

The War Within: A Personal Journey with Obsessive Compulsive Disorder/Complex Post Traumatic Disorder-The Struggle, the Fight, and Recovery

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1. Abstract

For years, I had suffered from OCD. I have been in and out of many psychiatric facilities both in the United States and in Canada. My experiences are complicated but also very informative for those seeking help with OCD. I have been in many crisis situations and have endured many treatments like CBT, mindfulness, guided meditation, ERP, hospitalization, and withstanding very intense OCD and CPTSD residential treatment programs. In time, with the right medical team, support groups, medication and self-motivation to fight against the debilitating symptoms OCD, I have gone from being on LTD for the inability to function and complete daily tasks like showering and dressing without compulsions, to reclaiming back my life and returning back to teaching. I hope to be able to pay it forward and speak to the great resources and staff available at Sunnybrook Hospital. I hope to share my story of struggle and recovery to help bring resource information and hope for those suffering from any mental illness. I have seen the good, the bad and the ugly. But, I have also seen hope and light. I now am able to know how it feels to be able to function again, as well as acknowledge a strength that I could never have known I had if it was not for the experiences I endured. I have the authority to now say OCD is not a life sentence, OCD can, in fact, be managed. I can be the voice that I so desperately needed years ago,

when all I wanted to do was end my life because I had a lack of experience around me of seeing those who made it, those who survived and not just survived, but thrive into productive individuals who are able to manage their OCD and be successful.

There are many moments in our lives, some that bring joy and others that bring hardships and sorrow. I can remember two very distinctive and pivotal moments in my life. June 27th, 2005 and October 27th, 2007 both of which served as two very different purposes one of great joy and the other as great turmoil.

My story begins June 27th, 2005, the day of my university graduation. I can remember not only the details of that day, but more importantly, how I felt as I crossed the stage and received my two honorary degrees. As I walked towards my bright future, I remember thinking of all the hard work leading up to this moment. As I stood there, shaking the dean's hand, and hearing my name being called out, I never felt so alive and so accomplished. My life was completely on track. I was excited, I was fearless and I felt empowered. This was one of the most joyful moments of my life!!

Unfortunately, the euphoria of living my dream of being a teacher, unknowingly to me, would soon come to a sudden and unexpected stand still. Fast

forward two years, almost to the day of my graduation, to October 27th, 2007, to where I am sitting in my GP's office, where I would unexpectedly face the second of my life's most pivotal moments. This one was not as joyful as my graduation, as my family doctor diagnosed me with a mental health condition called, Obsessive Compulsive Disorder or OCD, in the form of a question, "OCD Lucy?" This question, this diagnosis, was hard for me to process. Her words came crashing down on me like a ton of bricks breaking me into a million little pieces.

This diagnosis said to the world that I was damaged and not so perfect after all. I felt confused, scared and powerless. Life was going so well, why was the universe was throwing me a huge curve ball? This moment altered my life in the most profound and unexpected of ways. I came to realize that whether I liked it or not, prepared for it or not, this disorder would change me, challenge me, break me and build me into a whole new person.

Growing up I always knew that I was different from the other kids. It was in kindergarten that I realized that I did not think like the other kids. Both at home and school, I was always described as being neat and organized, and very jealous and particular of my things. This was made very clear to me one day, when I brought a box of my Barbie's to show and tell, where I was willing to tell about my Barbie's, but felt distress having other kids play with them.

Along with needing to keep things in order in my life from a very young age, I also had very distressful images in my head. Vivid, and unwanted intrusive thoughts, flooded my mind constantly. To explain, they were like having bad horrible dreams, but I was awake. The images were of terrible things happening to people I loved because of a mistake that I had made. I was convinced that if I did not follow the rules of checking and rechecking things I was going to cause some life ending event. The distress of simply taking my Barbie's out of their box came from the thought that if I did not put them perfectly back, something bad was going to happen. Back then, I did not know what, or to whom, but I refused to find out and as a result was placed in a time out for not sharing.

Growing up, I had a pretty good childhood for the most part. My parents always made sure that my brothers and I had everything we ever needed-tangibly at least. But life at home was not always perfect. From time to time, I had experienced first-hand arguing, yelling, physical, and verbal abuse, all

which had conditioned me to develop a distorted self-perception and low self-esteem about myself. Unknowingly to my family, I grew up secretly feeling very powerless, scared, ugly, unloved, but mostly really super anxious about everything. Very rarely did I display physical symptoms of this anxiety until the age of 6 when I went through a severe traumatic situation and I started to wet the bed. Between the ages of 6 and 7, I was taken to a sitter, who for nearly five hours a day would lock me in a basement bathroom in the dark. To spare you all the grueling details, I was basically verbally, emotionally and psychologically abused in that bathroom each day.

I never had the courage to tell my parents what was going on, mainly because I was told if I did, my sitter would kill my mom when she arrived to pick me up. This threat in fact, became the driving force behind of my intrusive thoughts later on when I was diagnosed with severe OCD as an adult. While held captive in that bathroom each day, there were "rules" that I had to follow. One rule was, "if things have been touched or moved my mother was going to die". And so, afraid that I would move things and cause my mother to die, I obsessively spent hours studying the positioning of the towels, the rug on the floor, even the pieces of dust in the corner of the bathroom. This was the same train of thought that would cripple me twenty years later.

Anxiety has always been a part of my being, like they were just there as far as I can remember, but they never interrupted my life in any significant way. If anything, the anxiety worked in my favour as it was the driving force to be the best at everything I did, and that made school, work, and making friends all very easy for me. But, the anxiety had no real impacting consequences to my successes, achievements or relationships. I was functioning just perfectly. That is, until October of 2007 when everything changed.

I can vividly remember the day my extreme struggle with OCD began. One afternoon in early October I was in my bathroom at my parents' home, where I had just finish showering. I recall using a Q-tip to clean my ears and as I bent down to throw it out into the waste bin I felt my brain shift and pop. Now to explain this, if you have ever experience a heart palpitation, where you feel your heart pop, it felt exactly like that just in your head. Then, I recall walking out of the bathroom and I noticed that my thought process had changed, all of a sudden bad images flooded my head and urges began telling me

to go back into the bathroom and repeat all of my actions, in an even amount of times.

All of a sudden, I needed my things to be super organized, more so than before. I was fixated on making sure things were put in the perfect order all the time. I felt like I had to do it, like I had no choice. I knew that what I was doing did not make any sense and that I should stop doing it. But whenever I tried to stop, something took over in my brain, and I just had to keep going. I remember feeling extremely distressed when I needed to organize and reorganize things multiple times and I could not do anything else until everything was organized perfectly. These images are what doctors refer to as obsessions. People with OCD experience many different types of obsessions, such as order/exactness, religious, sexual, violence, aggression, or contamination. Obsessions, then by definition are unwanted, intrusive and repetitive thoughts and images causing an extreme amount of uneasiness and anxiety.¹ People with OCD experiencing different types of obsessions know that they are unreasonable and excessive.

From the moment that I would wake up in the morning it was a nightmare. The images and thoughts started immediately. What side of the bed did I get on last night? What if I didn't wash my hair in an even amount of times? Something very terrible will happen and it will be entirely all my fault. I had to stop and think and rethink my morning routine just to be sure I had done it all correctly. I was exhausted, so anxious and almost always late for work. The obsessions created so much fear and uneasiness for me that I found myself being caught doing some kind of action to make myself feel better. I was afraid of telling anyone what was happening in my head for fear of being labeled as "crazy".

As time went on and the obsessions grew more, my need to "fix it" began full force. My OCD shifted from internal loud obsessions in my head, to external physical actions, that others could see, which meant I could no longer hide it. The "fix it" acts are what doctors call compulsions. A compulsion is defined as a ritual or action that is done when an obsession occurs to help ease the anxiety from that obsessive thought.² A compulsion is doing something like touching, counting, chanting, washing, cleaning, hoarding and or some mental ritual. A compulsion is doing something like touching, counting, chanting, washing, cleaning, hoarding and or some mental ritual. So, following true OCD style, no matter my obsession, my compulsion was to repeatedly touch, count or repeat words, numbers and actions in order to ease my anxiety. By Christmas 2008, I was unable

to function without repeating everything I did, even down to how many times I would blink, breathe or swallow. I could no longer see my friends, spend time with family, or enjoy life at all.

By late March of 2009 as the obsessions became even more frequent and more intense and so did the rituals. My whole day was filled with repetition and eventually with ordering, symmetry, perfectionism and ultimately avoidance behaviors. My OCD became so severe in symptoms that it was difficult and tiring to do even the most simplest of tasks like washing, dressing, and even eating. What first started off as an single action that needed to be repeated, for example, touch the door handle twice before exiting the house, turned into touch the handle 8 times to 16 times, to 32 times to 64 times and so on until touching the door handle was an 8 hour task on a good day. I eventually never left the house unless someone opened the door for me, but even then, I faced the compulsion of entering and exiting the house repeatedly. It was horrible. Everything had a rule, and sometimes it felt like my rules had rules. Ultimately, my illness prevented me from touching the door handle altogether because the ritual would tire me out, and the image/feeling of something bad happening, would not really pass.

By September 2010 the intensity and severity of my illness, trickled into my classroom where I taught, and I became too sick to teach. This was very hard for me to accept. Teaching was my passion, my whole life, the place where I felt most productive, needed, and loved. But consumed with hours of rituals, I secretly struggled at work daily with my OCD. It got so bad that I would spend hours after work arranging and rearranging, each pen on my desk by color, height and make, just touching and retouching them until they sat perfectly in my pen holder. When I finally felt relieved that I had satisfied my OCD demands, distress set in as I did not know how many times I had actually touched my pens. And now after fixing my pens for six and a half hours, I was back to square one, just feeling utterly defeated and hating myself for being so careless.

The compulsions which at first gave me relief allowing me to continue on with my day were now starting to be short lived and before I knew it, the compulsions were creating anxiety, which was bringing on more obsessions which created more compulsions. It felt like it was never going to end. The hours in which I would spend ordering and repeating, and avoiding had increased tenfold by this time. On a good day, I would spend anywhere from 12 to 16 hours in my bathroom or bedroom making

sure things were in their correct place. I felt like if I didn't something terrible would happen and then each time I thought I was done, the overwhelming stress would drive me back to repeat the same thing over and over for hours. It was exhausting, but I couldn't stop. Day by day my life was being destroyed more and more.

When I was no longer able to even leave the house for appointments, and sat with my hands clenched together in my lap afraid to touch anything, my parents knew that it was time to get immediate help. My parents and I spend many hours in different ER departments all over Toronto, looking for help, but after some time, we were finally blessed to be referred to Dr. Peggy Richter at Sunnybrook hospital, who is the leading psychiatrist in OCD treatment in all of Canada. The referral was sent in 2008 when I was still somewhat functioning, but three years later I was still waiting to see her.

Finally in September 2011, I was able to see Dr. Peggy Richter and after a brief second consultation, it was clear to her that I needed intensive treatment fast. Amongst all the psychiatrists I was evaluated by, Dr. Richter was the only doctor that took the time to explain what was happening to me so that I could understand it. She explained how the pathways connecting certain parts of my brain were firing really fast causing me to feel as though I am constantly in danger or something bad is going to happen. By taking the medication and changing my thoughts process in therapy, I could slow down the messengers and once they stop flooding my system with anxious thoughts, I would have more control over the thoughts and images in my mind and how I respond to them. This she said would help me deal with both my obsessions and my compulsions. By the time I had seen her, I couldn't touch anything, and I thought I had lost my mind. She corrected my views by saying, "Lucy I know you must be scared. It must be so hard for you to have so many obsessions and compulsions. I want you to know that you are not crazy. You have severe OCD, and it is causing a lot of problems in your life, but if you work with me I can help you with that. By joining my Cognitive Behavioral Therapy (CBT) group and taking this medication, both will help you manage your unwanted intrusive thoughts and overwhelming desire to do rituals.

This she said would help me deal with both my obsessions and my compulsions. Next to seeing how debilitating my OCD had become, Dr. Richter also acknowledged that my home life was not a safe place for me. Home was a complete disaster with so much

physical and emotional abuse, happening towards me daily as a result of my need to do rituals around the house. And as time passed, as the abuse increased, my OCD and need to ritualize at home got worse and worse which perpetuated more abuse. My parents were at their wits end with me. To them, I was behaving this way because I wanted to, and they refused to believe that I couldn't just stop it. As I began experiencing a lot of flash backs from the past and present abuse, Dr. Richter also diagnosed with Complex Post Traumatic Stress Disorder (CPTSD).

My first admission into the psychiatric ward was short, but very pivotal to my care. There, I met my now trauma psychiatrist Dr. Justin Weissglas who continues to help me with dealing with my past experienced trauma. However, back then out-patient care was not enough for me. So, in October 2012, I was sent over to Rogers Memorial Hospital, an OCD inpatient residential treatment centre in Wisconsin. There I learned, under intense 24hour treatment and surveillance, how to effectively use CBT, and Early Response Treatment (ERP) as the basis of my recovery.

After discharge, I continued CBT and ERP offered by the Frederick Thompson Anxiety Disorders clinic located at Sunnybrook hospital in Toronto. This anxiety disorders clinic is an emerging center for excellence, which offers many services that range from out-patient CBT, medication management, group psychotherapy, family support, education for mental health professionals, all the way to an inpatient residential program, the first in all of Canada, for those suffering with severe OCD, when other methods of treatments have failed.³ This clinic had taught me many tools that I still use today in my daily life. Tools that helped me manage the OCD. And it was working; I was starting to function better. I was beginning to challenge my thoughts and I was beginning to feel empowered again. But then six months later, when my physical health took a turn for the worse, and a sexual assault threw me back into the OCD and CPTSD lion's den, all the hard work was undone.

Over the next several years, I could not recover no matter how hard I tried and in fact my mental health just kept deteriorating. I was now experiencing daily severe panic attacks, anxiety attacks, flash backs, dissociative states, insomnia, and many hospitalizations. I was even formed under the mental health act at one point in my home for my own safety. I tried everything that was offered to me through the anxiety disorders clinic. I was introduced to many treatments like Dialectic Behavioural

Therapy (DBT), mindfulness, guided imagery, meditation and medications all in an attempt to help me get better. At the clinic, I saw a CBT therapist twice a week, as well as, Dr. Richter three times a week and Dr. Weissglas twice a week. My recovery was not going well and I was really struggling. I saw so many people get better in the clinic, but nothing seemed to be working for me. The frustration of being at the hospital daily and not being able to find a treatment that helped or a medication that worked so I could return to work, or at least function on some level had started to build. I felt like I was being pushed over the edge as Major Depressive Disorder kicked in with extreme bouts of suicidal ideation.

OCD is a mental illness that is not taken seriously. The portrayal of the illness is comical within social media and those without the illness loosely use phrases like "I am so OCD" as a way to say I was super clean today. The common response I typically get when I disclose that I have OCD, is, "oh so you wash your hands a lot"? No! That is not the only form of OCD. Even worse, the stigma surrounding mental illness as being dangerous was something I faced often. There were many times that people would walk away from me and would physically space themselves from being close to me when they learned that I had a severe mental illnesses like OCD. I mean I had OCD, I didn't kill anyone? Why such the harsh reaction? I felt like I was a monster, like I did not belong or fit in anywhere. People stared at me in public, whispered and laughed as I engaged in rituals. The need to hide my OCD, with the need to ritualize was getting so difficult to balance, that there were times that my body would go completely numb during ritual and I would feel nothing. My life was just a mess and I no longer wanted to live. My CPTSD symptoms amplified during this time, with more horrible nightmares and flash backs forcing me to mentally, physically and psychologically shut down. I could no longer fight. I had planned to die.

In a combined session with both my therapists one day, I sat in tears as I felt emotionally empty and I knew that the OCD had won. And my therapists knew that I had checked out. The bright light in my eyes was replaced with hopelessness and the sense of defeat within me was evident more than ever. In their final attempt to reach me, both Dr. Richter and Dr. Weissglas looked me straight in the eyes with so much compassion and said, "You are more than this. You have been through hell and back. You are a fighter. You got through it once you can do it again, we promise. Just give us a chance to figure it out. Don't give up just yet...please". But both Dr. Richter

and Dr. Weissglas never just only treated my mental illnesses, but they treated me as a whole person. They understood me. Doctors who did not really understand my illness, just laughed at my odd behavior. I recall one doctor watching me being stuck in a ritual and he just sat there and openly laughed while I repeatedly tried to get off of a chair. I felt humiliated.

After hearing the encouraging words from my medical team, I decided to search for one more option and not act out on my suicidal plan. Just one more inpatient residential treatment program and that was it, I promised myself and if it did not work, well then I was certainly done. I felt for the first time, that I needed to do this for me, that I could not live like this any longer or die because of this illness either. I needed to regain my strength and fight. And fight I did.

The encouragement of my doctors reminded me to use my skill of perfecting things in my past, towards now fighting this war within my head. So, in theory then, I was going to use OCD to recovery from OCD. I was going to then perfect my recovery. My mind set had shifted from "I can no longer fight this" to "watch me". But first, I realized that I needed to let go. Let go of all my past struggles, hurt, pain, and abuse before I tried to attempt to recover. I hated the OCD and I was bitter from all the abuse and ridicule I had experienced because of it, and the anger I felt towards the universe for making me sick like this. But mostly, I was angry that the OCD had imprisoned me in my own head with no way out. How it enslaved me to my thoughts.

So with a new determination and mind set and with a final attempt to manage the CPTSD and OCD, in June of 2016, I was admitted to the Post Traumatic Stress Disorder Clinic in Guelph and it was there that my medical team within that facility worked very closely with my medical team at Sunnybrook hospital in Toronto to help me. I recall standing at the front doors of Homewood in Guelph, and saying to myself, this is you... all you Lucy....so do it for you and nobody else. After three long months, and in one last final attempt, one last medication was tried and like an answered prayer, it worked. In combination with the new medication, I learned new coping skills in therapy of using thought records, mindfulness, art therapy, and grounding techniques to both manage my CPTSD, and OCD, but to also rebuild my self-esteem and self-perception. I was getting better again, slowly but surely.

Fast forward two years to today, to right here, right now, and I can proudly say that I have been in full recovery from OCD now for nearly two years and counting. I still see my therapists every few months and sometimes more often when life gets tough, but I no longer have the intense obsessions and compulsions. OCD only seems to rear its ugly head when I get really stressed, but my bad days now are what my really good days used to be. And, in September 2017, I returned back to work teaching full time. I can even finally spend quality time with my family again. My relationship with my parents is very strong and positive now. They themselves sought out help so that they could better learn more about my condition and how to respond to me in healthy and supportive ways. More importantly though, they now understand that OCD is not a choice but an actual chemical imbalance in my brain and that I can't just "stop it". My parents, who were once hindering my progress to get well, are now, with the help of education and counseling, become my biggest supporters, advocates and are here today proudly watching me speak.

I am now able to travel with my friends, and I am also finally well enough to date, which is exciting. My life feels back on track and with the support of friends and family, the expertise and patience of my amazing medical team at Sunnybrook hospital and my determination to help myself, as well as, God's grace, I am here, alive today. I am functioning and loving life again when statistically I should not be here. In that support, I found the strength within me

to fight, to hold on one more day and more importantly I found my voice and place in this world again. I had defied all odds. And I learned one of life's most valuable lessons from this challenging experience, and Henry David Thoreau said it best, with "not until we are lost, do we really begin to find ourselves". This experience, this hard fight, this war within me that brought on so much pain, loss and hurt, had in fact made me stronger, braver and more resilient than any lesson that I could have learned in any textbook. And so, when I face challenges today, I think back to my past struggles, and remind myself that, my story isn't over yet!!

2. Acknowledgements

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