

JW's Story

The following events took place in 2010 and 2011.

Background

I am a woman in her 50's. My transformation from being a healthy, independent and financially secure, white-collar professional to unhealthy, dependent and debt-ridden homeless person happened in just under a year (2010-2011) after I underwent psychiatric treatment. I was alternately diagnosed with Depression, OCD with Depression; Major Depression; Major Depression, Agitated; Major Depression with Psychotic Features; Bipolar Depression with Psychotic Features; and Schizoaffective Disorder, Depressive. I was hospitalized four times - once voluntarily and three times involuntarily, in three different psychiatric hospitals, including a commitment with forced medication. I now owe close to \$65,000 for psychiatric treatment that I did not want and that did not help, and I am facing bankruptcy. My entire psychiatric experience was punitive, terrifying, and utterly dehumanizing. I am still traumatized by it and I am still trying to regain my health and my ability to think and function.

I had been a multimedia designer at an academic library where I had worked for 15 years. I always received stellar performance reviews from my supervisors and the patrons I helped. I was a perfectionist and often did 'above and beyond' what was expected of me. But my downfall was to never say "No" at work. I became a workaholic. I frequently worked overtime, often working late into the night and on weekends. Because of lifelong feelings of low self-esteem, I felt that I needed to do more than others to earn my paycheck. I neglected my home life and my partner, and as a result, our relationship became strained and complicated. Not surprisingly, I often felt isolated, unrested, and physically drained. Adding to my feelings of distress was caring for my mother when she was diagnosed with lung cancer and my prolonged grief after she died. Afterward, I spent time taking care of my widowed father when he became ill. My despondency and fatigue intensified. In retrospect I can see that these feelings of distress were my mind, body and psyche letting me know that my life was out of balance and I needed to find balance, as well as that I was understandably still grieving.

Once I was within the psychiatric system, my lifestyle and work history were never considered in a positive way but only as evidence that I was 'mentally ill'. (I have learned that once psychiatric diagnosis comes into play, the emphasis is on searching for problems and not for strengths or resources in addition.) I was told that my 'brain was diseased' and that I needed prolonged hospitalization and powerful drugs which I would have to take for the rest of my life. And to my shock, once I was involuntarily hospitalized, I was treated like a criminal by the psychiatric system even though I had never committed a crime. They read the Miranda rights to people when they are arrested - but no one does that when you are forced into the hospital and no one told me what my rights were or how long I could be held against my will.

Diagnosed with Depression, OCD with Depression

After years of working too long and too hard, spending too much time 'burning the midnight oil' and not taking time off from the extreme pressures in my life, I began to feel fatigued and

unrested most of the time. I often felt irritable and easily became upset with ‘little’ things at work and at home. My relationship with my partner had become estranged, and we argued frequently. I completely lost pleasure in things I normally enjoyed doing. I sometimes felt I would be better off dead but no concrete plan for killing myself. I told my General Practitioner (GP) how I was feeling, but instead of looking at the factors in my life that more than adequately would have explained that, and then urged me to think about what I could change, she resorted to using the *DSM*, told me I was suffering from Depression and prescribed Prozac. I understand that once a person is labeled mentally ill, she is very likely to be put on psychiatric drugs, on the assumption that the suffering comes from a scientifically documented brain abnormality. My GP never even discussed my lifestyle or the events in my life that might be causing my symptoms. At my request, my GP also referred me to a Licensed Clinical Social Worker (LCSW) for talk therapy.

My sessions with the LCSW focused on her convincing me to take psychiatric medications, which she said would ‘calm my brain’; she said that I needed to do that before we could have ‘meaningful’ therapy. Her diagnosis for me was OCD with Depression. In a consultation with her colleague, a Psychiatric Mental Health Nurse Practitioner (PMHNP) I tried an SSRI (Celexa) at a very low dose, but it made me feel unsettled, with heightened feelings of restlessness (I later learned on my own that this was akathisia, a common adverse effect of SSRI’s). The PMHNP recommended I try another psychiatric medication to treat my OCD with Depression but I was very reluctant. Both the PMHNP and the LCSW told me that my fear of taking drugs was a symptom of my OCD. The PMHNP also said that she thought that I might have Bipolar with Depression but she couldn’t make a definitive diagnosis until she saw what type of medication ‘worked’ to relieve my symptoms. I now understand that this is part of the common pattern of deciding first that someone warrants psychiatric diagnosing and then “explaining” everything on the wrong assumption that she is mentally ill.

I continued my talk therapy with the LCSW but declined to take medications, even though that was all we talked about during our sessions. I began to work even more, because that was my habitual ‘escape’ from distress. I took on additional projects at work and sacrificed my sleep to fit them in, often getting only 4-5 hours of sleep a night for weeks at a time. But my ‘escape’ backfired - I began to have serious problems concentrating at work, and my productivity began to plummet. My thoughts raced and I had difficulty sleeping. I lost my appetite and lost weight from my already lean frame. Finally one day I could barely get out of bed – I had collapsed from mental and physical exhaustion.

Diagnosed with Major Depression; Major Depression, Agitated;

At the recommendation of my GP, I voluntarily entered a psychiatric hospital. My GP told me that I was ‘sick’ with severe Major Depression and that I needed help. At the hospital, the only bed available was in the geriatric ward. All night long I listened to the wails of another patient in a room somewhere down the hall. Every 15 minutes a psych tech checked on me by shining a light in my face. The place felt like a prison. The next morning, after talking with me for less than 15 minutes, the psychiatrist whom I saw there diagnosed me with Major Depression with Agitation. I believe this is part of a pattern of more labels being readily added after one gets an initial label. The same morning, I left AMA (Against Medical Advice) and went back into work that day. I felt ashamed that I had failed by being ‘weak’ and entering the hospital.

I tried to ‘soldier on’ at work, even though it took a monumental effort just to get out of bed in the morning. I still wasn’t eating or sleeping well. One night I awoke with my heart pounding, sweat pouring off my chest. I called 911 and was taken to the ER. It turned out I was dehydrated. I was given several huge glasses of ice water and immediately felt better. A social worker saw me in the ER, and I admitted to her that I had been feeling despondent and severely fatigued, with no interest or energy for pleasurable activities and that sometimes I had thoughts that I would be better off dead but that I did not have a plan for killing myself. She noted my recent AMA discharge from the hospital, and I was ‘blue-sheeted’ by the ER social worker and doctor and committed back to the hospital involuntarily and placed on a locked ward

The next day, while I was in the hospital, I felt much calmer and rested, but I couldn’t go home. Because of my admitted thoughts about killing myself and my lack of self-care from exhaustion, I was considered to be a ‘danger to self and others’ My psychiatrist told me “get with the program” (i.e. ‘take the drugs he prescribed’) if I wanted to be released. The locked ward was co-ed, with mostly male patients, some of whom talked about having done jail or prison time. One male patient said he had tried to kill his mother. I was terrified of the other patients and didn’t feel I belonged there.

I took the Prozac and Risperdal and had awful reactions. The Prozac made my foot tremor, made my blood pressure rise and made me more nervous and sleepless; The Risperdal made my heart pound violently and caused visual hallucinations. When I complained to the psychiatrist about these effects and asked for a change in the dosing, he became irate and screamed at me “THIS IS A ONE DOG TOWN, NOT A TWO DOG TOWN!! I’M IN-CHARGE!” He prescribed Cogentin for the tremors and Trazadone for sleep and did not change the dosages of the Prozac or Risperdal. Taking these drugs was torture I was sent home with prescriptions for 7 drugs to take all at once including Prozac, Risperdal, Cogentin, Trazadone, and Ativan. I didn’t know my diagnosis (Major Depression with Psychotic Features) until a year later when I retrieved my medical records.

When I got home I kept taking the Prozac and stopped the Risperdal because of its awful side-effects, But, I continued to feel more and more apprehensive and restless; I had tachycardia and a foot tremor so severe that it was hard to walk. I also had developed an itchy, scaly, red rash all over my body. I was never given any information by the psychiatrist or nurses at the hospital about these negative effects of the psychotropic drugs. I called the pharmacist at the hospital and she told me that the symptoms I had could all be from the Prozac and that I could stop the Prozac ‘cold-turkey’ because I hadn’t been on it for that long and because it had a long half-life. Unfortunately, no one told me about withdrawal effects.

Within a couple of days after stopping the Prozac, I began to have episodes of sudden terror and the feeling that I was dying. I had bizarre, gruesome nightmares. Over a period of seven days I ended up going to the ER on my own once and called 911 eight times – each time because of my ‘terror attacks’. The eighth time that I called 911 I was taken to the ER, where I was ‘blue sheeted’ (involuntarily admitted) to a private psychiatric hospital. A year later I learned that I was very likely having classic adverse effects and then withdrawal symptoms from the Prozac as well as the Risperdal, but all of the healthcare providers I saw identified these as symptoms of

my allegedly mental “disease progressing.”

Diagnosed with Major Depression with Psychotic Features; Bipolar Depression with Psychotic Features; Schizoaffective, Depressive

On the first day in this private hospital, I became extremely unsettled by the smell of the smoke venting into my room from a refinery near the hospital. A nurse told me that I was being ‘psychotic’ and to stay in my room. By now I have seen repeatedly that once one has been given a *DSM* label, the “fact” that one is “mentally ill” is used to explain many things in mistaken and harmful ways. I persisted in begging the staff to move me to a different room. An hour later, a psychiatric technician dropped off commitment papers on the night stand next to my bed without explaining what they were about.

I was kept at this hospital for 30 days, never told my diagnosis, never told my rights and never told how long I would be held. No one told me that I could get a lawyer or explain what would happen at the commitment hearing. An assigned lawyer finally consulted with me less than an hour before my commitment hearing and at the hearing I was committed to treatment for 6 months. I kept begging to be released so I could get back to work, because I was afraid I would lose my job, but the social worker and psychiatrist said that I “just needed to get better” and ‘stable’.

I had awful reactions to the psychiatric medications, but the social worker and psychiatrist told me that my complaining about the medications’ negative effects was ‘perseveration’, a symptom of my ‘disease’. On one occasion, I was pinned down and force injected with Haldol because I had become panicked by my extreme dizziness and faintness after taking an increased dosage of Zoloft and was persistent in begging for help.

As part of my commitment, I was force medicated with Zyprexa at an extra high, off-label dose without tapering (20mg - 30mg/day), given in combination with Risperdal and Zoloft. The poly-drugging was torture – I had extreme tachycardia, unstable blood pressure, excruciating radiating arm and leg pain, hallucinations, and vertigo; I fell twice on my head without breaking my fall and had a black eye and swelling in my face.

I was finally released from this hospital so tranquilized I could barely talk, but I didn’t complain or have panic attacks and thus was deemed ‘stable’. During my involuntary stay there, my mental health insurance coverage was capped, and I now owe more than \$35,000 for this psychiatric hospitalization. A year later, when I viewed my medical records from this hospital, I was shocked by my differential diagnosis of Major Depression with Psychotic Features (on intake), then Bipolar with Psychotic Features vs. Schizoaffective Disorder, with Depression (the latter was my diagnosis on discharge). I was also shocked by many false claims by the staff and my mental healthcare team– for example, it was noted that I heard voices (I didn’t) but that I denied it when asked. Upon release from this hospital the social worker arranged to have me stay involuntarily at a Community Treatment Program (CTP) center, because I now had a history of non-compliance with medications. On discharge from the hospital I was told by the psychiatrist that I would need to take Zyprexa at a high dose for the rest of my life because my brain was ‘diseased’. No one told me my diagnosis. I kept complaining that I needed to get back to work, but the social worker would only nod at me and then say “We need to get you better”. Again, the assumption was that I was mentally ill and thus needed strong drugs to fix my brain, rather than that getting back to work would have done much to help me feel better. I was released from CTP when the staff decided I was well-enough to go home and admitted they didn’t know why I had been sent there, because I was highly functional and able to hold a coherent conversation. They were also shocked to learn that I owned a home and a car. The CTP was for homeless persons who had severe mental illness and needed a place to transition after they got out of the hospital

“Adverse Results” of DSM Diagnoses: I Lose Everything

I finally went home, but because of the tranquilizing and mind-numbing effects of the very high off-label dosage of Zyprexa, I found it difficult to go back to work at my job as a multimedia designer. Under the supervision of my GP, I weaned off the Zyprexa to a lower dose over a period of several weeks. Then I started taking Lamictal (a ‘mood stabilizer’) which my GP said was less tranquilizing than the Zyprexa and would help ‘level out my moods’ as I continued to take the Zoloft. While I tapered off the Zyprexa I started having severe headaches and became restless; my mind raced, and I began to have panic attacks again even as I started taking the Lamictal. Then I started to lose track of time, and when I took my medications. I had difficulty sleeping at night and found it hard to get out of bed to go to work and get to my doctor’s appointments. I almost crashed into another car while driving to work one day. The room would spin while I lay in bed or if I got up too quickly. It turned out that I was never able to get back to work and function. As a result, in March I was given termination notice from my job of 15 years at the library. The same week, my partner decided he had ‘had enough’ and wanted to move out and sell our house.

I collapsed at home and got worse and eventually couldn’t get out of bed. I again had feelings that I was dying of a heart attack or a stroke. My headaches were so severe I thought that I had cracked my skull from the falls in the hospital. I had “brain-zaps” (the feeling that something like lightning bolts shot through my head) and vertigo. As a result, I became trapped in my house. I couldn’t even go to the grocery store to buy food. My partner eventually called the social worker from the CTP, who arrived at our house with a police officer and an ambulance and said I needed to go to the hospital because I couldn’t take care of myself and wasn’t compliant with my treatment. The police officer was very brusque and threatened to hand-cuff me if I wouldn’t go voluntarily. Even though I had never threatened anyone and was not threatening self-harm, he made me spread my legs and frisked me outside my house in front of all the neighbors before I was loaded in the ambulance. Again, I was horribly treated, because I had been labeled mentally ill.

In retrospect, my symptoms of ‘relapse’ were actually very likely the adverse withdrawal effects from the Zyprexa while experiencing new side effects to the Lamictal. But my GP and LCSW, and the CTP Social Worker all told me that this was my ‘disease’ relapsing.

I was admitted to the University Psychiatric Hospital. This is a hospital for the criminally insane. The psychiatrists never even considered that I could be experiencing drug withdrawal symptoms. It was, I believe, easy for them to avoid considering this possibility, because the *DSM* labeling, and the general lack of knowledge that such labels are not scientific, increased the likelihood that any difficulties I had were due to the “mental illness.” I wasn’t forced to take medications, but I was told in a nice way that I could leave sooner if I was compliant. I was prescribed Zoloft and Lamictal and then Abilify – none of these drugs seem to do much to improve my symptoms. I continued to feel unsettled and confused; my thoughts raced and I was consumed with fear of losing my house and all my belongings. By this time I was essentially a complete mental and physical wreck. I couldn’t even brush my hair.

On intake, I told the hospital billing officer that my insurance would not cover me, because I was losing my job and insurance, and my mental health coverage had been capped. But I was admitted anyway. I was kept for 10 days before being released because I seemed ‘stable,’ but my *DSM* labeling was not removed. On discharge day, the staff told me they were sorry I had lost everything, and they dutifully gave me pamphlets on homeless shelters and trade schools. I now owe more than \$29,000 for this hospital stay.

After I got home, my partner had a court order served to have me evicted from our house, so he could sell it. My family moved some of my belongings into storage; much was thrown away. I was moved out of state to live with my father. I saw a psychiatrist who I asked to review my medical records and help me sort out what happened as well as manage my post-psychiatric-drug side-effects. He asked me if any of the mental healthcare providers I saw had ever told me to just ‘take a vacation’ and catch up on my sleep. (I said ‘No – the focus was on taking medications.’)

Had I known that *DSM* labels were not scientifically based and do not improve outcome, I do not believe that I would have been so forthcoming and sought help from mental health professionals in particular, and thus left myself open to being classified as mentally ill, with all of the subsequent harm that came to me.

The Harm I Suffered:

My psychiatric labeling experience has negatively affected my entire life.

Financial Harm

I owe more than \$65,000 for psychiatric treatment that I did not want and that did not help and that has also left me with long-lasting adverse physical and mental ‘side-effects’.

My auto insurance premium has more than doubled since my insurance agent was notified of my hospitalization. Right now I am paying a COBRA premium of \$550 per month for health insurance via my former employer, but that extended benefit runs out soon and I will be without healthcare insurance.

On September 20, 2012, I learned that one of the hospitals where I was held involuntarily has rejected my application for charity assistance and has sent my debt to a collection agency that is now threatening me with legal action. Though I am unemployed, have very little money left in savings, my only assets are my 5-year old-car, a few thousand left in savings; and a very small amount in retirement savings, the hospitals say I can afford to pay the \$65,000 they are billing me. So I am unfortunately left with no other option but to file for bankruptcy.

I haven't been able to write a resume or put together a portfolio to begin looking for work, because I haven't been well enough physically or mentally. And I look terrible. Because I am not actively seeking employment, I haven't been able to collect unemployment from my former employer.

Nonfinancial Harm

I moved from the state where I had lived for the almost 40 years and I am now living in another state with a family member under daily threats of expulsion or forced re-hospitalization. I have lost everything that I had worked so hard for all my life.

As of September 2012, I am now unemployed after being always employed since the age of 18. I lost my partner of 20 years, my house, my career, and my ties with colleagues, most of my friends as well as family. I lost my health and attractively-healthy appearance. I used to be lean and fit but now I have pre-diabetes symptoms, have 30 lbs. of extra abdominal weight that I can't lose even with diet and exercise. My once thick and long hair is now gray and thin and short, my skin is dry and cracked and wrinkled, and my eyes are sunken. I am told I have a 'zombie stare,' and I lost the radiant smile people said I used to have. I used to be an artist but the creative spark I had has been dulled.

I can't remember things; I have trouble constructing a sentence. [Note: this story has taken me months to write.]

Since my psychiatric experience, I am now viewed as 'the mental patient' by family and former friends as well as healthcare providers, even though I am psychiatric drug- and psychiatry-free. Old friends and colleagues no longer answer emails or return phone calls, and in the rare exchanges I have with them I am always asked if I am "taking medications". My family members have many times threatened to call the police to 'take me away' if I argue or disagree with them, because in their words: "We thought you were doing better, but you have relapsed".

When I see a healthcare provider, anything I say about myself or my experience with psychiatry is open to doubt or discounted entirely, since I am a 'mental patient'. I am always asked if I am taking 'meds,' and when I say "No," they ask "Really?" as if they are incredulous that I could be sitting in front of them talking coherently without being medicated. And even though I have no mental or physical complaints other than being depressed about losing my once rich life and that I am anxious because of my medical debt and my future I am ALWAYS asked if I would like medication and when I say "NO!" they ask "Are you sure?" I live in fear that I will be involuntarily hospitalized and force-medicated for being 'non-compliant'.

My driver's license and auto insurance were canceled after I had been hospitalized, and I had to get a doctor's letter to reinstate them.

Most of my clothes, books, computer files, photos, prints, furniture, and other belongings are in storage in another state. In the chaotic move and the fast sale of my house, many of my belongings were 'lost in the shuffle' because my family threw things away.

My mind is finally starting to come back, but it's taken more than a year.

Because of my age and the stigma of a permanent psychiatric diagnosis, I face significant challenges in finding a job and recovering my economic self-sufficiency.

I have lost so much I don't know where to start to get back on my feet – my ground floor was swept out from under me.

What Has Helped

I have found some things that have helped me that do not involve calling me mentally ill and the kinds of "treatments" that are usually prescribed when one gets a psychiatric diagnosis:

- I found safe and non-pathologizing ways to improve my energy. From my own research and the helpful advice from some individuals and groups, I have used exercise, diet, extra-nutrition and supplements (adding more protein and calcium and vitamin D3 plus omega-3s)
- My new ObGyn referred me to a psychiatrist for short-term therapy to help me sort out my experience and provide advice on healing from the psychiatric drugs. This psychiatrist was also able to receive my medical records from my involuntary hospital stays and allowed me to review them.
- I had tele-counseling sessions with a psychologist whom I found via the International Society for Ethical Psychology and Psychiatry (ISEPP) web site. This psychologist was very kind and generous with his time and counseled me (without charge). He validated that I was mistreated and had not been mentally ill, and he gave me advice on how to heal. He directed to me resources that describe the common adverse effects of psychiatric drugs, many of which I had experienced, but which none of my healthcare providers had recognized. He helped me identify the sources of my distress – the lifestyle, family history, and environmental causes as well as my feelings of low of self-worth that drove me to ignore my physical and emotional needs. He also recommended nutrition, and exercise, meditation, yoga, and talk therapy (without the use of psychiatric medications) as part of a program of 'holistic self-care' to help me heal emotionally and physically from the trauma of my psychiatric experience.
- I found online psychiatric survivor support groups on Facebook most helpful –where group members shared experience, knowledge and advice. I am working with a county legal aid organization to help me reapply for charity assistance, a settlement or bankruptcy in order to resolve my huge medical debt. (This is TBD)
- TWO BIGGEST SUPPORTS: a good friend (SM) who has not abandoned me and who listens without judgment and is always there when I need him and my dog, D.