Stories of Recovery

My Journey Back To Sanity



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Story

She had gone to the best doctors about her symptoms, yet for years no one had recognized the signs of her illness. The story of one woman's triumphant struggle with manic depression.

I had been married for two months when my husband committed me, his 27-year-old bride, to a locked psychiatric ward. In the 12 years since I was diagnosed as manic-depressive, I have never fully thanked or forgiven him. And I've never forgotten how frightened I was as I watched the man I love cast me off behind closed doors. Yet despite my

fear and humiliation, I was relieved to think that at last someone might be able to help me. Being involuntarily committed was the defining moment of my life.

Back then, in 1982, I didn't know that manic depression, also called bipolar disorder, is due to a chemical imbalance in the brain that can cause an individual to swing from states of manic excitement and energy to periods of overwhelming anguish and despair. I had no idea that this disorder affects more than three million Americans, that it can cause physical as well as mental symptoms or that it can be life threatening if left untreated.

Looking back, it's a miracle that I survived long enough to get the help I needed. As a little girl, growing up in a loving and large extended Italian family in Chicago, I felt an emptiness, a sadness, I could never explain. The nuns at school didn't know what to make of me. I was either withdrawn or vivacious and I always had mysterious physical problems, such as unstoppable nosebleeds and blinding migraine headaches. I'd vomit. I'd have to lie in darkened rooms. If there was an ounce of light, I couldn't move.

When I was 14 years old, my doctors began to suspect I had a "female" problem, because I'd stopped menstruating. There weren't any noninvasive diagnostic tests like CAT scans then, so I had one exploratory surgery after another.

During my teens, I saw every type of physician except a psychiatrist. I was told I had neurological problems, endocrine problems, a blood disease, a brain tumor. I became a regular at the hospital's teen unit. I looked forward to Friday nights there because they served surf and turf - lobster and steak - for dinner. After every operation, my parents and I would feel such relief: It wasn't an ovarian cyst that was causing my menstrual problems, it wasn't a tumor causing my headaches. But recovery took weeks, even months.

I remember thinking that the desolation would never end, that I wouldn't live to be older than 40, that the doctors eventually would find something terribly wrong with me. And I felt that somehow it had to be my fault. I kept wondering, "What did I do to cause all this?"

As an only child, I didn't want to scare my parents with such thoughts. Anything that went wrong with me frightened them, because they loved me so much. My friends couldn't understand either. They were thinking about what they were going to wear on Saturday nights, where they were going to go on dates. So I eventually became more and more withdrawn.

By the time I graduated from high school, my parents had become so protective that they were treating me like a Dresden-china doll. I'd been dating a boy who was a few years older. We got married shortly before my 19th birthday. He knew I'd been sick a lot, but neither of us really understood what was wrong. I thought marriage might be an escape from all I'd been through, but it wasn't. We split up after a year and a half.

I continued to have headaches and menstrual problems, but at least I wasn't having operation after operation. I went to court-reporting school, specializing in aviation law. When I was 23 years old, I opened my own court-reporting business, which became very successful. On the surface, everything seemed wonderful. I lived in a beautiful high rise in Chicago. I vacationed anywhere I wanted. I got to "party hearty," something I'd never done before.

What I didn't realize was that I was becoming manic. I started spending money outrageously. I hardly slept - a classic symptom of mania - but that suited me fine. I'd type up notes from depositions until 2 or 4 A.M., sleep a few hours and be back at work by 8:30 A.M. I was radiating energy. Despite migraines and menstrual problems, I felt better than I ever had before.

But as I later discovered, mania makes you reckless and self-destructive. I overdrew my checking account, not realizing how deep into debt I was getting. I began to spend the corporate payroll. It was okay, I would tell myself, because tomorrow there would be more money. Not even Joanne, my business partner, knew. Yet despite how

seemingly fabulous my life was, how invincible I felt, I realized something was not right.

I was dating an attorney, Dan Meenan. He couldn't understand why no one had ever found a reason for my medical problems. In 1981, the year before I ended up in the psych unit, I had \$32,000 worth of diagnostic tests, because I was still having the same problems: migraines, menstrual troubles, difficulty sleeping. When the tests didn't show anything wrong, the doctors suggested I must be working too hard and needed a good vacation.

On January 1, 1982, Dan and I decided to get married. The following week I saw a neurologist for my migraines. He gave me methadone and Elavil, a mood-elevating drug no patient with mania should ever take. It pushed me over the edge. I became psychotic and started hallucinating. I called Joanne and said, "I'm in the shower, and there are bugs everywhere. They're crawling up and down the ceiling." She called my parents, and when they arrived, I was nude, freezing cold, saying over and over, "Don't you see the cockroaches?" My father gave me red wine and bread to help me throw up, until the drugs were out of my system. At that point, I'd had it with doctors. I refused to see another one.

Over the next five months, the mania kept building, feeding on itself. I spent tens of thousands of dollars on clothes. If I saw a sweater I liked, I'd buy it in nine different colors. I flew from Chicago to Los Angeles and back to see friends a couple of times a week. I stopped eating. My wedding dress had to be sewn on my body because by June 5, the day of my wedding, I'd lost so much weight you could practically see through me.

I was getting concerned, and so were my parents and Dan. But at the same time, we were caught up in the momentum of the wedding. When Dan and I got back from our honeymoon, I left for a convention in New Orleans, where I did stupid, dangerous things like jogging along the river at four o'clock in the morning. I learned later that having no sense of fear can be a part of mania.

Back in Chicago, I started to lose touch with reality. I showed up for a deposition wearing blue jeans, gym shoes, a Cubs T-shirt and no makeup. When the witness mentioned that his house had been bombed, I became paranoid about someone bombing our office. Dan was so alarmed that he called my mother. She came over and stayed up all night with me - just as she'd done when I was a kid and couldn't sleep.

The next day a lawyer friend said, "Everybody's worried about you. Let's go to the hospital and see what's wrong." I said, "Okay, I'll go, but I know the doctors aren't going to find anything."

When I got to Rush-Presbyterian-St. Luke's Medical Center, I was talking 285 words a minute and slurring my speech - typical signs of mania. The psychiatrist who interviewed me knew, just from the way I was talking and acting, what was wrong. He told me, Dan and my parents that I had a classic case of manic depression and that I should be treated with antipsychotic medication and lithium (a mood-stabilizing drug). Before I knew it, I was being escorted to the hospital's locked psychiatric unit. I freaked out. I said to Dan, "If you leave me here, it's over. We'll never have a marriage." He said, "Susan, I'm not taking you home." I handed him my wedding band.

My parents were devastated because they had no say about my being locked up. They wanted to take me home, but as my husband, Dan was in charge. I was so angry and so frightened. I remember sitting at the foot of my bed, wondering whether I would ever recover the full faculties of my mind.

I refused to take medication. I'd had so many wrong diagnoses; I wanted to know what made them think they were right this time. Finally the head nurse in the psych unit called me into his office and said, "You're doing yourself a disservice. They've come up with the answer for what's been wrong with you for years." He talked to me about manic depression for three-and-a-half hours and gave me material to read. I thought, "This is it. This is truly it." The symptoms - euphoria, racing thoughts, sleeplessness, grandiose ideas - described exactly what I'd been going

through. For me, mania was the primary problem, though for many others it can be depression. Once I accepted the diagnosis, I felt a sense of hope. I knew it would change things: that my marriage could end, that I might lose my business, but though all of this was scary, I couldn't help smiling to myself. We'd hit it at last.

Two days after I started taking the medication, I got my period - after three years without one - and I haven't missed a period since. I also haven't had a migraine headache. Most people don't realize that mental illnesses can cause physical symptoms. But as I learned, the abnormalities in my brain chemistry may have been causing my headaches and menstrual irregularities all along.

I was hospitalized for 28 days, and it was demeaning, degrading, worse than all the things I'd been through, to have your rights taken away. To receive flowers from your friends and have them put in a paper carton because you're not allowed to have glass on a psych unit. To be threatened with being put in a "quiet room" in restraints. I don't think I'll ever get over that. It's one of the reasons I work so hard to stay well.

The hardest thing for my family was learning that manic depression can be hereditary. In my case the genetic predisposition comes from my mother's family, though it had not been recognized. My mother has felt a lot of pain and guilt, which I've tried to ease.

While I was hospitalized, Joanne went through the books of our court-reporting business. They were a disaster. I didn't think I'd ever be able to face the staff again. But as I got better, my psychiatrist decided I had to do it. He said, "I want you to face your staff while we're here to support you."

Dan brought me a suit, panty hose, a purse, my makeup - all the things that had been taken away from me when I was admitted. I couldn't stop crying. Finally I took the cab fare the hospital gave me - seven dollars, just enough to get to my office and back. I had the cabdriver let me off a block away. I started to cry again. I thought, "How am I going to

face them?" I walked into the office, and it wasn't easy. People were understandably angry because I had put their jobs, the whole business, in jeopardy. I'll relive that day in my mind a million times.

After my discharge, a lawyer advised me to file for bankruptcy and start the business under a new name. I said, "I am going to pay back every cent, no matter how long it takes." Within three years, I'd paid every bill. The firm is still in business, although I've sold my interest and stopped court reporting.

By the time I left the hospital, I was really angry. I'd been cheated out of so many years. I'd had classic symptoms of manic depression, yet the best doctors in Chicago had focused only on my physical problems. I found out about what is now the National Depressive and Manic-Depressive Association (DMDA), at the time just a local support group, and two days after I got out of the hospital I went to a meeting. Each sentence I started, someone in the group could finish. It felt wonderful to be among people who understood what I'd been through.

I'll be 39 years old next month, and I know I am going to have to take care of this illness for the rest of my life. Every day I take a total of 16 pills, including some for asthma. In 12 years I have never missed a dose. These drugs are not mind altering but mood altering. I keep a mood chart so my doctor and I can spot changes that may require an adjustment in treatment. I truly believe my illness is controlled day by day, dose by dose.

Psychotherapy has helped me tremendously, but had the therapy preceded the medication, I'd have been on the couch for the rest of my life. It wasn't until I was on medication that I could start dealing with the emotional issues.

Therapy helped me pick up the pieces of my marriage. Dan and I had four years of marriage counseling. We went over some real rocky road. I compare what happened to my being trapped in a burning building, with Dan as the firefighter who rescued me. I would have died if he hadn't thrown me out the window, but I got burned by the flames, and there was a lot of scarring. At times I still get angry at Dan for locking me up. But there's a real bond between us. I would be lying if I said I have 365 good days a year. I don't. When I'm going through a particularly bad time, the pain feels interminable. And I know that the ultimate threat with manic depression is suicide.

More than 15 percent of those who are seriously depressed and do not receive adequate treatment take their own life. What helps me most to get through the dark days is the support of the DMDA and my work as a mental-health advocate.

I didn't set out to become an advocate. But ever since I first spoke publicly about my diagnosis, I've been asked to address mental-health groups and to talk at different hospitals.

During my own recovery, I learned how important and effective self-help groups are for people coping with mental illness. The DMDA, which became a national organization in 1986, now has 275 chapters. I became its first executive director in 1989. We are the only organization in health care run by patients.

My life today is made up of a lot of travel, a lot of speechmaking and a lot of fund-raising for research; of working with Congress, the media and advocacy groups around the world. It's very fulfilling. I've worked with wonderful people, like Tipper Gore, who has been a staunch mental-health advocate for years. Last year the American Psychiatric Association presented me with a public-service award in recognition of my contributions to the cause of the mentally ill. That was very gratifying. But what matters most to me are the people I've helped get treatment. It's wonderful to see how well they're doing.

The journey back to sanity and health isn't an easy one. I know. But in all my years of struggling with manic depression and being involved in the National DMDA, I have never felt so hopeful. The shame that once went with mental illness no longer exists. And I firmly believe that in my lifetime more effective treatments will be developed.

Those of us leading the fight in public for more research, more recognition and more acceptance are not going to give up. A lot of days we wake up smiling. We know there's going to be a brighter tomorrow - for us and millions of others.

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Warning Signs To Watch For

Manic-depressive disorder is characterized by mood swings that can include episodes of depression and mania lasting for days, weeks or even months. It is one of the most treatable psychiatric illnesses. If you suspect you suffer from this disease, consult a doctor for a complete medical evaluation and possible referral to a specialist.

Symptoms of depression include: sadness or tearfulness; lost of interest or pleasure in once enjoyable activities, inlcuding sex; trouble sleeping; a sense of helplessness, hopelessness or inadequacy; difficulty thinking clearly; persistent thoughts of death or suicide; physical symptoms, such as headaches, fatigue aches and pains.

Symptoms of manic include: feelings of unusual excitement, energy or irritability; a sense of supreme self-confidence and inflated ability; grandiose thoughts and plains; decreased need for sleep; talking more rapidly than usual; racing thoughts, jumping from one idea to another; reckless behaviour, such as buying sprees, sexual indiscretions or foolish business investments, that could lead to painful consequences.

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Resources

- For more information about manic depression and a listing of support groups near you, call the National Depressive and Manic-Depressive Association at 800-82-NDMDA.
- In addition, the American Psychiatric Association (APA) offers a free pamphlet on manic depression. Just send a self-addressed, stamped business-size envelope to: APA, Dept. MC 94, Division of Public Affairs, 1400 K St. NW, Washington, DC 20005.

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