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Crohn’s Disease Does Not Define Me

How two African-American women translated their Crohn’s disease diagnosis into an opportunity to educate and empower others about the inflammatory bowel condition.

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Tocombamaria Murphy
Shaker Heights, OH

Although Tocombamaria Murphy, a community outreach worker, and Logan Thornton, a doctoral student, live in different states, the two have something in common. They are both black women who have Crohn’s disease and refused to let the condition isolate them from others and stop them from living full lives.

Crohn’s disease is an inflammatory bowel disease that causes chronic inflammation of the gastrointestinal (GI) tract. Symptoms of the disease include persistent diarrhea, painful stomach cramps and rectal bleeding.

Currently, more than 500,000 people are living with Crohn’s disease in the United States. Docs usually diagnose it during someone’s late teens or early 20s. There is no cure for the lifelong condition, but several treatment options exist, and it’s possible to put the disease in remission.

While Crohn’s is more common among whites, incidence rates have been increasing among African Americans.

“We don’t know why African Americans have a high rate of Crohn’s disease,” says Marie Borum, MD, MPH, director of gastroenterology at The George Washington University Hospital in Washington, DC. “We know that it happens most frequently in whites of Jewish ancestry, followed by whites of non-Jewish ancestry. But the next big category is African Americans.”

People may suspect diet as the cause for higher rates of Crohn’s among African Americans, but as Borum explains, no clear-cut evidence links someone’s eating habits to their likelihood of developing the condition.

Since African Americans don’t fit the disease profile, they are often misdiagnosed and treated for other gastrointestinal disorders. This is what happened to both Murphy and Thornton before doctors diagnosed them with Crohn’s.

Murphy’s story began several years ago when severe abdominal pains caused her to double over at her desk at work. The pains stopped her from performing her office manager duties at the health care facility. When she visited her doctor, the physician told her she had ulcerative colitis.

After a year of worsening symptoms, Murphy was hospitalized. While there, docs diagnosed her condition as Crohn’s disease.

Logan Thornton
Houston, TX

Thornton’s introduction to the illness began with bouts of indigestion after eating spicy foods. But soon anything she ate made her sick. Her doctor suggested she follow a bland elimination diet to figure out the cause of her illness. But after six months, she found no relief. Thornton instinctively felt that something was wrong. She sought the help of another physician, who diagnosed her with Crohn’s.

Although misdiagnosis could pose a setback for some, these women embraced those experiences on their journey to understanding this condition. It has helped them educate, advocate and empower themselves and others about Crohn’s disease.

Since being correctly diagnosed, Murphy has carefully followed her doctor’s treatment plan. The meds he prescribed has put the disease in remission, and she is living successfully with Crohn’s. But medication isn’t the only thing that helped Murphy get this far. She feels that disclosing her condition to others—close family and friends—enabled her to build a helpful network of trusted people who played an important role in her success.

“I learned that it does not help me to keep it a secret,” Murphy says. “I developed a support system, and I let people know what I was dealing with.”

Aside from her family and friends, the most significant support Murphy receives is from her membership in the Crohn’s Advocate program. She is one of five advocates who hold events across the country in efforts to educate and empower others living with the condition. In addition, the program produces a quarterly magazine featuring the experiences of those living with Crohn’s.

“The more I talk about it, the more often I find people who realize that they might have Crohn’s or know somebody who has the disease,” Murphy explains.

At the last forum Murphy attended, she met an African-American mother and daughter. The daughter has Crohn’s disease and learned that there are other African Americans living with the illness.

“At the events, she got a chance to see somebody who looked just like her speaking about living with Crohn’s,” Murphy says. “It made a difference for her, and that made me feel good.”

But being your own advocate is just as important as helping others. Self-advocacy was key to Thornton getting correctly diagnosed with Crohn's.

"Know your body, know who's treating you, and learn about the disease," Thornton says, "because information is a powerful weapon in your arsenal."

She explains: "You may not necessarily hear what you want to hear, but knowing the unknown really can help fight the disease."

Being a persistent advocate for her own health, Thornton says, connected her with a tenacious and caring physician. And because of that, she has been in remission for three years.

But Thornton has always seen herself as an advocate for the underdog, even before her Crohn's disease diagnosis.

After a visit to the emergency room to care for her diabetic, hypertensive father (he had stage four end-stage renal disease and kidney function failure), Thornton learned that advocacy makes a difference.

"In the hospital, I saw lots of people who didn't have somebody there for them," she explains. "I felt like if I didn't speak out and advocate on behalf of my father with the doctors and nurses who would."

Now, both Thornton and Murphy are speaking out about Crohn's disease and being the voice for those they feel may be suffering in silence.

The two women believe it's empowering to share your experiences and connect with others. They also feel that some people with the condition isolate themselves because of the limitations Crohn's puts on their social activities.

While neither woman claims to have experienced stigma from others because of the disease, they believe people stigmatize themselves, which can be just as devastating. (Remember, not only is the disease often painful and debilitating, but it involves the bowels and, at times, the bathroom—topics most Americans are not comfortable talking about.)

How do people with Crohn's overcome this tendency to self-stigmatize? "By knowing that you can still achieve any of the things you want to achieve," Murphy says. "You have to know that you are not your disease. You can't define your life by it or because of it."

Thornton adds that to avoid self-stigma, it's important to have people around you who understand your condition. This cuts your anxiety in half, she says.

Although there is no cure for Crohn's disease, the condition is manageable under the care of a gastroenterologist—a physician specialized in gastrointestinal tract and liver diseases.

“Crohn’s is a lifelong condition,” Borum says. “The disease may create other associated complications that aren’t connected to what’s happening inside your intestines. For example, you can have arthritis, liver, eye and skin conditions, kidney stone development, malnutrition and fistulas [small channels that create connections to different parts of the intestines or link parts of the intestines to other organs].”

If Crohn’s significantly involves the colon, the disease may also pose a colon cancer risk, Borum says.

There are several categories of treatment used for Crohn’s disease, the doc adds. They range from steroids to biologic therapies. The physician’s goal is to induce remission, which can occur within weeks of starting the prescribed medications.

But for some it can take longer, Borum says, depending on the severity of their Crohn’s condition.

While they wait, advise Murphy and Thornton, Crohn’s patients should make individual lifestyle changes that will better help them manage the disease while enjoying a normal life.

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