

# What's Wrong With Me?

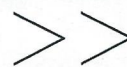
DESPITE CRIPPLING PAIN,  
GINA ROBERTS-GREY LET  
EMBARRASSMENT AND FEAR  
PREVENT HER FROM GETTING  
THE DIAGNOSIS SHE NEEDED.



WHEN MY SON, ZACHARY, WAS A BABY, his diapers were a constant source of conversation. I compared war stories and swapped notes with family, friends and other mothers to reassure myself that his poop was perfectly normal. And it was. But when it came to me, what happened in the bathroom stayed in the bathroom.

My lips were sealed about the fact that over the years, that little room of relief began to hold a very special place in my heart. I grew up with what I thought was a sensitive stomach. A few times a year, without predictability, one porcelain bowl became a best friend as my digestive tract turned into my worst enemy. These episodes always started with abdominal churning and rumbling that in as little as 15 minutes grew into overwhelming severe pain. Whether I had to expertly maneuver myself out of the bleachers at my high school's basketball game or give the illusion of calmly getting up from my chair during a deadline-filled day at work, I'd speedily make it to the toilet. Once there, I was never sure what I'd face: diarrhea or constipation. Either way, one trip was rarely enough, so to prevent an accident I'd stay close to the bathroom. At times I've curled up in a ball on its cool tile floor or doubled over on the toilet to try to block out the blinding aches...until the next wave of urgency hit. It could go on like this for a few hours or a few days.

When I realized I wasn't the only person in my family who spent lots of time in the bathroom, I accepted that I was doomed to this fate. But to protect my pride, I still kept my episodes a secret. Who wants to call in sick from





work or cancel a date at the last minute with the excuse that they can't be more than 5 feet from the bathroom? Instead, I blamed my disappearing acts on less humiliating ailments like migraines, sudden colds and possible bouts of food poisoning. In my early 20s I experimented with eliminating certain foods from my diet, built me-time into my schedule to de-stress and clocked eight hours of sleep a night. Nothing made a difference. However, I did discover that eating foods like broccoli and granola seemed to send my stomach into a rage in the first few days after an attack, so I started avoiding them.

By the time I was 23—having suffered for about seven years—I'd had enough. An excruciating episode timed to my period (as happened occasionally) sent me to the gynecologist for a cure. He gave my illness a name: endometriosis, even though I didn't have excessive bleeding or consistently painful periods. Over-the-counter pain relievers and birth control pills were prescribed but they didn't help. I tolerated a handful of difficult days and

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nights in the bathroom over the next year until a new symptom commanded my undivided attention: bloody diarrhea. I called my PCP and within minutes of walking into his exam room, I had an accurate diagnosis: ulcerative colitis (UC), a chronic inflammatory bowel disease of the large intestine (colon) and rectum that affects around half a million Americans. (So much for thinking it was my stomach!) He gave me the name of a gastroenterologist who, after analyzing my stool samples, x-rays and blood tests, confirmed his conclusion.

"Parents, siblings and children of people with inflammatory bowel disease have an increased risk of developing UC, but genetics alone are not enough to cause it," says gastroenterologist James

D. Lewis, MD, a professor at the University of Pennsylvania's Perelman School of Medicine and chief scientist of the Crohn's & Colitis Foundation of America's IBD Plexus research initiative. An overactive intestinal immune system and foreign substances in the environment may contribute to the onset of the disease.

My doctor prescribed steroids and antibiotics for a few weeks to tame my symptoms and get me into remission. Most people need daily medication to control UC, but except for a few relapses, I was fine for almost 15 years. Then right before my 40th birthday my old nemesis returned. More than a decade of remission meant I'd never had to deal with telling many family and friends about my condition. So my relapse sent me back to spinning lies—only this time I made my spouse an accomplice. "Gina's not feeling well," Rob would offer up when we arrived late to dinners with his family. "Gina has a bad headache," he'd say when I skipped a birthday party.

But my son, Zachary, began to question our cover-ups. When he was in junior high, I missed a family function due to a bad attack and he asked me, "Mom, why do you lie about being sick?" My immediate response was "I don't."

But then I realized that years of excuses about headaches that weren't really happening and dangling the idea that I might have a touch of the flu sent my son mixed signals and set a terrible example. Moms guide their children to tell the truth, no matter the consequences. But I, unfortunately, sent a message to my son that it's okay to lie if you're embarrassed.

Rob and I explained to him that our fibs were wrong, even if they were meant to protect privacy and spare shame. I started being honest with friends and family, offering the brief explanation "I have ulcerative colitis" without divulging bathroom details. But it took three more years of agonizing episodes before I was honest with my MD and went for an appointment. Denial and stubbornness led me to try to self-medicate with probiotics, herbal remedies, clear liquid diets and an emergency stash of Jell-O (the only thing that goes down easily during flare-ups). I convinced myself

## *How to Get Diagnosed—Despite Yourself!*

**RECOGNIZE THE RISK.** Delaying treatment didn't just put me on the sidelines of life; it also could have compromised my health. Untreated ulcerative colitis left me at risk for colon surgery, arthritis, colon cancer and even mental health issues like anxiety. "The longer you wait, the less likely some ulcerative colitis medications are to be effective," adds gastroenterologist Sonia Friedman, MD, an associate physician at the Crohn's and Colitis Center at Brigham and Women's Hospital near Boston.

**ACCEPT IMPERFECTION.** We all have moments when we feel like our bodies are betraying us, but why put up with symptoms when you can actually fix them? "Almost half of people with ulcerative colitis are in remission," says Friedman.

**WRITE IT DOWN.** If you're too embarrassed to tell your doctor your symptoms out loud, email them or share them on paper instead.

that my will was somehow stronger than the disease. It wasn't. I gritted my teeth through episodes until the night I had to pull my husband out of a friend's birthday party because an attack was brewing and I was reluctant to use someone else's bathroom. I immediately set up an appointment with my doctor. A short course of steroids coupled with anti-inflammatory drugs helped me once again achieve remission, which I've been in since 2012.

There are no do-overs in life. But when I look back on all the joy I've missed—leaving baby showers early, sleeping on my bathroom floor, skipping dinner parties—I'm filled with regret. I shouldn't have waited to seek treatment and should have questioned my misdiagnosis. I've promised myself that if I ever relapse, I won't go back to making excuses. I'll make an appointment.

**WHERE TO LEARN MORE** Crohn's & Colitis Foundation of America [ccfa.org](http://ccfa.org), American Gastroenterological Association [gastro.org](http://gastro.org), National Institute of Diabetes and Digestive and Kidney Diseases [niddk.nih.gov](http://niddk.nih.gov)