

Accepting the DIAGNOSIS

By Donna Jackel

At age 29, Julie Coultas seemed to be at an enviable place in life. She had good friends. She had come out as a lesbian and was comfortable with her sexuality. And she had a fulfilling job that took her to far-off places: She was coordinator of the Toronto-based Stephen Lewis Foundation's Grandmothers to Grandmothers Campaign, which supports African women who care for grandchildren orphaned by the HIV/AIDS epidemic.

That life began to slip away from her in 2007, when she was beset by money and relationship problems. Coultas became suicidal, was hospitalized twice, and treated for depression. But her psychologist knew another side of the young woman—the high-energy, high achiever who could sometimes work at a

furious pace with little sleep. In 2008, the psychologist told Coultas that she believed she had bipolar disorder.

"I was terrified at first," Coultas recalls months later. "I had this dropping feeling in my gut. All the stereotypes I had about [bipolar] came flooding into my head. I have a friend who is bipolar and she has been almost homeless a couple of times, and in and out of hospital. I thought, 'Oh my God—is this what my life is going to be?'"

Coultas, now 31, has accepted her diagnosis. She is stable and feels much better than in the past. She takes her medication daily, maintains a regular sleep schedule, works out, and has improved her eating habits. She still works for the Stephen Lewis Foundation, but is planning to move back to her hometown and work long-distance.



Photo: DAVID KRAMA for bp

“I had talked myself into thinking I had bp-light...”

—JULIE COULTAS

For others, the road to acceptance can be long and circuitous. Peggy Lynn Mullikin, 38, of Burlington, Wisconsin, has experienced highs and lows since her teens. Although Mullikin was diagnosed with bipolar in 2002, acceptance did not come until six years later when she had her first negative work evaluation. Mullikin received a poor rating in several areas; the comment that hurt most was “poor communication skills.” “I have a master’s degree in communications. [The review] was a direct contradiction to what I knew about myself,” Mullikin says. “That’s when I finally had to admit it was the bipolar affecting my work.”

Many factors influence how well a consumer is able to adapt to bipolar. These include the severity of the illness, level of self-awareness, one’s attitude about mental illness, availability of a support system, and access to quality health care. Some consumers are able to accept their illness after one or two manic episodes. Others remain in denial for years, burning through relationships, jobs, and money until they hit rock bottom.

“Bipolar is one of the illnesses people have the hardest time accepting,” says Sagar V. Parikh, MD, deputy psychiatrist-in-chief at the University Health Network in Toronto and professor of psychiatry at the University of Toronto. “Maybe one-third accept [the diagnosis] right away. At least a third totally reject it, and a

third believe it, but when they are better for a while, begin to doubt it again.”

“It’s common for acceptance to take years,” agrees Evette J. Ludman, PhD, a clinical psychologist and researcher at Group Health Cooperative in Seattle and coauthor of *Overcoming Bipolar Disorder: A Comprehensive Workbook for Managing Your Symptoms and Achieving Your Life Goals* (New Harbinger Publications, 2009).

Fully accepting the diagnosis is “almost like joining the priesthood,” Parikh says. “The commitment to treatment is a major one that involves going to the doctor regularly and paying a lot of effort to regulating one’s lifestyle. It’s not just a commitment to medication, but a way of life.”

In his research, Parikh found that consumers with bipolar II have greater difficulty acknowledging the diagnosis than do those with bipolar I, which

is typically characterized by clear-cut episodes of mania and depression.

The symptoms of bipolar II are subtle, he explains, making it difficult to perceive the hypomania as a symptom of the illness, rather than part of one’s identity. “Your highs are mild, your brain is working faster, you have more confidence and energy, you need less sleep—it’s the ideal human condition,” says Parikh. Because the symptoms of bipolar II tend to be sporadic, “it is difficult to conceptualize it as an illness,” he adds.

In his 20 years as a Methodist minister, Ron C. Melzer encountered people with bipolar disorder—there was the female parishioner who had threatened him with a knife, and the wild young man who had stripped off all his clothes.



Photo: LINDSAY A. MILLER for bp

“I told myself, ‘There is no way I’m bipolar.’”

— **RON C. MELZER**

Because Melzer associated the illness with such extreme behavior, he missed his own symptoms when they began in early 2003. He attributed his racing thoughts, restlessness, auditory hallucinations, and crying jags to depression. His behavior resulted in Melzer being placed on disability leave by his denomination; he began seeing a psychiatrist and a therapist and started taking an antidepressant. Eight months later, Melzer was diagnosed with bipolar II and prescribed a mood-stabilizer. He continued to tell himself he was “only” suffering from depression, however.

“I was convinced that if I could tough it out, I’d be fine,” he says. “I told myself, ‘There is no way I’m bipolar.’”

During this period, his marriage of 20 years ended. Looking back, Melzer says it was this denial that prevented him from getting adequate treatment. Despite his skepticism, Melzer began reading about bipolar disorder and keeping a mood chart. By the summer of 2004, he had accepted his diagnosis. “The research indicated that my moods and cycling were pretty consistent with

the disease,” he says.

Since this breakthrough, life has “gotten a lot easier,” Melzer says. He is more open-minded about taking medication. And by continuing to chart his moods, he can predict the ups and downs. “I will have five to seven good days and then I will crash and have about seven to 10 dark days,” he says. “You can almost set your watch by my cycling.”

Meanwhile, a series of changes have enriched Melzer’s life. He moved from St. Louis to Tucson to be near family and friends; medication adjustments have brought him greater wellness, and last January he fell in love and remarried. “When I grieve for how my life used to be, I remind myself that if it was like it used to be, I would never have met her,” he says of his wife.

Because of his rapid-cycling, Melzer, now 52, does not believe he will be able to lead a congregation again. However, he finds great fulfillment helping others as president of the Tucson DBSA (Depression and Bipolar Support Alliance) chapter. “I force myself to go to meetings when I’m not feeling good,” he says, “And when I am feeling good, I need to go so I can share with someone to help them in their time of struggling.”

Indeed, the stigma and discrimination associated with mental illness is a huge barrier in coming to terms with bipolar, consumers and experts agree. It is because there are so many misconceptions and preconceptions about mental illness that Ludman, the Seattle psychologist and researcher, hesitates using phrases like “accepting the diagnosis.” “I’m not very fond of labels,” she explains. “Everyone has their own story of what ‘accepting’ [the illness] means. It may mean ‘I’m crazy,’ or ‘No one loves me.’”

Jo Rivers, an executive assistant for an Atlanta-based optometry association, resisted her 1997 diagnosis for eight years. To her, bipolar disorder meant that she could no longer trust her own mind. “After 36 years of living, I couldn’t think my thoughts were incorrect,” says Rivers, who grew up in poverty in the small hamlet of Jasper, Florida. “I was intelligent and had accomplished a lot,

so I couldn't be crazy."

Rivers told herself that her sleeplessness and psychoses were side effects of her antidepressant. Denial cost her deeply: She lost two jobs, resulting in bankruptcy and the loss of her home. But it was not until she spent a week in a state mental hospital that the reality

of her situation fully hit.

"There was a beautiful woman there who yelled and barked like a dog; there was another girl who urinated on herself," she says. "The people there were crazy, and I was among them, so I was one of them. I told the doctor, 'I'm ready to do whatever I need to do to manage this.'

“Being bipolar forces you...
to be the best you can be...”

—JO RIVERS



Photo: Mikki K. Harris for bp

That's when I accepted the diagnosis."

Rivers, now 48, made good on her promise, learning all she could about bipolar and what she needed to do to stay well. Today, she works full time and has her own apartment. She keeps a mood chart and a journal, exercises, takes her medication, and avoids "toxic" people. Indeed, Rivers is so vigilant about maintaining her down time and getting enough sleep that friends and family know not to call her after 9 p.m. She carefully tracks her spending, keeping to a strict budget and recording all her purchases. "The bipolar diagnosis has been a true blessing," Rivers now will tell you. "Being bipolar forces you to change to be the best you can be ... to live a good life."

The first step following a diagnosis of bipolar—even before medication—should be learning about your illness, says Parikh. "It is the single most effective remedy aiding acceptance. You're not going to follow any treatment plan unless it makes sense to you."

Mental health experts generally agree that accepting the diagnosis makes it easier to follow a treatment plan. Yet disagreement exists as to how to best approach patients who are in denial. Gary S. Sachs, MD, founder and director of the Bipolar Clinic and Research Program at Massachusetts General Hospital and an associate professor of psychiatry at Harvard Medical School, doesn't "push acceptance as a requirement." "Many patients will be willing to accept some form of intervention if I don't require that they accept the label as well," he says.

"Ambivalence about treatment is kind of the norm," agrees Mark S. Bauer, MD, professor of psychiatry at Harvard Medical School, director of the Harvard South Shore Psychiatry Residency Training Program, and a coauthor of

Overcoming Bipolar Disorder. “Studies show that only 20 percent [of consumers] come to treatment fully on board,” he says. Rather than try to convince skeptical patients, Bauer teaches them how to recognize their mood swings, understand how episodes have affected their quality of life, and how to control these patterns. He also helps consumers “develop a detailed plan for living a full life, based on their values and core goals.”

But others believe that accepting the diagnosis is integral to treating the illness effectively. “By accepting what the problem is and informing yourself about

the disease and treatment, you are empowering yourself to control the disease,” says Francis M. Mondimore, MD, assistant professor at Johns Hopkins University School of Medicine’s Department of Psychiatry and Behavioral Sciences and author of *Bipolar Disorder: A Guide for Patients and Families* (The Johns Hopkins University Press, 2006). “My message to people is that we know a lot about how to treat this problem; how to manage the symptoms. You need to know all the options, so you can make an informed health-care decision. Once you’ve named something, you’ve got

some control over it.”

Lise Ewald of Northfield, Vermont, grew up around mental illness. Her father committed suicide when she was 17 and her late sister had schizoaffective disorder. “I was always in fear of being like my sister,” Ewald admits. A librarian at Norwich University in Northfield, and the mother of three teenaged boys, Ewald, 48, had for years been treated sporadically for depression. Then a 2003 car accident—a drunk driver totaled the car she and her family were riding in—heightened her depression. Her family doctor switched her antidepressant and

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Learning that you have bipolar disorder can be difficult, even if it brings relief. Accepting the diagnosis and moving ahead is different for each person. Describe at what point after your diagnosis you were able to accept it and begin the process of living with bp.

Our readers replied:



I was 18. After spending a week in bed, I walked to a psychiatrist’s office where I was diagnosed with bipolar. Walking back to my dorm, I found hope after years of

battling a nameless enemy. I realized that life would change and that depression couldn’t keep me from achieving my goals. I challenged myself—I transferred

to Northwestern University, where I graduated cum laude and cofounded an organization that helps depressed students find friends and psychiatric help. Now I’m looking to publish my how-to book on finishing school while fighting bipolar or depression.

—Jessica Lynn Gimeno, Des Plaines, IL (**bottom left**)

Difficult is a hard word to describe the diagnosis of bipolar disorder. When

diagnosed three years ago, I can honestly say it was far more than difficult. Did it bring relief? Absolutely—it finally brought me the answers about myself I had constantly been looking for. It did not take me long to move forward, [though I was] often embarrassed to discuss it with people and felt that I had a disease rather than a disorder. These feelings passed, however. I am now able to live my life with a sense of worth—almost enlightenment that what had been unexplainable in me can now be explained.

—Robert Gibson, Oshawa, ON

I was diagnosed with bipolar in 1990. However, this just gave me a reason for being “crazy.” It was not a reason to change my lifestyle. Not until 2007—when it got so bad that I couldn’t take care of myself—did I finally accept my bipolar and begin to seriously try to live with and manage it. It took almost losing myself completely before I began to control my bipolar, rather than vice versa.

—Timothy Hebert, Greenwood, WI (**above**)



It was the day I was diagnosed: I was so relieved to have an answer as to why I was doing the things I was doing. I knew it wasn’t “me.” So to find out there was help to become “me” again was a wonderful feeling. Don’t get me wrong; it was scary as hell. But as soon as the doctor said “bipolar,” a wave of relief came over me. I was able to accept it and to start dealing with it immediately.

—Gretchen Gauthier, Pasadena, MD (**left**)



before long Ewald became manic. She left her husband and sons and moved into an apartment. A hospitalization and a diagnosis of bipolar II followed.

"At first, I was just dealing with the ramifications of what I had done, and was kind of in shock—how could I lose sight of my kids and my family?" Then Ewald had to learn to live with a new diagnosis. Instead of the more socially acceptable label of depression, she had a severe, chronic mood disorder. "It was scary and it made me sad," she recalls.

In fact, consumers often "get very caught up in whether symptoms indicate

depression or bipolar," says Mondimore. "What we're learning about mood disorders is there is a lot of overlap. As time goes on, we probably won't even have separate categories for depression and bipolar. Instead, there will be a classification for mood disorders."

Ewald found that her family history actually strengthened her resolve to reclaim her life. "I lost my father to suicide and I will not do that to my kids, no matter how hard it is," she says. "I go get help as soon as I feel those [suicidal] thoughts coming."

Medication adherence is the biggest

roadblock to fully accepting bipolar disorder, according to Mondimore.

"That is the hardest thing—admitting that you are not always able to control your emotional life," he says. But these feelings subside with the support of loved ones and by undergoing psychotherapy, he adds.

Side effects are a more tangible reason people refuse, or go off, psychotropic medication. For example, Rivers had to learn to live with a 100-pound weight gain and hand tremors.

For her part, Coultas initially refused to take lithium because it was so heavily

I was diagnosed in 1986 and spent many years in denial, stopping and starting my medications. Finally, in 1994, I reached a crisis and my brother intervened. He assisted me in getting disability and encouraged me to be proactive about my illness and my care plan. At that time, I also started getting therapy with a wonderful woman who has helped me to regain my balance. I am now in school and facilitating a support group. At last, I can accept my illness and move ahead in my life. I look forward to completing my education and to rejoining the workforce.

—Jill H. Stout, Wabash, IN

I have been diagnosed with bipolar for 30 years. Not until five years ago, however, did I finally accept the doctor's recommendation to raise the antipsychotic meds. I came to accept my diagnosis. My wife stuck with me for 35 years. When I see my triggers for mania, I call the doctor and do a temporary med change. I can finally let go of the anger the disease has caused me.

—David Fitch, Westminster, MD (left)



I went for so many years without being diagnosed that I thought that I was either crazy or very much a living "Dr. Jekyll & Ms. Hyde." It became worse over the years, even past motherhood and two failed marriages.



After reckless living with anger, self-abuse, and suicidal thoughts, I sought help. Finally, after a diagnosis, I felt relieved but was afraid. The road to finding the right medication was a long one.

I was puzzled about having this disorder. However, once you realize that you can live a normal life with the right medication, family support, and self-love, it is easier to live with. My life with bipolar is my life now. I accept it just as someone with MS, cancer, or depression. You treat it and embrace what you have.

—Gladys, Maple Ridge, BC (above)

Before my diagnosis, my experience of mental illness involved taking care of very ill people; I believed that no one got better. So when I was diagnosed with bipolar I believed my life was over. For six years, I was in and out of hospitals. I was paralyzed with anger

and depression. Finally, I got sick of being sick and started to learn what recovery was. It has taken nine years to learn about recovery and that I have hope. I now teach people about recovery and hope, and I love it.

—Name Withheld, Wyoming, MI

Although I immediately began treatment after my diagnosis in April 2007, it wasn't until February of 2009 that I accepted that my whole life must change. I've had to do a major overhaul on friends, recreation, and the whole nine yards. I've learned that recovery is one moment at a time. I've also learned to be grateful for the little victories.

—Tameka Haywood, Chicago, IL (right)



I'm 27 and have been living with bipolar for the past 12 and a half years. I wish I'd had a mentor growing up who could have told me that it was okay to have mood swings, they would pass, and the clouds would become sunshine very soon. My point is, children these days need mentors to tell them to look on the bright side of life, that

associated with bipolar disorder. "I had talked myself into thinking I had bplight—that I had a very mild version of what other people had," she says wryly. "Friends also told me not to take it—that I could manage without it." But then Coultas began cycling more noticeably. "One week I would be excited and the next I would think the world was ending," she says. "My therapist said lithium would help that."

It can also be deeply frustrating to accept that medications can only manage, not cure bipolar, Ludman points out. The notion of having to take pills

every day for the rest of her life intimidated Wendy Link, 55, of Owensboro, Kentucky, who has "trouble doing anything routinely." But there was a more basic reason Link at first resisted medication: "I liked my manic highs—I felt very productive. I didn't want them taken away," she says. After discussions with her husband, however, Link decided that for his sake she needed to stabilize her moods. "We'd been married for 30 years and I put my husband through hell those 30 years," she says.

Diagnosed at age 50, Link has gradually learned to live with "flat" moods. "I

was used to flying high and feeling all these ranges of emotions and that wasn't there anymore." Missing the soaring highs and bursts of energy leads many to stop their medication and land back in the hospital. "It's very common for patients to stop taking mood-stabilizing medication when they begin to feel better," Ludman says.

Sachs of Massachusetts General believes that having someone in your life to help you stay on track is so crucial for patients with bipolar that he helps those who don't have an existing support system to develop one. "Mood disorders

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the dark isn't the end of all days, and [this mentor] would like to help. I would like to offer my own rainbow and my sunshine to clear up their skies. Do you know where I can start to do this? Everyone deserves a helping hand!

—Melanie Ostrowitz, Manalapan, NJ

I am not my diagnosis. I have an illness called bipolar disorder. I am not mentally ill—I have a mental illness. Before knowing what was "different" about me and before getting treatment, my life was a roller-coaster of ups and downs. Stereotypical terms such as "crazy," "psycho," and "insane"—all borne out of ignorance—are no longer a big deal

for me, compared to what I was going through before people knew of my diagnosis. I am still loved and accepted by God, my fiancée, my family, and my friends. With time, education, therapy, and



prayer, I am now living a content, joy-filled life. Bipolar is like any disease; it is something I have—it's not who I am.

—T.O.M. (left)



poverty, and fathomless despair, but I refused to get medical treatment. I'd read dozens of articles and books, recognizing myself in the descriptions, but still refusing to swallow the pills. Nine years after my diagnosis, I finally took them and here I am, still alive.

—C. A., Asheville, NC (above)

For years, I knew that something was different about me. People commented on how outgoing I was and my great personality, so it seemed like a good thing. Yet from time to time my life would spin out of control. Then I'd "wake up" and realize that I had to try to pull it together. After reading an advertisement [headlined] "Is it really depression?" I diagnosed myself at age 57. I had eight of the 10 symptoms. Finding a reason for my out-of-control life (hidden from most who knew me) was devastating.

It wasn't until I'd lost nearly everything that matters to me—for the third time in my life—that I accepted treatment for my bipolar. I'd experienced homelessness, drug addiction,

Yet I was so grateful to find medication that could help me focus; I tried to put my life back together. It has been a struggle and I wonder where I would be if I had been diagnosed sooner. Still, I move on and appreciate the healthy days.

—Name Withheld, Atlanta, GA

I was diagnosed bipolar in 1985,

took lithium, and was very stable for years. Several years ago, I had to switch to another mood-stabilizer because of my kidneys. I began seasonal cycling; dealing with the instability of seasonal cycling helped me to completely accept my illness. I now take different medications and have been stable for three years. I am at peace with my illness and I work to maintain recovery.

—Michele Bibby, Austin, TX (above)



As a bipolar identical twin I refused the diagnosis ... since I was manic-high most of the time, and my brother was low and depressed. He died 10 years ago from

include periods when your perceptions are distorted, so the most important thing to include in your treatment plan is a care partner," he says.

Those fortunate enough to have a loved one willing to join them on the road to recovery travel a less lonely path. "My husband educated himself. We sat down, talked about the symptoms, signs, and different triggers that had happened over years," says Link. "He was willing to work through the changes. He was so accepting of it that it helped me accept it."

You don't have to be in a romantic relationship to find support—an under

standing boss who lets you come to work a bit later because a new medication is making you sleepy; family and friends who visit you in the hospital; or a relative with bipolar who shares what worked for him—all can contribute to your wellness.

Coultas, who was living in a small town when she came out as a lesbian, believes society is more accepting of homosexuality than mental illness. "In my office, I don't care if people know I'm gay," she says. "The few co-workers who do know about my bipolar will be like, 'So are your meds working now?' as if I'll get on some meds, and then I'll

be normal. That's not going to be it—I'll have to manage my illness—even when I'm well."

When Coultas told her boss she had bipolar, the woman, who is also a good friend, responded: "You are still the same person. Nothing has changed, except that you know something about yourself that can make you feel better." ●

Donna Jackel is a Rochester, New York-based health writer whose work has also been featured in Gannett Newspapers, Bark Magazine, Rochester Magazine and Her Magazine.

over-smoking and not taking care of himself. This is a "yin-yang" case, or two sides of the same coin. I just visited his grave and have a special site (a split tree) that reminds me of him. Has anyone heard of this type of bipolar split in twins?

—Martin Cody, Bethesda, MD

Though I've been diagnosed with bipolar disorder for 30 years this October, I still have a hard time accepting it sometimes. Bipolar disorder has just become a part of me. The process of living with bipolar, however, has not yet come about for me. Every

day is a challenge in terms of what symptoms may be associated with the bipolar and which ones are simply a part of life. As I haven't been able to work in 11 years because of this



illness, I feel like a failure and have become very bored, except when I finally muster up the energy to leave the house. It has been quite a challenge for me.

—Betsy Simmons, Torrington, CT (left)



After the doctor made several attempts to stabilize me on medications, I still had urges to drink and to take drugs. I was 22 at the time, feeling hopeless, and walking a tight-

rope. Then in the 1970s, I was introduced to lithium. Coupled with psychotherapy, I was able to go back to work and to have better relationships. At that point, I accepted my disorder and felt less frenzied and more focused.

—Stan Tolpen, Las Vegas, NV (above)

I found out that I have bipolar only after years of seeking to understand why I didn't fit, despite working with various kinds of counselors, three years of trying several antidepressants, and [undergoing] more intense therapy. Finally, at 39, after a suicide attempt and a strong course of antidepressants in hospital, I was clearly hypomanic and could see the bipolar pattern throughout my life. The helping people I worked with had all been told my sister had died of bipolar/suicide. However, none of them picked up the shadows of [the illness] in

me—they should have! I phoned my most recent psychotherapist from the ward to illuminate him. Hopefully, the helping professions are now more insightful concerning unreported bipolar history. It was a huge relief to finally—and clearly—know what I had to deal with. I'm doing pretty well mood-wise, and am enjoying life more now than ever, 20 years after the diagnosis.

—Bruce Saunders, Victoria, BC

next issue's SOUNDOFF!

In each issue, *bp* asks a question and in the following issue, selected responses are printed. In the Fall issue, answers to this **SOUNDOFF!** question will be printed:

Many persons struggle not only with bipolar disorder, but with the secondary issue of substance abuse—alcohol, drugs or both. If you are someone who has been able to overcome substance abuse, can you share some helpful words of advice with *bp* readers?

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