted his insistence as love.

I also prayed and knew many were praying for Andy and I. God's love brought peace to my soul but living on Earth, in human form, with my sick and disabled husband, I also needed material, pragmatic help for the physical, mental and emotional needs. When people offered us help, we received so much more than the money, time or advice they gave. We received the gift of feeling connected.

I have approached my own healing. I have learned to pay careful attention to who I give my precious energy to and when it is better to sit with it myself. I use natural treatments and have begun to strengthen my life force through conscious deep breathing, quiet times, rest, flower remedies, and protecting myself from helping when it is not the best choice for me.

There is much suffering in this world and many people who have suffered more deeply than I. To those people, I bow down in humble respect with the hope that they have given themselves time to heal and integrate the suffering into a life that includes joy. It is clear that every person, who has sacrificially given a part of their lives to another or who has sustained a trauma in another way, needs to regain balance and find expression for the pain felt when living that role.

It was time for us to do exactly that.

Now that Andy was better, we were going to proceed much as we had lived during those most difficult years, by living the best lives we could design and staying present in our new circumstances. As in many challenges, the remedy was within. Our awareness of our pain would now be balanced with the reality of our joy and step by step we moved towards healing.