



Prevention

Conditions like inflammatory bowel disease (IBD) can be complicated, tricky to diagnose, and terribly disruptive both physically and emotionally. Read on for the latest news about IBD and other knotty GI problems.

BY MALLORY CREVELING

GUT

REACTIONS

Kate Kareha keeps a folder in her attic filled with notes, doctor's appointment summaries, photocopies of books, and flyers about inflammation. She also has a saved email with her medication history, the supplements and herbs she takes, and diet info as well as details about the emotional side of a Crohn's disease diagnosis; she fires it off to friends suffering from gastrointestinal symptoms to give them an idea of where to start. She knows that if they've got a form of

inflammatory bowel disease (IBD), like Crohn's, the road to remission can be long and winding.

Kareha, a 36-year-old business owner in Allentown, PA, started experiencing symptoms of Crohn's disease seven years ago, during her first pregnancy (though, looking back, she might have had symptoms as a kid, she says). She and her doctor chalked up the blood in her stool to the hemorrhoids that can be common in pregnancy, but when she was six months postpartum, the blood returned. After she had a colonoscopy, her doctor diagnosed ulcerative colitis, one of the two main types of IBD. Inflammation in the lining of the colon is a sign of colitis, but she later learned that she had inflammation in other areas of her digestive tract, which changed her diagnosis to the other type of IBD, Crohn's disease.

STRUGGLING TO GET A DIAGNOSIS

About 3 million U.S. adults live with IBD—a condition often confused with irritable bowel syndrome (IBS), which also causes disturbances in bowel function but doesn't trigger inflammation (see box at right). Patients frequently go through several exams, doctors, and sometimes misdiagnoses before landing on IBD. In fact, one survey of Crohn's patients found that for a majority, the delay in diagnosis could span more than a year, while another showed that ulcerative colitis might not be diagnosed

IBS VS. IBD

Irritable bowel syndrome (IBS) is more common than inflammatory bowel disease (IBD), affecting 10% to 15% of the U.S. adult population, according to the American College of Gastroenterology. The main difference is that IBS involves how the brain communicates with the gut, says Anne Mary Montero, Ph.D., a licensed clinical psychologist and an assistant professor of medicine at Indiana University School of Medicine Digestive and Liver Disorders Division. IBD is characterized by inflammation and may be related to the immune system.

But IBS is not purely psychological, says Kirsten Tillisch, M.D., chief of integrative medicine at the Greater Los Angeles VA and professor of medicine at UCLA's Vatche and Tamar Manoukian Division of Digestive Diseases. "The brain fine-tunes the gut's behavior, so when there's a disorder of that brain-gut interaction, the gut might

be hyperactive in response to experiences, thoughts, or emotions."

Another difference is that while IBD will typically show up on an endoscopy, a colonoscopy, or a biopsy, IBS will not. "The gut looks fine. It can absorb, it can move things through, but it can do it too fast or too slowly," Dr. Tillisch says. To figure out what's going on, the doctor will do a full physical exam and health history and look for IBD red flags. If there are none but the person has pain on a weekly basis (not just a few times a year), it's likely IBS, Dr. Tillisch says. A doctor may also test for small intestinal bacterial overgrowth (SIBO), another common gut issue that presents with symptoms similar to those of IBS, says Nisha Chellam, M.D., an internal, integrative, and functional medicine physician at Parsley Health in Ann Arbor, MI.

As with IBD, researchers don't know what causes IBS, but risk factors include changes in gut bacteria and



antibiotic use (which may also play a role in IBD); chronic stress; a diet with many highly processed foods; and a family history of the condition, says Dr. Tillisch. It's also associated with trauma-related events in early life and anxiety, says Montero.

But while IBS is common, you don't simply have to live with it—a range of medications work for IBS, and many people come to feel better through making dietary changes and/or employing meditation techniques, says Dr. Tillisch.

for two years from the first symptoms.

"The lag time between when symptoms start and an accurate diagnosis is usually because the clinician doesn't think of it initially," says David Rubin, M.D., codirector of the Digestive Diseases Center at University of Chicago Medicine and chair of the National Scientific Advisory Committee for the

Crohn's & Colitis Foundation. Many doctors first pinpoint IBS, hemorrhoids, anxiety, or stress as the cause of stomachaches, urgency, diarrhea, or constipation. And for women, the Crohn's symptom of anemia (a lack of healthy red blood cells) is often chalked up to menstruation.

Also, women sometimes underplay the seriousness of their symptoms.

Brooke Abbott, 37, thought the extreme fatigue she experienced for two years (along with bowel issues) was a side effect of a busy schedule. Eventually, when she got so tired that she passed out, a doctor recommended a colonoscopy, which revealed inflammation. She was diagnosed with ulcerative colitis. Abbott now writes the motherhood- and

IBD-focused blog *The Crazy Creole Mommy Chronicles*, and she cocreated *IBDmoms*, a community and newsletter.

Once your doctor knows to look for IBD and performs the proper tests, including a colonoscopy with biopsies and additional imaging, making a diagnosis is relatively straightforward, Dr. Rubin says. Being truthful with yourself and your doctor about what you're experiencing can streamline the process. "Symptoms can be embarrassing, and some people don't like to talk about diarrhea or constipation, but being honest with your physician or your gastroenterologist is really helpful," says Laura Wingate, executive vice president of education, support, and advocacy for the Crohn's and Colitis Foundation.

FINDING THE RIGHT TREATMENT

Determining the best long-term treatment for IBD depends on how sick the patient is as well as on the location of

the inflammation, says Dr. Rubin. After Kareha received her initial colitis diagnosis, her condition progressed. She'd spend hours in the bathroom, unable to leave her house for half the day lest she need to run back to the toilet. Two years after she first saw blood in her stool, she went on steroids and finally found some relief. "I was only in remission for about two or three weeks that time, but when you've been dealing with these symptoms for years—it was like heaven," she says. "It was like this veil had been lifted, and I thought, *OK, I'm back. I can figure this out.*" With this new clarity, Kareha began working with an herbalist to address the inflammation. Using a mix of Eastern and Western treatments has put her into a four-year remission.

While a steroid can help get the inflammation under control, it shouldn't become a maintenance drug, says Reezwana Chowdhury, M.D., an assistant professor in the division of gastroenterology and hepatology at Johns Hopkins University. Amy Btiebet-Washington, 35, who lives with Crohn's

GUT Q'S TO ASK YOUR DOC

Before you agree to the first treatment suggestion your doc makes, Wingate and Dr. Chowdhury advise raising these questions.

- What are the various treatment options available to me?
- Can we talk about specific treatment goals and outcomes?
- What are the side effects of these medications?
- How will my disease or this treatment affect my ability to have children?

disease and now serves as the executive director of the Crohn's and Colitis Foundation of Northeast Ohio, started with a steroid and eventually, after trying maintenance drugs that didn't work, went on a biologic. "The most important thing from [a doctor's] standpoint is to bring the inflammation down, because having inflammation can put you at higher risk of colon cancer," Dr. Chowdhury says. Biologics come from antibodies created in a lab to help stop proteins from causing inflammation.

STAYING IN REMISSION

Finding a doctor who takes your concerns seriously is critical. Even after Abbott was diagnosed with colitis, doctors dismissed many of her symptoms as being related to pregnancy, childbirth, or hemorrhoids or all in her head. Without proper treatment, she ended up in the hospital for emergency surgery to remove her colon. Once she recovered, Abbott began advocating for the IBD community, and that was when she found a physician she really trusted: a person of color, like her, who she felt understood her and communicated openly with her.

That doctor helped Abbott put together a care team including a rheumatologist, an endocrinologist, and a gynecologist. "He's the one who said, 'We're going to get your whole body fixed, and we're going to make sure you can go and do the things you want to do, like coach and travel and advocate and be the



mom you were meant to be," she recalls.

While there's no cure for IBD and the exact causes of it are uncertain (genetics and environmental factors likely play a role), researchers continue to investigate the disease and why the number of sufferers is rising not just in the U.S., but globally. "My thinking for the future is that we use anti-inflammatory treatment to get patients into remission and then switch to non-immune-modifying but microbiome-based treatments—but we're not there yet," Dr. Rubin says. Still, he adds, there's cause for optimism: "We've made progress in monitoring the disease; we can measure inflammation in the bowel with stool tests, and soon there will be an at-home test. All these things can change the trajectory of the disease."

