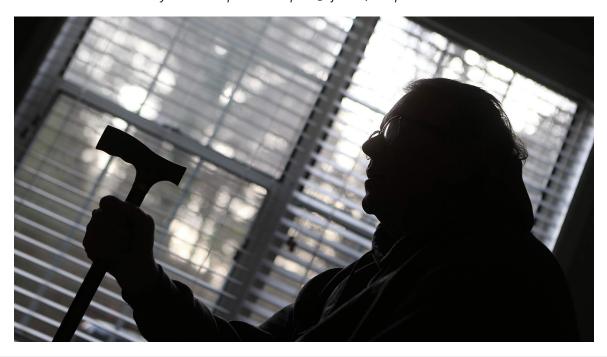
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Fixing to die

Battle with deadly superbug upends writer's life.

He's one of the lucky ones.

By Doug Monroe
For the Atlanta Journal-Constitution
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Photos by Curtis Compton / ccompton@ajc.com, except where indicated



On Feb. 6, 2015, I was a dead man riding.

I was strapped to a gurney in the back of an ambulance racing up I-75 in middle Georgia. A quick-thinking gastroenterologist in Atlanta had ordered my transfer to Piedmont Hospital from Oconee Regional Medical Center in Milledgeville.

It started three days earlier when I was teaching a writing class at Georgia College and State University.



Monroe was hospitalized for two five-day stints in February 2015. Contributed by Doug Monroe

I've been a writer for 44 years, including stints at The Atlanta Journal-Constitution, Atlanta Magazine, Creative Loafing and United Press International. But just as I approached the age when most people start planning in earnest for retirement, I changed careers to education.

I moved to Brooklyn and earned a master's degree in special education at night while teaching middle school near Coney Island. They say you're supposed to move to New York when you're young. I was 60. It was like going to another planet. I moved back south in 2012 to teach media writing at Georgia College.

In class one day last February, I started feeling woozy, like I was coming down with a bad cold. I went home, but I kept getting sicker with

diarrhea, extreme fatigue and a hacking cough. By Friday, I was so sick and disoriented that I woke up about 3 a.m. and struggled to find my way out of my bedroom. A few hours later, I called my doctor in Milledgeville, Reid Roberts, for an urgent appointment.

"I'm the sickest I've ever been," I told the receptionist.

I ran off the road twice before I got to his office 10 miles from my house. The nurse sat me down and slipped a cuff on my arm to take my blood pressure. It was so low, it didn't register. As I stumbled back to the examination room, I bounced off the wall and my pants, which I'd failed to fasten sufficiently, fell down.

"You seem very confused," Roberts said. "I'm calling an ambulance to take you to the hospital."

He thought I had the flu or pneumonia, but I'd had vaccines for both.

I spent most of the day at Oconee Regional Medical Center where they X-rayed my lungs and ran some tests. As the day wore on, I asked the emergency room doctor to call my gastroenterologist, Dr. Randy Yanda, who was treating me for

ulcerative colitis. He requested I be transferred to Piedmont immediately.

By the time I arrived at Piedmont that night, my white blood cell count was 59,000. It's not supposed to be over 10,000. The intensive care staff discovered I had Clostridium difficile colitis, commonly known as C. diff, a deadly superbug, often contracted at hospitals.

According to WebMD, Clostridium difficile is one of a thousand species of microorganisms that benignly reside in the human digestive tract. But when something upsets the balance, it can grow out of control and release toxins that attack the lining of the intestines. The result is virulent diarrhea so severe it can rupture the intestines. Spread via feces, C. diff spores can survive on dry surfaces for a long time. Its transmission can be prevented by frequent hand washing using soap. Nevertheless, medical facilities have become a breeding ground. More than 200,000 cases are reported every year.

I'll never know where I contracted C. diff, but I had undergone cataract surgery a few weeks earlier.

It turns out C. diff was only part of my problem. The bacterium had run so wild in my body, it had triggered septic shock. All systems were shutting down. My kidneys had failed. My lungs were infected. My heart was weak. My blood pressure was perilously low. Death beckoned.

My son Matt, a lawyer in Philadelphia, called to check on me.

Your father has a 30 percent chance of living through the night, a nurse told him.

I was 67, and I was fixing to die.

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'Not afraid to die'

I was too sick to be scared. But I knew I wasn't ready to die. My life to that point had been like a bumper-car ride at the fair. I hopped jobs. I drank too much until I quit at 35. I sank into deep depressions but kept climbing out. I got

divorced, but we had two amazing kids. I wanted to finish a book I've been working on forever. I wanted to see my grandson grow up. I had left so much undone that my heart ached.

I used to joke about my musical children: "I've seen both of my kids play at The Earl in East Atlanta. My life is complete."

But it wasn't complete. It wasn't nearly complete.

The intensive care unit doctor at Piedmont told me I needed so many drugs so fast that he wanted to put an IV in my neck. I signed a form acknowledging the procedure might produce a blood clot. The ICU staff saved my life.

C. diff is wildly contagious. Everyone who enters your hospital room has to wear a gown and gloves. After five days, I was released to stay with my sister, Trisha Campbell, in Lilburn. She cleaned everything I touched with bleach, just in case. She took care of me for two weeks.



Monroe recuperates at his sister's house in Lilburn following his two hospitalizations. Contributed by Doug Monroe

After nearly three weeks away, I was overjoyed to be back home. I loved Milledgeville, my house at Lake Sinclair, spending time at Flannery O'Connor's Andalusia Farm. But two days later, my right hand began to swell. Then my forearm swelled. The next day, my upper arm puffed up. I called the office of my gastroenterologist, Dr. Yanda, and his nurse told me to get to his office right away. They were shutting down at noon because a snowstorm was coming in. As an Atlanta native, I knew that even a hint of snow meant wild-eyed insanity on the roads. I floored it and got to Piedmont in less than 90 minutes.

Dr. Yanda took one look at my balloon of an arm and diagnosed a blood clot. He sent me to the emergency room next door. The ER doctor found

a deep vein thrombosis that extended from my neck to my right elbow. A nurse told me it could kill me. For the second time in a month I was looking at death.

I called my son, crying.

"I'm not afraid to die," I told him. The only thing that mattered to me now was family. Just family.

A pulsating catheter was inserted into a vein in my arm just above the elbow and antibiotics were administered one drop at a time. My arm was immobilized for two days, and then the catheter

was inflated to help break up the clot.

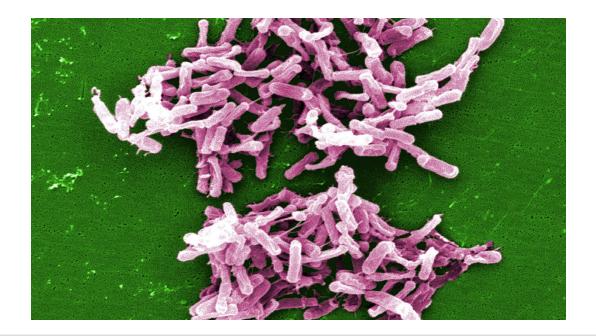
After my second five-day hospitalization that month, I was cleared to go home. I was prescribed the blood thinner Xarelto but grew alarmed watching a barrage of TV commercials from lawyers rounding up clients to sue the drug-maker for causing internal bleeding. That was a huge concern because my ulcerative colitis can cause bleeding.

My son, who has handled medical malpractice cases, told me to ignore the commercials and take the medicine anyway.

He flew in from Philadelphia and drove me to Milledgeville. We stayed in a motel because my house was so foul, from the effects of C. diff. He couldn't find a cleaning service, so he donned gloves and a face mask and attacked my house with Clorox to clean up the hideous mess.

Matt arranged for me to receive home health care visits several times a week through Medicare. I was so unsteady and disoriented I had to use a cane to walk, but mostly I just slept. My mind was in a fog. I filed for short-term disability. I kept hoping to return to teaching, but I carried a heavy load — five writing classes of 15 students each. The grading wore me out when I felt good. I just couldn't do it in a fog. I had to accept the reality I probably would never return to the classroom.

But before I could feel too sorry for myself, I started finding out how lucky I was.



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'Why are you alive?'

A mile north of me on Lake Sinclair, Ed Whiting was mourning the loss of his wife, Hope, to C. diff and sepsis seven months earlier. She had gotten strep throat in May and went to the hospital in nearby Eatonton, where a doctor prescribed an antibiotic. Her condition worsened and her doctor gave her a stronger antibiotic. She continued to get worse and developed nausea and diarrhea. Whiting took her to the emergency room at Oconee Regional, where she was diagnosed with C. diff.

She was so sick that doctors wanted to operate on her colon. Whiting decided to transfer her to Emory University Hospital. The ambulance attendant warned him that Hope probably wouldn't live through the trip. Infuriated, Whiting demanded the driver take her anyway. A surgeon removed her colon and small intestines. At one point she appeared to improve, but six days after arriving at Emory she died.

Whiting said an Emory doctor told him that if Hope had started taking probiotics along with the antibiotics, she might not have gotten so sick. Antibiotics can wipe out good bacteria, turning the intestines into a breeding ground for C. diff. Probiotics are intended to replenish the good bacteria.

"Why didn't anybody tell me that?" Whiting wants to know. "I lost the most important person in my life. I'm still angry about it."

He wonders why doctors didn't recognize her dangerous state before it was too late. Hope, who was 62, had been healthy. She walked six miles a day.

I, on the other hand, was already sick when I contracted C. diff. I had a compromised immune system from the ulcerative colitis. Both Hope and I were transferred from Milledgeville to top Atlanta hospitals. Why did I live and she die? One reason, perhaps, is that I was already taking a daily probiotic for the colitis. But one thing working against me was that I had started taking a "biologic" drug that carries a warning that it can make an infection worse. I didn't know I had an infection. When the C. diff kicked in, I just thought the colitis was flaring up.

When I was at Piedmont, I was given daily doses of a yeast-based probiotic, Florastor. Many other probiotics are bacteria-based and their effectiveness can be diminished by antibiotics.

After a while, I began making the rounds of follow-up visits to the doctors who had saved me. At one office, a nurse looked at my chart and said, "I have only one question: Why are you alive?"

Photo: A year after he got sick, Monroe still takes a multitude of medications, vitamins, and herbal remedies, as evident on his kitchen counter in Athens.

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Preventable death

As I tried to piece together what had happened to me, I learned that incidents of C. diff and sepsis are becoming increasingly more common.

Dr. Cliff McDonald, an epidemiologist at the Centers for Disease Control in Decatur, said 29,000 people a year die within 30 days of contracting C. diff. And it is no longer just a hospital-acquired infection.

"We have better data now," he said. "Twenty-three percent of all C. diff cases have the onset while someone is in the hospital. Around that many occur in nursing homes. But about half of the cases have their onset outside a healthcare facility. Thirty-five percent of the cases are community-associated, meaning they've had no overnight stay in a healthcare facility for the past three months."

That means you can get it anywhere.

While there are people like me who contract C. diff without taking antibiotics, McDonald said that antibiotics "make people vulnerable to C. diff — they kill a key component of the normal intestinal microbiome."

I asked him about the effectiveness of probiotics.

"The CDC does not have an official position," he said. "We don't make a recommendation for or against probiotics. There is evidence that they might work in preventing C. diff." Despite the lack of definitive clinical trials, McDonald said probiotics are considered by the FDA to be GRAS — "generally recognized as safe" for the general population.

Just in case, I take a probiotic every day. So does Ed Whiting.

I also discovered that I was among about half of Americans who didn't know anything about sepsis, the sudden condition that nearly took my life. I came across the Sepsis Alliance, which seeks to raise awareness of sepsis.

When you read an obituary that says someone died from "complications" from pneumonia, cancer or some other condition, it generally means they died from sepsis. The Eagles guitarist Glenn Frey recently died at 67 from "complications" of rheumatoid arthritis, ulcerative colitis and pneumonia. His manager blamed Frey's death on the medicine he was taking but didn't identify it. It sounded like a medicine I'm taking now.

Sepsis strikes 1.5 million Americans each year, killing 258,000 — more than breast cancer, prostate cancer and AIDS combined. Sepsis is the No. 1 reason patients are readmitted to hospitals. So far, Congress hasn't allocated any funds to fight it.

"It's incredibly common," said Thomas Heymann, executive director of the Sepsis Alliance. "It's very possibly the most preventable cause of death on earth."

Dr. James O'Brien, an ICU doctor at OhioHealth Riverside Methodist Hospital in Columbus, Ohio, is chairman of the alliance board. He got involved because "I got sick of telling three to four families a week they had lost a loved one to something they'd never heard of."

Sepsis is the body's overreaction to infection. "The body has an army to fight infection, the immune system," O'Brien said. "In sepsis, the body starts suffering friendly fire. Instead of shooting bullets at a bacteria or virus, the army is throwing hand grenades and lobbing mortars that damage the body itself."

It becomes septic shock when blood pressure becomes dangerously low.

The Sepsis Alliance website lists the symptoms of sepsis, but O'Brien summed it up simply: If you feel like you are the sickest you've ever been and have confusion or delirium, you should get to an emergency room as fast as you can.

I fit both of those descriptions.

The chance of surviving sepsis drops about 8 percent for every hour you are untreated. I was incredibly fortunate to survive. But I found out there was more to survival than going home from the hospital.

Sepsis survivors, lucky though we are, often suffer from post-sepsis syndrome, which can present as post-traumatic stress disorder. Some of the symptoms are fatigue, anxiety, depression and loss of cognitive abilities bordering on dementia. I call it brain fog. And because recurrence of C. diff is not uncommon, many of us live in fear of getting sick again.

A reason to live

Today, he spends as much time as possible with grandson Madoc Boyd near Monroe.



Photo: Monroe was forced to retire and move closer to family after he fell ill. Now an Athens resident, he takes frequent walks around the University of Georgia campus and downtown Athens as part of his recovery. PHOTOS BY Curtis Compton / ccompton@ajc.com

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A reason to live

As I slowly recuperated, I found myself watching a lot of TV, drifting in and out of naps. I cried at commercials. I didn't write a word for months. I embarked on

only one major social outing: my 50th high school reunion — Westminster, Class of 1965. It was a blast. The guys were still funny and the girls were still pretty.

No longer able to teach, I moved to Athens to be closer to my daughter, Caroline Boyd, her husband, Joe, and my grandson, Madoc, who live in nearby Monroe.

I rented a townhouse in west Athens in June. I was excited to be close to the University of Georgia, my alma mater. I looked forward to going to games, concerts, art exhibits and plays. I started to feel better and write again. I joined the YMCA to work out. Things were looking up.

Until I broke my back.

A former student was helping me move a bookcase. I felt something pop in my back. An MRI revealed I had a fresh compression fracture of a vertebrae and several older fractures. Because I had taken so much prednisone over the past decade for ulcerative colitis, I was diagnosed with "steroid-induced osteoporosis."

In July, it all came crashing down. My back hurt so much, I despaired of ever getting better. I was sick of the endless degradation of ulcerative colitis. The depression and brain fog were getting worse. I began to think about killing myself.

But instead of going to a gun show, I strapped on my back brace and drove to Smyrna to see my long-time psychiatrist, who helped me climb out of the abyss. I got into physical therapy and my back started to improve.

I've had setbacks. I went to see the new "Star Wars" movie, fell on the stairs in the dark theater and hurt my back again. My new primary care doctor has sent me to the emergency room twice for swelling in my feet and ankles to check for blood clots. None so far.

I'm making progress with physical therapy. I got fitted with a new back brace. The guy who delivered it said I needed an XL to fit my "pendulous stomach."

"That's not very nice," I said.

I weighed 218 that morning, down from a steroid-bloated 265 a couple of years back. I've cleaned up my diet to avoid sugar, gluten, soy and dairy. I know that a poor diet has led to many of my health problems.



Monroe monitors his weight daily at his home

After this year of living precariously, I want to live.

The main reason is this funny little guy down the road.

My grandson, Madoc, is 21 months old.

I cautiously stayed away from him for a long time after I got C. diff. But I've stepped up my visits. He calls me "Papa." We had wonderful holiday celebrations at my daughter's house.

My son and his wife, Jen, came down for Thanksgiving. Matt started poking fun at me again after so many serious months.

When I mentioned to him that my back problems were causing me to shrink — we used to be the same height, almost 6 feet, 2 inches; now I'm 5 feet, 10 inches — he looked down at me and said, "Dad, you're becoming a hobbit."

On Christmas morning, as Caroline led Madoc into their den to see the toys Santa left him, he stopped and let go of her hand. Spotting my cane on the floor, he picked it up and handed it to me. Only then did he dig into his loot.

I cherish that moment. I cherish life.

Now that he lives nearby, Monroe often visits his daughter, Caroline Boyd, and her son Madoc at her home in Monroe.



Behind the story

Monroe has an hour-long session of stretches and exercises with his physical therapist, Heather Jones, at Athens Neuro & Balance Rehabilitation in Athens.



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ABOUT THE STORY

I was just starting my newspaper career when I first met Doug Monroe. He was editor of the Cobb Extra, a now-defunct neighborhood edition of the AJC. I made an appointment with him, hoping he'd give me a job. I'll never forget him taking the time to carefully read through all my clips while I sat there silently fidgeting on the other side of his desk. When he was done, he broke the news that he had no openings, but then he praised my writing in a way no one ever had before. He advised me to get on a daily, any daily, and to keep at it. I took his advice; it has served me well. Being able to share his story today is so gratifying for many reasons. But mostly I'm just glad he's still here and healthy enough to tell it.

Suzanne Van Atten
Personal Journeys editor
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ABOUT THE WRITER

Doug Monroe is an Atlanta native who worked for The Atlanta Journal-Constitution for 13 years. During that time he wrote a column about traffic called "Monroe Drive." He was also a writer for Creative Loafing, Atlanta Magazine and United Press International.

ABOUT THE PHOTOGRAPHER

Curtis Compton joined the AJC as a photo editor in 1993 before returning to the field as a staff photographer. Previously he worked for the Gwinnett Daily News, United Press International and the Marietta Daily Journal. He has a bachelor's degree from the University of Georgia and won a World Hunger Award for his coverage of the famine in Sudan.

Read the story of another former AJC staffer's battle with c. diff.

(http://www.myajc.com/news/lifestyles/med ical/please-wash-your-handsplease/nZ8RN/)

