Bipolar Disorder: Stories of Coping and Courage





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Depression and Bipolar Support Alliance (DBSA) Previously National Depressive and Manic-Depressive Association We've been there. We can help.

Bipolar Disorder: Stories of Coping and Courage

his booklet is about real people. They have decided to share their stories to help others understand how it feels to have a mood disorder; what treatment, relationship, and work issues arise; and what really works in coping. They are helping all of us fight the social stigma that prevents so many people from seeking help, and they are giving us hope that recovery is possible, no matter what the circumstances.

While each person has a unique story, the stories share common themes, including:

- Determination: They continue seeking the best treatment possible and are dedicated to improving their lives;
- Commitment: They stick with their treatment plans, despite setbacks or relapses;
- Support: They seek help from multiple sources, including doctors, talk therapists, family, friends and support groups;
- Hope: They believe that they will get better over time.

If you have depression or bipolar disorder, also known as manic depression, it does not mean you are weak, flawed, or alone. These physical illnesses affect more than 22 million people. With the right treatment, symptoms can be managed and do not have to interfere with your life. Seeking treatment does not mean you have failed in any way, it means you have the strength, courage and sense to look for a way to feel better.

The stories in this brochure are about people at different stages of wellness. Sometimes it takes some time to receive a correct diagnosis, or to find the right treatment. Some have to try more than one method or wait awhile for treatment to become effective. Although it may be difficult, it's important not to give up hope. If you or someone you care about is coping with bipolar disorder or depression, keep searching to find the right treatment and look for support from others who understand.

For more information about bipolar disorder, see the appendix on page 13.

I felt like I would be giving in. Missy, age 42, husband Bill and daughter Katherine

A Ithough Missy struggled with bouts of depression since childhood, she refused to take medication. "Therapists recommended that I take medication, but I always resisted. I felt like I would be giving



in. I didn't need medication, and I could do it on my own." Missy finally sought treatment in order to be well for her daughter. At first the prescribed antidepressant helped, but then Missy became manic and was hospitalized. She continued to suffer for years, until she received a correct diagnosis of bipolar disorder and got the treatment she needed.

What works

The turning point was when my doctor changed my diagnosis to bipolar disorder and prescribed a mood stabilizer with an antipsychotic medication. The combination of the new medications, along with the joint counseling for Bill and me, and support from our church and family, is what works for me.

To help their family, Bill learned as much as he could about bipolar disorder. Though Bill and Missy drifted apart due to stress for awhile, they are now re-united and better than ever. Missy continues to work with her doctor to fine-tune her treatment plan and is doing well. I was hospitalized several times after stopping the medication and I hated being in the hospital.

Zack, age 19, and mother Nancy

ess than a year ago, Zack had his first major manic episode while away at college. After using some recreational



drugs with his friends, he felt a sudden change come over him that persisted even after the effects of the drugs wore off. "The next day, I thought that I was enlightened and knew the meaning of life, like I was a Buddha or Gandhi," he recalls. "I felt invincible, like I was on top of the world and could do anything. I even thought I had psychic powers, like ESP. I didn't sleep because I felt like it was a waste of time. I stayed up all night writing poetry. I talked nonstop even though I'm usually quiet. I spent a thousand dollars on CDs, clothes, and food for my friends." When Zack came home, his mother, Nancy, realized that Zack was manic because her daughter also suffers from bipolar disorder. She immediately got him to the hospital.

What works

Things are good when I stay on my medication. At first I wouldn't – I was afraid it would change my personality and I didn't want to accept that I had an illness. Then I was hospitalized several times after stopping the medication and I hated being in the hospital. I also lost two girlfriends that I really cared about because of things I said when I was manic, so I need the medication.

Nancy has helped manage Zack's hospitalizations, consulted with doctors, and overseen his prescriptions. She has also found support by joining the parent-run Child and Adolescent Bipolar Foundation. Zack's friends accepted his condition after he talked to them openly about having bipolar disorder and they saw him go through his hospitalizations. Now they are protective of him and help him stay away from drugs. He is stabilized on medication, feeling well, and looking forward to

4 returning to school in the fall.

I couldn't imagine living past a certain age.

Siu Wai, age 44, and husband Rich

Siu Wai was adopted from a Hong Kong orphanage when she was two years old. She had been so neglected in the orphanage that



her growth was stunted and she couldn't walk. She believes that this trauma contributed to her depression. "When I was a child, I got a diary for Christmas," says Siu Wai. "I wrote on the last page, 'I died of pneumonia,' because I couldn't imagine living past a certain age."

After a difficult pregnancy and the birth of her second child, Siu Wai's depression worsened. "When my daughter cried in the crib, it tore me apart because it reminded me of myself as an orphan baby girl," explains Siu Wai. "I was so upset that I started hitting my head against the wall." Five years after that, Siu Wai became intensely suicidal and had to be hospitalized. It was at that time she received a correct diagnosis of bipolar disorder.

What works

I have to stay on my medications. My doctor and I are working together to adjust them, to reduce side effects and control my depression. But I realize that this is part of the process. Rich provides stability. He manages the finances and the house, and can take over caring for the kids when needed. I have regular contact with my friends, belong to a supportive church, and attend a structured therapy group.

Now that Siu Wai receives the right treatment, her moods are more stable. She enjoys being a mother, playing the piano and using her new computer. When Siu Wai feels depressed, Rich supports her by reminding her of her positive traits and her children's love for her. "Siu Wai carries this darkness with her," says Rich, "but she has an equal desire for life. She is a caring mother and our children really open up to her."

I will use any method I can to give people hope.

John, age 67

A fter his initial diagnosis of manic depression in 1979, John threw away his medications and denied there was anything wrong. He later had a manic episode on a business trip. "I was on an airplane," he recalls, "and I thought I could fly it. Later, I ended up locking myself in my hotel room. When I got home, still manic, my family wanted me to sign myself into a hospital. I spent three days in that hospital's quiet room and I did a lot of praying. I said, if I ever get out of here, I'll do anything I can to help other people who have this illness."

John realized he needed to be around people who understood his illness and joined the Chicago chapter of the Depression and Bipolar Support Alliance (DBSA—previously National DMDA), which was then in its infancy. John and his wife worked together to make the groups more inclusive of families and get more groups started.

What works

Being with people who understand what it's like to have this illness and sharing my experience with others have been extremely helpful. In 1981, some of the first support groups for people with depression and manic depression were beginning to form in Chicago. I called them and they told me to show up at a restaurant several towns away. I thought, who are these people – what are they trying to do? But I didn't have a choice. I drove 45 miles to the restaurant to see them. That's where I met the people who changed my life.

Early in his recovery, John began speaking about his experiences, and he continues to do so today. His goal is to inspire people and make them believe they can get better. John speaks to a variety of audiences, including patients, psychology and psychiatry students, social workers and primary care physicians. "I will use any method I can to give people hope," he says. "I tell them my story and I stress that it's just one person's experience. Everyone may not agree or understand, but that's all right with me." The fact that I know mood episodes don't last forever has helped me cope.

Jane, age 51

ane first experienced depression as a freshman in college. "I became extremely depressed,



my grades dropped, and I left school for a year," she remembers. At age 26, after graduating from medical school, Jane had another severe depressive episode that lasted a year. "I was suicidal and started driving around, looking for a gun shop. That's when I decided to get help," says Jane. She was diagnosed with major depression and went into psychotherapy. Still, she did not receive proper treatment. Instead, her therapy was focused on "fixing" her sexual orientation.

Jane went on to become a psychiatrist, treating patients with eating disorders. While still undergoing psychotherapy herself, she stayed up one night, obsessed with thoughts of how she could restructure psychiatric theory. She realized something was wrong and told her psychiatrist about her symptoms. It was then that she was diagnosed with bipolar disorder and medication was added to her treatment plan.

What works

The fact that I am a psychiatrist and know that mood episodes don't last forever has helped me cope. I know that there are always new treatments coming out that may improve my condition. I realize it takes time to get well, and as long as there is something that I can try, I can hang onto hope.

In the last two years, Jane has developed a deep sense of spirituality. "I came to accept the Serenity Prayer, to let God grant me the serenity to accept the things I cannot change," she explains. "My partner, Eileen, has also helped me, just by being there. Her support makes me feel like I am not a burden or a failure."

"My opponent tried to use my illness to discredit me."

Lynn Rivers, age 45

ynn Rivers is a 4th term United States Representative for Michigan's 13th district. In 1995, one year after she was first elected, Rivers was the



first member of the U.S. Congress to talk openly about having bipolar disorder. "I had made a promise to myself during the campaign that I would speak out," says Rivers. "Then, my opponent tried to use my illness to discredit me. So, I gave a speech about my experience at a fundraiser." Encouraged by the crowd's positive response, she went on to tell her story to the press. Today she continues to give talks to audiences around the country.

Rivers had her first daughter at age eighteen and soon after began experiencing severe anxiety attacks. Three years later, her anxiety increased and depression followed with the birth of her second daughter. Sensing something was very wrong, Rivers sought the help of a psychiatrist. She was first diagnosed with depression; then her diagnosis was changed to bipolar disorder. Over the next 12 years she worked closely with her psychiatrist to find a combination of medications that stabilized her.

What works

I've managed to reach balance with my medication and have been in good health for ten years. But I had to continue working with my doctor for 12 years to get to this point. I had a number of relapses and each time it was not only heartbreaking to feel I was losing, but also very embarrassing. I had to keep starting over, fighting the same battles. There is a real anger and frustration that goes along with that. Psychotherapy has also been a great help. I've learned how to function as a healthy person and had a chance to talk through my feelings. My family and community have been very supportive and we talk openly about my condition.

"I've been episode-free for more than 20 years."

Rich, age 59

ich suffered his worst major depressive episode in 1979, followed by a manic episode in 1980. It took him a while to get the proper treatment, even in New York City. Rich recognized that he could benefit from the support of others who were living with mood disorders and he knew there were others who needed help. So he, his wife and a small group of others started the Mood Disorders Support Group (MDSG), an affiliate of DBSA, in 1981. The group has grown to include a lecture series, newsletter and website (www.mdsg.org) and now serves approximately 10,000 people per year at three sites in New York City.

What works

I am one of the fortunate ones who has responded extremely well to treatment and I've been episode-free for more than 20 years. I owe my recovery to four factors: excellent treatment with my psychopharmacologist; a wonderful supportive wife; dedicated work with a good psychologist; and my work with MDSG. Despite the absence of episodes and symptoms, my road to recovery has still been long and difficult. *My greatest challenges have included guilt, self-stigma,* and a tendency to spend too much energy looking for symptoms.

My involvement with a DBSA support group has given me a lot of confidence in my executive and leadership skills. After my initial bout with mania and a long reactive depression, I worried that I would lose these skills, but I use them now more than ever. Today I have everything I need including a loving family, an interesting job, sufficient income, plus the enormous satisfaction of helping others manage their illness in a way that we could only have dreamed of in 1981.

"I can track my moods and look back to see how I'm making progress." Sharon, age 42, and fiancé Calvin

G rowing up, Sharon had constant tantrums and cried for no apparent reason. "There were times when I would break every glass in



the house," says Sharon. "I would get angry, destroy things, then go to sleep and feel peaceful." Her tantrums continued as an adult, she quit jobs constantly, and her relationships never lasted longer than six months. Gradually, Sharon realized she needed help.

When she was 25, Sharon sought treatment from a doctor. But her family discouraged her, telling her pills were bad, doctors were quacks, and faith would help her get over her problems. Sharon stopped the medication and tried to control her moods by herself.

At age 38, Sharon vowed she would get help. She had to try several doctors before she found one who could give her the treatment she needed. She meets with him regularly to monitor her treatment plan.

What works

Calvin, my fiancé, really helps me. He takes the lead on finding and reading information about bipolar disorder. Everyday he asks me, "Did you take your medicine?" When I'm not feeling well, Calvin takes over household duties. We both try to talk about how we feel so we don't bottle up resentment. My doctor is also a godsend. He works with me to improve my treatment. He suggested that I keep a diary, so I can track my moods and look back to see how I'm making progress.

Today Sharon is very satisfied with her treatment. Although she still has some bad days, she feels that she is better than ever and on her way to recovery. "Writing has helped bring me back to sanity." John McManamy, age 53

ope was the last thing on John McManamy's mind in January 1999 when his family brought him to the local emergency room for suicidal depression. He was diagnosed with bipolar disorder, an illness he had long suspected but denied that he had. One of the first things he did once he was able to crawl out from under the covers was get to the computer to educate himself. Soon after, he began writing articles about bipolar disorder treatment and his own experience. Eventually he started a website devoted to educating people about bipolar disorder (www.mcmanweb.com) and an e-mail newsletter, *McMan's Depression and Bipolar Weekly.* By sharing his experience and knowledge, he was able to help himself and countless others.

"I remember one mixed manic episode," says John, "that left me jobless and nearly penniless in a far away country, and the depression that landed me in the emergency room. I know what's at stake should this illness try to reassert itself. I'm in complete awe of the destructive power of this perfect mental storm. Maybe that's why I'm still here."

What works

Staying informed has given me the tools to actively manage my illness. In addition to sticking with my medications and treatment plan, I also jog, do yoga, meditate and regularly attend my Wednesday support group meetings.

Writing is another thing that helped bring me back to sanity. For me, it is a healing activity. When my writing takes full flight, there is no time and space. The sun takes its leave, booming music falls mute, and the steaming hot cup of tea by my side is stone cold when I pick it up a minute later. "Support groups have really helped me" Dennis, age 55, and wife Joan

ood disorders can place a huge strain on close relationships. Dennis and Joan have experienced hospitalizations, job losses,



and financial difficulties as a result of mood disorders, but their struggles have brought them closer together. Joan has major depression and Dennis has bipolar disorder. Dennis recalls that during manic episodes, he had more energy than usual, felt very creative and started writing a play, then in the snap of a finger, became psychotic. He felt he had learned all the secrets of the world, but couldn't quite articulate them. He later became depressed and had suicidal thoughts. It took both Dennis and Joan decades to find the treatments that now work for them.

What works

In addition to my medication and Joan, support groups have really helped me. When someone else is talking, I can identify with it, because it resonates with my experience. I don't have to speak, all I have to do is listen and make connections. There is a profound recognition and connection to other people that really drives the group. We all feel like we can finally breathe, relax, and be with other people in way we haven't been able to before.

Dennis is a support group leader for DBSA Boston, where he and Joan first met six years ago. He says that when people first come to a group, their reaction is usually, "I'm home, I've found people that finally understand me." Dennis and Joan were married last year in a poignant celebration that marked newfound stability and wellness. They continue to draw strength from each other and from their support group involvement. Their compassionate understanding of one another's illness, a common Irish Catholic upbringing, and a

12 strong will to recover have united them.

Appendix

What is bipolar disorder?

Bipolar disorder, also known as manic depression, is a treatable medical illness involving extreme changes in mood, thought, energy, and behavior. A person with bipolar disorder has moods that usually alternate between mania, or an extremely "up" mood, and depression, or an extremely "down" mood. These changes or "mood swings" can last for hours, days, weeks, or even months.

Manic episode: A distinct period of elevated, enthusiastic or irritable mood which includes at least three of the following symptoms.

- Increased physical and mental activity and energy
- Exaggerated optimism and self-confidence
- Grandiose thoughts, inflated sense of self-importance
- Excessive irritability
- Aggressive behavior
- Decreased need for sleep without feeling tired
- Racing speech, racing thoughts
- Impulsiveness, poor judgment
- Reckless behavior such as spending sprees, impulsive business decisions, erratic driving and sexual indiscretions
- In severe cases, delusions (believing things others do not – that you have special powers or are receiving messages from something or somewhere) and hallucinations (seeing or hearing things that aren't there)

Hypomanic episode: Similar to a manic episode, except that it is less severe and there are no delusions or hallucinations. It is clearly different from a nondepressed (euthymic) mood with an obvious change in behavior that is unusual or out-of-character.

Major depressive episode: A period of two weeks or more during which at least five of the following symptoms are present.

- Prolonged sadness or unexplained crying spells
- Significant changes in appetite and sleep patterns
- Irritability, anger, agitation

- Anxiety, worry
- Pessimism, indifference
- Loss of energy, persistent exhaustion
- Unexplained aches and pains
- Feelings of guilt, worthlessness and/or hopelessness
- Inability to concentrate; indecisiveness
- Inability to take pleasure in former interests; social withdrawal
- Excessive consumption of alcohol or use of chemical substances
- Recurring thoughts of death or suicide If you or someone you know has thoughts of death or suicide, contact a medical professional, clergy member, loved one or friend *immediately*.

Mixed state (also called mixed mania): A period during which symptoms of a manic and a depressive episode are present at the same time.

What is the difference between bipolar disorder and ordinary mood swings?

The three main things that make bipolar disorder different from ordinary mood swings are:

Intensity: Mood swings that come with bipolar disorder are usually more severe than ordinary mood swings.

Length: A bad mood is usually gone in a few days, but mania or depression can last weeks or months. With the rapid cycling type of bipolar disorder, moods last a short time, but change quickly from one extreme to another and "level" (euthymic) moods do not last long.

Interference with life: The extremes in mood that come with bipolar disorder can cause serious problems. For example, depression can make a person unable to get out of bed or go to work, or mania can cause a person to go for days without sleep.

Resources

Other Organizations That Offer Help

The following organizations also offer information about bipolar disorder, depression and related topics. While you may find additional support from these organizations, DBSA and Families for Depression Awareness assume no responsibility for the content or accuracy of the information they provide.

Help in a Crisis

National Hopeline Network (800) 442-HOPE (800-442-4673) (800) SUICIDE (800-784-2433)

Or, contact your or your family member's doctor or a nearby hospital, or call 911.

Finding a Health Care Professional

You or your family member may need to consult a primary care physician for a referral, or contact your insurance company to see what treatment and doctors are covered. Or you might find a doctor referral at one of the following sites.

American Association for Marriage and Family Therapy (703) 838-9808 • www.aamft.org/therapistlocator/index.htm

Amercian Medical Association www.ama-assn.org/aps/amahg.htm

National Association of Social Workers (NASW) (202) 408-8600 • www.socialworkers.org/register/default.asp

Information About Mood Disorders American Foundation for Suicide Prevention (888) 333-2377 • www.afsp.org

American Psychiatric Association (APA) (888) 357-7924 • www.psych.org

American Psychological Association (800) 374-2721 TDD: (202) 336-6123 • www.helping.apa.org May also offer doctor referrals through state associations.

Child and Adolescent Bipolar Foundation (847) 256-8525 • www.bpkids.org

National Institute of Mental Health (NIMH) (800) 421-4211 • www.nimh.nih.gov

National Mental Health Association (NMHA) (800) 969-6642 • www.nmha.org

Suicide Awareness/Voices of Education (SA/VE) (612) 946-7998 • www.save.org

U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services (CHMS)

(800) 789-2647 TDD: (301) 443-9006 • www.mentalhealth.org

DBSA and Families for Depression Awareness do not endorse or recommend the use of any specific treatment or medication for mood disorders. For advice about specific treatments or medications, individuals should consult their physicians and/or mental health professionals.



118 Waltham Street, Watertown, MA 02472 email: info@familyaware.org (617) 924-9383 www.familyaware.org

Our mission is to raise awareness of depression and reduce stigma surrounding this treatable medical condition.

Families for Depression Awareness is a nonprofit organization helping families, especially family caregivers, recognize and cope with unipolar and bipolar depression in the family. The organization provides education, outreach, and advocacy to support families. Families for Depression Awareness is made up of families who have lost a family member to suicide or have watched a loved one suffer with depression, with little knowledge about how to help.

We offer educational materials and seminars, helpful resources, advocacy support, online profiles of real people with mood disorders and their families, and much more.

Depression and Bipolar Support Alliance (DBSA)

Previously National Depressive and Manic-Depressive Association (National DMDA)

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Our mission is to improve the lives of people living with mood disorders.

Depression and Bipolar Support Alliance (DBSA) is the nation's largest patient-run, illness-specific organization. Incorporated in 1986 and headquartered in Chicago, Illinois, DBSA has a grassroots network of nearly 1,000 support groups. It is guided by a 65-member Scientific Advisory Board comprised of the leading researchers and clinicians in the field of mood disorders.

We offer educational materials, annual conferences, helpful resources, online advocacy tools, research updates, discussion forums, bipolar screening, and much more.

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