Terry Wright

Terry Wright is a 57-year old African American cystic fibrosis patient who was misdiagnosed for 54 years.

I have Cystic Fibrosis (CF). I was diagnosed three years ago when I was 54 years old, and all these years, I knew something was going on with my body. I was experiencing all these different things: chronic pneumonia, sinusitis, very bad stomach pains, chronic headaches.

I used to wonder as a child why I was sick all the time. I would eat certain foods, and it seemed like it would trigger me to get sick. My stomach would just protrude at the top, and I would have excruciating pain.

I just used to cry, miss school a lot, home sick for weeks at a time. I used to hear my parents talk about how I must be sick, because I would get really quiet and just go in my room and cut the light out and just be balled up.

My mom started taking me to the hospital. They told me I had a virus, I had ulcers, and then just shot me with pain medication. That would just dull the pain, just to get me home, and then it would get to throbbing back. I was getting to a point, seriously - I just wanted to die.

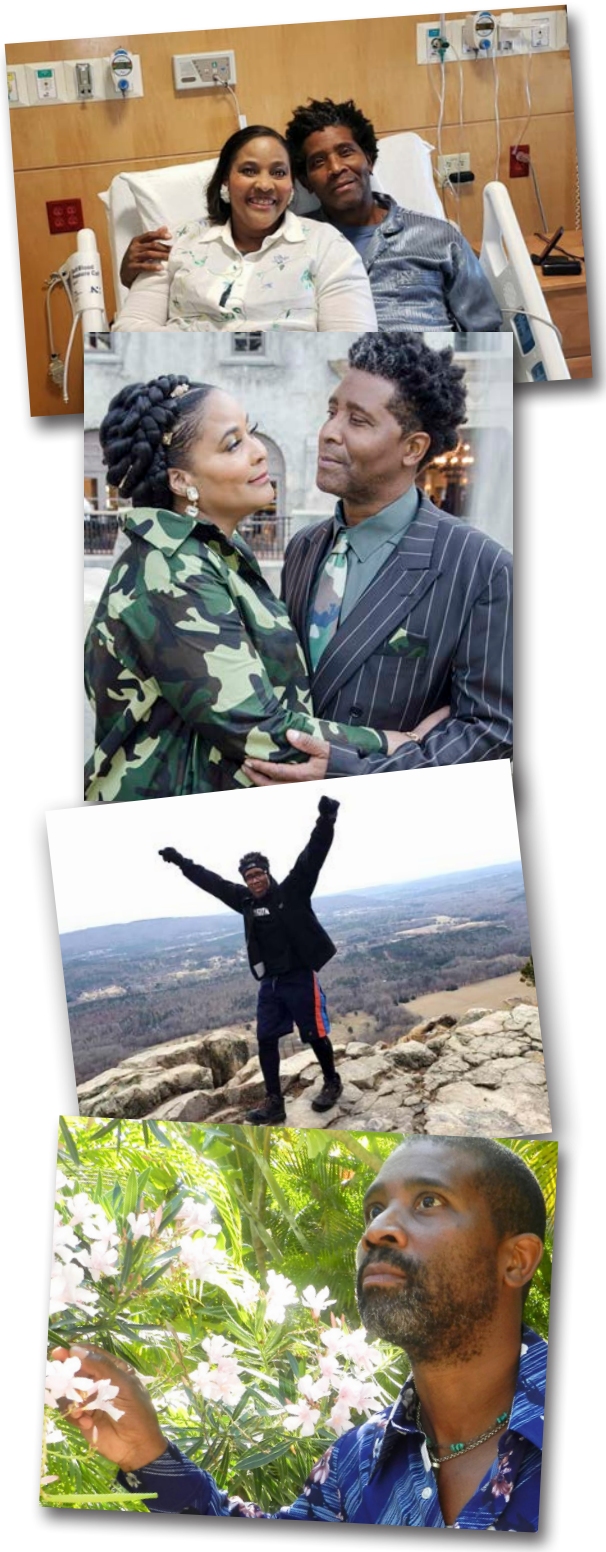
It also was in my lungs, but at that time it was in the form of a really bad seasonal asthma. I remember playing sports and I'd be breathing rapidly while the other children had already recovered. And no one knew, they just thought I was tired. I kept that part away from my parents. They never knew I had some breathing issues. It was kind of embarrassing, you know, to have different things going on with your body, and have no answers. Emotionally, these are things that come with CF. It was just devastating.

I was so glad, in 2001, when my wife pushed me to have surgery. They removed a piece of my pancreas and one of my ducts. That solved the problem with intense pain in my GI. I wouldn't be alive right now without that. I also started taking enzymes which really helps break down my food. It makes a difference.

After the surgery, the mucus moved into my lungs and sinuses, where it wreaks a lot of bad havoc. It's a thick mucus, like snails. I use irrigation and antibiotic ear drops to break it up. My joints ache in certain areas because that mucus just clogs up everything.

I push so hard on taking care of yourself, even just drinking water, staying active, or going and doing something for someone else. It's a horrible feeling when you can't breathe. You can go into all types of places with your mind, especially if you don't have information about why you feel this way. This is something you have to live with all your life, so you might as well keep a positive mind and do fewer things that can harm you. There are so many things CF patients can do to harm ourselves, like not doing our treatments. It can get us to a point where we can't get help because it's gotten too severe. It's also important to have someone to advocate for you.

I believe that each patient deals with CF differently. I'm just so happy that I feel like it's getting a breakthrough, and we can get a word out. Someone needs to hear my story. Emotionally, I have many scars, but I've learned to live with it and try to keep a positive attitude and just go forward and not be stopped. You have to develop mental stamina in addition to physical stamina when you're dealing with CF.



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When I met my husband, Terry, I saw death. I felt love but I saw death. He was going to the hospital two to four times a week. I didn't know what was going on, but I knew when he would eat something, he would throw it right back up, violently. I knew something was wrong.

Fortunately, because of my pharma background, in 2000 he told me his chest hurt, and I told him he had to go to the clinic. I believed he had pneumonia. You don't play with pneumonia. Terry was diagnosed with double pneumonia, but interestingly the young doctor said, "You know, if you were not African American, I would say you have cystic fibrosis." That was the first time we heard the words "cystic fibrosis."

Terry continued to get so sick that I knew that if we didn't do something, he wasn't going to make it. I started reaching out to everyone I could. I finally found this doctor who worked on the pancreas. He said that in his entire career, he had never seen a pancreas that bad. He didn't know how Terry was walking, or doing anything, and Terry had just run a marathon! That's when the discussion of the pancreas surgery came up. I was still new in his life, and I was pushing for surgery, but his family was worried about the risk. I don't think anybody realized he wasn't really living; he was barely surviving.

He had the surgery but still by the end of 2016, Terry was hospitalized back-to-back for four to five weeks at a time with pneumonia. He was on several antibiotics but getting worse. I was worried he wasn't going to make it to 2017, and when your advocate starts to give up hope, that's a bad story. At that point he'd seen every top specialist, and it was not looking good.

I tried to think of what we were missing. I thought back to when I used to work with infectious disease doctors. When no one else could find the issue, they could. We needed a fresh set of eyes because doctors had been missing something for 54 years.

I found an infectious disease doctor, and when they asked me what was wrong, I said "EVERYTHING!" I am not exaggerating, within 30 minutes, the doctor said that had Terry not been African American, he would have diagnosed him with CF, but he still wanted to rule it out.

We looked at each other, and said 'Wait a minute, that came up 17 years ago!"

They wanted to send him back to the children's hospital for tests, and we decided we didn't want to go. Finally, I told Terry that

he should just get that check in the box so they can really find out what's really wrong, even though it was wasting our time. We still believed the doctor from way back in 2000, and had ruled out CF. We had the tests done, and I got a phone call a few days later asking that he come back to repeat it. I asked what happened, if there had been a mistake, and the person I spoke to told me to ask the doctor. I thought they found cancer or something. We went back to repeat the test, and they asked if they could send the results to another hospital to confirm. Terry had CF.

Nobody knows the pain patients go through like the people closest to them. To see what he's gone through is just remarkable. This is a person who will do 100 miles on a bike, and then he's done, he's beaten everybody else, he's drenched in salt, he's dehydrated to the point of maybe having to go to the hospital, but he keeps going. He is also a certified Master Gardener and Master Naturalist, and he was Master Gardener of the year. His dream was always to be a Master Gardener, and when they selected him, he had to do the interview in his hospital bed. Ever since then he's been on the top garden projects, like maintaining the Governor's Mansion. We've been married 20 years, and if he's not hospitalized, he's at his mother's house every week, doing her yard.

Disparities happen when assumptions are made – sometimes on demographics, like race. About five percent of CF patients are African American. One misdiagnosed case is too many. There are no excuses. We need to see faces. ■

Cystic Fibrosis (CF)

Cystic Fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. Those with only one CFTR mutation are carries and do not have it. If both parents are carriers there is a one in four chance their child will have the disease. While there is no cure, life expectancy has steadily improved the median survival exceeding 45 years in the United States. Some other facts about Cystic Fibrosis are:

- There are now more adults than children with CF in the United States.
- Newborn screening for CF done on blood samples can identify most children before one month of age, which allows for early treatment and disease monitoring.
- Older children and adults are usually diagnosed based on symptoms, such as frequent respiratory infections, malnutrition, and/or male infertility.
- CF individuals have abnormally thick mucus, which blocks the airways (obstruction) and leads to repeated infections and damaging inflammation in the lungs. Treatments are directed at trying to prevent and treat these problems.

Learn more

ATS Patient Education Series. "20 Facts About Cystic Fibrosis." New York, NY.

http://www.thoracic.org/patients/patient-resources/resources/cystic-fibrosis-facts.pdf