

SPECIAL REPORT

# the stigma of illness

Getting sick is bad enough, but being judged for it may be even worse

BY JOAN RAYMOND PHOTOGRAPHS BY DAVID LAND

AIDS activist **Rae Lewis-Thornton** challenges stereotypes through her blog, Facebook page and speaking engagements.



**I**magine being interviewed about your work as an AIDS activist and the reporter asks you how many men you've slept with. Or confiding in a friend that you were just diagnosed with lung cancer, only to be met with the accusatory question, "How many packs a day do you smoke?" Or working up the nerve to tell a family member that you have bipolar disorder, only to be told, "That's not a real disease."

While great strides have been made in the treatment of conditions like AIDS, lung cancer and bipolar disorder, the people who live with them face another hurdle: stigma.

For years, social scientists such as Gregory Herek, PhD, a professor of psychology at the University of California-Davis, have been trying to unravel why certain conditions seem to carry "marks of dishonor." Their conclusion: Whenever there's a widespread perception that something can be attributed to personal weakness or poor lifestyle or moral choices, that disease is going to be stigmatized.

Take alcoholism, for example. Though science shows that you can inherit a predisposition to it and that brain chemistry plays a role, many people believe that alcoholics simply lack willpower or good morals. As a result, alcoholics rarely get the same level of empathy and support as, say, people suffering from heart disease. Those with mental illnesses face similar problems. In fact, about 1 in 5 people surveyed by the National Al-

liance on Mental Illness (NAMI) and the National Depressive and Manic-Depressive Association believe people with bipolar disorder can control their illness without medication if they really want to.

When it comes to AIDS, the stigma is directly tied to the fact that HIV (the virus that causes AIDS) is most often spread through sexual contact or the use of intravenous drugs. Misinformation plays a huge role as well: In a survey by the Kaiser Family Foundation, 37 percent of people polled thought that HIV might be spread through kissing, 22 percent believed it could be spread through sharing a glass, and 16 percent said it could be spread by touching a toilet seat—none of which is true.

Even cancer carries a stigma—especially lung cancer. Although smoking increases your risk, 1 in 5 women who develop it have never smoked. Yet about 60 percent of people believe that lung cancer patients are at least partly to blame for their diagnosis, according to a Lung Cancer Alliance survey of nearly 1,500 people.

The worst part about stigma is that patients often internalize those feelings of shame. "It's a vicious cycle," explains Bob Carolla, JD, media relations director for NAMI, who lives with bipolar disorder. "People hear the misconceptions, and they start to believe them." As a result, they feel isolated, which may prevent them from seeking help, says Carolla.

Fortunately, you can help stigmas fade. For starters, catch yourself when you're about to make a sweeping judgment. "Ask yourself, 'Am I sure that this information is 100 percent accurate?'" says Janine Gauthier, PhD, a clinical psychologist who studies the emotional aspects of illness at Rush University Medical Center in Chicago. Don't risk spreading misinformation. Stop yourself and learn the facts from credible sources (such as websites

like [mayoclinic.com](http://mayoclinic.com) and [nih.gov](http://nih.gov), which are run by large mainstream medical groups). Also pay attention to your language: Avoid words like *all* or *everyone* that lump people with a disease into one category, as well as those that imply that an illness is due to a personal weakness (for example, saying it's her *fault* that she got sick or referring to someone with a mental illness as *crazy*).

These efforts really can make a difference—as does the willingness of patients to share their stories. Not too long ago, the words *breast cancer* were considered unspeakable. When high-profile women like Betty Ford started talking about their disease in the 1970s, that started the movement for better treatment and more honesty.

Opening up helps educate others, and the more people know about an illness and see people in their lives facing it, the less likely they are to stigmatize it. "When you know someone's story, it's much harder to

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make negative generalizations," says Dr. Herek. That's why we asked the following women to share their personal accounts of living with bipolar disorder, AIDS and lung cancer. They've all risen above the stigma, the misconceptions and the prejudice, and perhaps most important of all, they're not so different from you and me. *(Please turn to 134)*

# “I’m smart, I’m straight, and I have AIDS.”

RAE LEWIS-THORNTON, 49, CHICAGO



**W**hen I started taking AZT, a drug used to treat HIV and delay the onset of full-blown AIDS, I used to peel the label off the bottle and flush it down the toilet. I didn’t want anyone to know I was taking the “AIDS drug.”

Most people think that everyone with AIDS is promiscuous, gay, a drug user, uneducated or all of the above. They’re wrong. I’ve never done drugs and I’ve never slept with anyone on the first date.

I was diagnosed with HIV when I was 23 years old and working in Washington, DC, as a political strategist. I got infected during what I thought was a monogamous heterosexual relationship. In fact, I had no idea I was sick until I donated blood and the Red Cross informed me of my HIV status.

For the first seven years, I only told five people—and swore them to secrecy. When I got sicker and started losing weight, I let people assume I was working out a lot. But keeping my condition a secret was isolating, and I got very depressed, so I finally told a few people. Soon after, a teacher at a Chicago high school asked me to talk to her students. I was reluctant, but it went so well that I started speaking to other local groups. In 1994, the editor of *Essence* magazine heard me speak and put me on the cover. In some small way I changed the face of AIDS for black women.

I don’t regret speaking out for a second, but I admit that going public can be overwhelming. During an interview for a local TV station in Florida, the reporter had the nerve to ask me how many men I had slept with. I told her, “It doesn’t matter. All it takes is one.” And that’s the truth.

I’d like to think that things have changed a lot since I was first diagnosed, but sometimes I doubt it. A few years ago I was talking to a group of students in Arkansas, and I reached for a girl’s hand to demonstrate that because she didn’t have any open wounds she was perfectly safe. But when I reached out, she recoiled her hand in disgust.

People often ask me about how my condition—and the stigma attached to it—has affected my love life. I do date, but it’s been hard. One man always wanted to eat dinner at either my house or his, and he always had an excuse about why we couldn’t go to a restaurant. Another always introduced me as his *friend* instead of his *girlfriend*. A few years ago I de-

ecided that if a man wasn’t willing to be with me publicly, he could not be with me privately.

Today I’m no longer working in politics. Because I’m immune compromised, I’m always battling fatigue or some infection, like pneumonia. Since then, I’ve launched a line of HIV/AIDS awareness bracelets and I’ve gotten my divinity degree. I’m very proud of that; I believe that God has given me a unique gift to speak about my illness. I give talks across the country in which I’m very candid about my experience with AIDS, and I often get letters from people thanking me for sharing my story.

The most memorable ones are the letters that arrive years later and say things like, “If I hadn’t heard you speak when I was 16, I would have started having sex right then. Instead, I waited until I was 21.” Knowing that I might be able to help change minds and behaviors is the reason I keep doing this. *(Please turn to 136)*

**AIDS AND HIV,** the virus that causes AIDS, were once thought of as something that primarily affected gay men. Today, women account for more than 1 in 4 new HIV/AIDS diagnoses and deaths in this country. About 71 percent of women diagnosed with AIDS in the U.S. in 2005 (the last year for which detailed data about women is available) contracted the disease through heterosexual sex. African-American women are 18 times more likely to contract HIV than Caucasian women, according to amfar, The Foundation for AIDS Research. Famous faces with AIDS include sports stars Magic Johnson and Greg Louganis and ’80s supermodel Gia Carangi. Learn the facts at [thebody.com](http://thebody.com), [amfar.org](http://amfar.org) and [womenshealth.gov/hiv](http://womenshealth.gov/hiv).



## “I had lung cancer and never smoked a day in my life.”

KATHLEEN SKAMBIS, 53, ORLANDO, FLORIDA

**G**etting lung cancer is shocking enough, but having everyone try to figure out what you did “wrong” is almost as bad. When I was diagnosed in 1999, everyone wanted to know if I was a smoker. Even in the hospital, one of my nurses asked me, “So, how many packs a day did you smoke?” I wanted to say, “Are you kidding me?! No one deserves cancer.” But I just told her the truth: I have never smoked.

You would think that would put the issue to rest, but it rarely does. A common follow-up is, “Really?” I sometimes wonder if people think I’m lying. Next, people want to know if I was exposed to secondhand smoke. Well, I grew up in the ’60s and ’70s. My parents didn’t smoke, but cigarettes were everywhere.

No one knows why I got cancer, but most people who have breast or colon cancer don’t know why they got it, either.

**LUNG CANCER** kills more than 160,000 people annually. Breast cancer, in comparison, kills about 40,000 people each year. Yet in 2009, about \$685 million was spent on breast cancer research and less than \$300 million on lung cancer research. Approximately 85 to 90 percent of lung cancers are due to smoking, but 1 in 5 women with lung cancer have never smoked (it’s 1 in 10 for men). Other risk factors include exposure to radon or asbestos and having a family history of the disease. Famous people who battled lung cancer include Dana Reeve and opera singer Beverly Sills. Learn more at [lungusa.org](http://lungusa.org), [lungcanceralliance.org](http://lungcanceralliance.org) and [lungevity.org](http://lungevity.org).

I was on my honeymoon when I came down with the flu, which became bronchitis. Fortunately, my husband insisted I get a chest X-ray. It showed a suspicious mass in my lung. The doctor mentioned cancer in passing, but he quickly discounted it. It wasn't until I had CT scans of my chest and throat (as well as biopsies) that we learned I had lung cancer as well as (unrelated) thyroid cancer. I ended up having multiple surgeries and chemotherapy.

Whenever I talk about my story, people often say how unfair it is, as if because I'm a nonsmoker I didn't "deserve" to get sick. But smokers and nonsmokers are in this boat together. I have close friends who smoke; they've tried absolutely everything to quit. It's not that easy.

Despite the dismal statistics (only about half of people diagnosed with early-stage lung cancer survive for at least five years), I've been cancer-free for more than a decade. I continue to practice law and I love to run, bike and travel. But I have to say, it's hard

to see all the pink ribbons for breast cancer while lung cancer is fairly invisible. It's great that breast cancer patients have that support; I just wish lung cancer patients did, too.

One day, a few years ago, I walked into a Starbucks and spotted a sign for an American Lung Association (ALA) event, "Climbing Heights for Lung Cancer." Finally, a program to raise awareness and funds! That day I decided to volunteer with the ALA.

Since then, I've learned that the amount of money devoted to lung cancer research is extremely low compared to funding for other diseases. I know one of the hurdles is that people blame smokers for bringing it on themselves. That makes very little sense. Heart disease, for example, is pretty well funded, even though certain lifestyle habits may raise the risk of developing it. Rarely does anyone think, "Why should I write a check? They could just eat fewer cheeseburgers." It's not right to blame anyone for any illness—no matter what it is.

## "I have bipolar disorder, and no, I'm not crazy."

HEIDI NORDIN, 45, ST. PAUL, MINNESOTA

Several years ago, shortly after I was diagnosed with bipolar disorder, I was chatting at an Easter celebration when a family member turned to me and said, "You know, I don't think mental illness is real. I don't know why you bother taking medication."

I was so dumbstruck that I just turned and walked away. I couldn't help but wonder if I had made a mistake in telling him in the first place. When I was first diagnosed in 2000, I didn't tell anyone for the first year because I was afraid they would think less of me. When I finally told my family, they *(Please turn to 138)*



initially seemed to be receptive.

For the most part, my condition is well controlled. But I have several episodes every year, and each one can last for months. (Medication does help, but I often have to change doses and switch to different ones.) When I'm severely depressed, I don't want to leave the house. Reading or even getting out of bed seems like too much effort. When I'm in a manic phase, I become very impulsive. Once I bought an \$8,000 motorcycle that I didn't know how to ride. I've since taken lessons and I love it, but that was a lot of money to spend without really thinking about it.

Given how I feel when I'm experiencing an episode, I can't believe that some people don't accept that mental illness is real. Plus, research shows that chemical imbalances in the brain cause this illness. It's not something you bring on yourself; why would anyone choose to live or feel this way?

Still, I'm cautious about whom I confide in. Once when I was on the way to a restaurant with a group of friends, we passed a homeless person. One of them said something like, "Did you see that crazy guy?" In my head, I was thinking about how that person probably has a mental illness and needs help. But if I'd said anything, they probably would've thought that there was something wrong with me too.

For similar reasons, I've told very few coworkers about my condition. Most of the time I can make it through the workday OK. If I'm re-

ally depressed I'll take a sick day, though once I missed a week of work because I was hospitalized for suicidal thoughts. In the past I worried that I could lose my job if more people found out about my condition, even though I know that's illegal. I also worried that colleagues would think I was less competent, but I realized I've already proven myself. I've been at my current job (in an IT department for a large company) for about five years, and I supervise 10 people.

Many people think that everyone with mental illness is flaky or weird, but the truth is, in most respects I'm just like everyone else. I've worked since I was 18 years old, and I work really hard. I have a lot of friends, and I love going to the movies, museums and Minnesota Twins games.

Since getting involved with the mental health organization NAMI in 2005, I've been trying to be more open about my condition. I help out with NAMI Walks (a big annual fundraiser) and represent NAMI on the Minnesota Mental Health Advisory Council. But the scariest thing I've ever done was give a talk at a NAMI event. I had never done public speaking before, and my hands were shaking as I stepped up to the podium. I looked at the crowd of about 250 people staring at me and I almost froze, but I took a deep breath and just dove into it. As I started speaking I felt myself relax a little, and when I finished, everyone applauded. I thought to myself, *I could get used to this.* ■

**BIPOLAR DISORDER**, also called manic depression, is a mental illness in which people experience extreme highs (mania) and lows (depression). It may be caused by a combination of brain chemistry, genetics and your environment (for example, it's more common in people who've lost a parent at a young age). Finding the right treatment—usually a combination of medication and talk therapy—can be difficult, but it enables people with the disorder to lead productive lives. Well-known figures who have bipolar disorder include Jane Pauley, Richard Dreyfuss and Carrie Fisher. Learn more at [nami.org](http://nami.org), [nimh.nih.gov](http://nimh.nih.gov) and [dbsalliance.org](http://dbsalliance.org).

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