

*My Lived Experience – A Patient’s Story:
An Unheard Voice for Many*

This essay is about some of the difficult and sometimes challenging experiences I have had on a daily basis because of decisions I have made regarding my healthcare. I am not alone in facing challenges in life or learning ways to handle them. However, at times I have felt on my own in creating a healthy lifestyle in my recovery. I have been and still am facing many unexpected struggles and obstacles which have challenged my progress. My story is about the healthy recovery tools that I implemented while dealing with these barriers. At one time in the past, I was prescribed at least eight psychotropic medications at the same time. But these unanticipated barriers began after the discontinuance of a powerful antipsychotic medication that had been prescribed to me for at least fifteen years.

During my last hospitalization in January of 2011, a negotiation was made to discontinue this antipsychotic, and a newer, more marketable one was immediately prescribed. I also agreed to inform my out patient psychiatrist if any of my symptoms worsened. I had frequently expressed concerns about my increasing weight gain which I knew was a possible side effect from this medication. In September of 2002, I was diagnosed with morbid obesity at a weight of 287 pounds and a body mass index of 47.8.

I had a job working at a patient drop-in-center for a few hours a week in the mental health system that I really enjoyed. But after discontinuing the medication, things began to change. A cloud started to lift, and the sedated effect that I was not aware of was being exchanged by clearer thoughts. I felt like I was coming to life. I began practicing self assertion and working on self esteem. This became unacceptable to my supervisor who said, “You did better when you were on the antipsychotic.” And, “I should have never allowed you to go into the hospital.”

My job that had given me a meaning and purpose in life had resulted in my first unexpected barrier. I resigned for mental health reasons while feeling like Miss America losing her title. I continued to complete peer assessments with patients until I unexpectedly became ill and could not return.

I began to realize that I was experiencing the birth of a life that I never knew, and the death of the only life that I had ever known. In the past, I received standing ovations at mental health functions after presenting my recovery story. I had included taking all medications as prescribed as part of the physical component of the recovery model. Now I felt like I was the only one standing. A mental health system that had provided me support while under sedation was becoming less supportive now.

By June 2011, I lost nearly 100 pounds. In July, I began experiencing physical problems, and had been told by a physician that I was having an allergic reaction to a cleaning chemical. By August, I had to go live with my eighty-six year old mother because I had become so ill.

Because of the rapid weight loss and dramatic change in my appearance, I was misjudged by my medical providers and friends. I could not understand how this antipsychotic medication that was supposed to improve my symptoms, limit my hospitalizations, and give me a more productive

life resulted in so many complications after discontinuance. I reacted with anger and tears. I felt like I had not only lost my identity in mental health, but my personal identity as well. I was certain that I had cancer or something incurable besides the withdrawal.

Several times, my mother and I cried and prayed together just for me to make it through the night. Prayer became a source of strength and hope during this lonely time as I struggled. I asked God what He wanted me to learn from all of this, and what He wanted me to do for my peers. I turned my will and my life over to God, and I surrendered. I was powerless.

During this time, I went to a local emergency room hoping to be seen for physical complaints. My mother noticed how ill I had become and told me that I should be seen by a physician. We cried and prayed together. We feared that I was not going to live through this withdrawal. I took a suitcase in the event that I would require medical hospitalization since my mother would not be able to help. I explained all of this, including how I was physically feeling, the allergic reaction to the cleaning chemical, and the discontinuance of the long term antipsychotic to hospital staff and the attending physician.

Prior to seeing me, the ER doctor reviewed my list of medications which included the newer antipsychotic. Without an exam, this physician asked me what my diagnosis was and recommended a psychiatric evaluation. I replied that I did not need an evaluation, I was taking my medication, and my symptoms were under control. I also said that I had a psychiatrist, and I was well aware of when I needed psychiatric intervention. I was then told that I would not be provided any medical treatment or hospitalization without the psychiatric evaluation. I was subsequently asked if I wanted to leave AMA.

My diagnosis was always questioned after any new health care provider reviewed my list of medications which included the antipsychotic. When I had medical concerns, my existing health care providers often considered my psychiatric diagnosis first, and my medical problems second. I was labeled as a chronic patient and always felt shame when listing my medications, a shame that was never sedated on the antipsychotic.

I started to feel depressed over all of the unexpected and stressful events that I hadn't dealt with when on this medication. I was feeling my feelings without sedation, and I had to learn how to cope. Many people have a life time in learning how to deal with situations, however, I felt like most of my time for learning had been sedated and taken away. When I was finally able to return home, an individual from where I had been hospitalized many times in the past said, "You deserve the life that you never had."

I was feeling displaced so I created a healthy environment while still living at my mother's house. I improved the surroundings to help me cope with all of my overwhelming feelings and struggles. My deceased father's room became my room by adding special things to make me feel safe. Listening to soft music on the radio calmed and comforted me throughout the day. I placed pictures of my cats on a dresser, and emptied some drawers for my clothes and personal items. A fan provided cooler air, and a cool mist humidifier provided moisture. Some days were entirely spent cleaning and organizing my room as a stress management tool. I opened the window shades every morning to let the sunlight radiate through my room and throughout my

body. Warm oatmeal baths were soothing and sleep was essential. Most evenings were spent resting with my mother and watching television with her. Neighbors became my friends without even knowing my mental health issues. My pastoral counselor remained in contact with me offering his support and encouragement, and he scheduled sessions when I had other appointments near my home. My family also supported, encouraged, called and visited me. I journaled and wrote a gratitude list before going to bed.

During this time I made an appointment with my primary care physician. He told me that he felt bad that I was being labeled and stigmatized. Without asking, he gave me a medical leave from the minimal amount of work that I had been doing, along with medical follow up.

Initially, I attempted to blame my new health problems on anything I could imagine and was vulnerable to the judgments of others. I was actually afraid that others, including my physician, would think that I was crazy, rebounding, and needing the antipsychotic again. When I told my physician that I believed the problems were related to the antipsychotic, he said that he didn't know anything about it. Because my doctor discounted me, I continued to search for other cases for my symptom. I thought that my struggles would stop if something serious would be found. I felt I had to defend myself to medical and mental health professionals as well as to my friends. At my last appointment in February of 2012, my physician said that he was beginning to believe what the ER physician said; i.e., that I needed a psychiatric evaluation. I felt hurt, betrayed, and labeled.

Throughout this time, I had several appointments with my psychiatrist whom I have been seeing for at least five years. She insisted that I had an eating disorder and said, "You're just not telling me yet." Because of the rapid weight loss she asked, "Do you like yourself and how you look?" I cried because I felt discounted and misunderstood. In addition, friends that I made over years through mental health connections acted suspicious. My mother had been questioned several times, and when I returned home, I was told by a friend that she had been instructed to make sure that I was eating. I was, in fact, eating more healthy meals than ever before but I was still being misjudged.

When I told my psychiatrist that my weight loss was because I was withdrawing from my antipsychotic, she replied, "I was told that you were on the antipsychotic because of all of your hospitalizations." I was still on other psychotropic medications, and she said, "Do you want to get off of one of them or all of them?" After I had returned home, I saw a health practitioner who knew that I was on the antipsychotic as well as many other medications. I shared some of my story, and the response was, "Do you think that you were overmedicated?" In reference to a previous psychiatrist I worked with, she said, "A lot of us think that he does overmedicate, but he's the psychiatrist." I was no longer on any antipsychotic medications; however, my psychiatrist pressured me to take one. At one appointment, I asked her if she was aware of any research being done on the long term effects of these medications, and she said "no".

I returned to my home in October, and I had lost at least 150 pounds. Skin was hanging on me, and I felt unattractive. Everyone that supported me was telling me that this was the best that I ever looked, but I was not yet accepting of my new appearance. Even though I was close to my normal weight, I was not used to seeing myself look healthier. I did nothing to lose weight

except discontinue the antipsychotic medication and eat regular and healthier meals. An individual who works in the system saw me and had known that I was on the antipsychotic didn't even recognize me at first. This individual said, "You look great." When I said that I was no longer taking the antipsychotic, the response was "That will do it."

My self esteem was low, so I created special times and activities in my life. I began shopping at the Goodwill. Even though I was buying larger sized clothing because I felt embarrassed with my weight loss, it was fun and a special treat when I was feeling down. It wasn't until August of this year that I was finally able to begin accepting my weight loss and my new appearance. New and more fitting clothing was purchased during my first shopping experience with my family. I was overwhelmed with tears and emotions when I actually saw my new shape in the mirror that I had been shamefully hiding for so long. I also started to do self pampering. Now I was able to fit comfortably in my bathtub with soothing bath beads while sipping chamomile tea, listening to soft music, and having my cat at my side.

At times I felt like a stranger in my apartment where I had lived for fourteen years. I was finding things that I never remembered owning, and it became an adventure. My family and others were saying, "I've already told you that," and I couldn't remember. I purchased memory games to hopefully reverse some of the possible damage to my brain. Multi-tasking was and still is overwhelming, so I began making lists of things to be done in specific order. I learned how to prioritize, pace myself, and not expect to get everything done in one day.

Feelings and emotions were now flooding me. I had to grieve over the loss of my ten year old cat. My other cat became a very healthy part of my life. I never really knew how to take care of my cat, and we learned how to take care of each other. I turned my kitchen area into a dance floor, and began dancing to music with my cat in my arms. We both loved it and still do. It became a fun way to relieve stress.

I created easy stress management techniques that did not involve memorization and that were more fun and spontaneous. I developed healthy and easy sleep and relaxation techniques, along with healthy ways to improve depression without medication. These were all essential coping strategies that I needed to practice in my life every day without sedation, but I continued to be faced with unexpected barriers to my recovery.

Last November, I returned to a few limited hours of work in the mental health recovery field, and was observed by many. Mental health professionals who I had told about the antipsychotic, the withdrawal, and the side effects were not receptive, so I stopped trying to share. Once again, I was afraid that people would think that I was crazy. I wasn't accepted since stopping the antipsychotic medication. I was being labeled by everyone. Some friends expressed serious medical concerns because of the weight loss. All they saw was that I was not taking the antipsychotic. They did not see the positive things I was trying to do for myself.

I began taking better physical care of myself. I started on a probiotic, fish oil, and eventually vitamin C and B complex. I sought professional guidance in selecting nutritional supplements that aided my recovery. I developed a short exercise routine including weights and floor exercises. I began walking, which I was not able to do when I was so heavy. Walking enabled

me to meet new friends. Some individuals who knew me for many years couldn't believe how much healthier I looked. I began and still am receiving weekly chiropractic care from a doctor who has become a strong support and coach in my life. He told me that I had a long way to go.

In April, I was betrayed by a colleague and faced another challenge to my recovery. With a lot of counseling, prayer and support, I resigned from a peer support job for physical and mental health reasons. Because I felt rejected and isolated, I became withdrawn. So I started working for someone for just two hours a month which gave me a little sense of purpose. I developed new connections and increased more healthy activities in my life. Returning to my church was helpful. By invitation, I presented the various coping strategies that I had implemented to my peers on the unit where I had been hospitalized, and I remained in contact with an individual who had always supported me there. In addition, I continued to stay connected with the new friends I had made last year.

In July of 2012, I became depressed and discouraged due to all my losses and personal challenges. Since the withdrawal from the antipsychotic and my drastic weight loss, I have developed health issues requiring additional supplements which are costly on a limited income. I developed another serious side effect: lymphedema, which is chronic and requires on-going treatment. I felt defeated from trying to take care of my ongoing physical and mental needs. I started to doubt my own progress.

I recognized that I was trying to be in control of situations that I had no control over. Again, I surrendered my life and my will over to God. I practiced mindfulness meditation by staying focused in the moment and setting aside any quick judgments or projections. I learned Yoga wall exercises to help tighten my flabby arms and increase blood circulation in my legs. Reading again became relaxing and enjoyable, and I reconnected with some close friends that I had left behind throughout the years. In addition, I applied for a sponsorship at a community activity center for exercise, groups, and socialization.

I have been navigating around many barriers in search of acceptance and meaning for over a year, and my life long journey in recovery has just begun. The healthy recovery tools I have implemented have been helping with the stress, anxiety, depression and trauma that I have been experiencing. Caring for my physical and mental health needs on a daily basis has become an important part of my life. Monthly meetings are being maintained with my mental health caseworker, and I have weekly sessions with my pastoral counselor, along with scheduled medication management by my psychiatrist. I am still dealing with a lot of issues that I need treatment for, and I still need support from the mental health system. I am gradually reclaiming my personal power in making healthy decisions. My experience has left me with many unanswered questions and with many unmet needs for myself and for my peers. I am still asking God what He wants me to do with all of this. I am a lived experience, an unheard voice for many voices.

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