



IS YOUR DOCTOR MISSING THE MARK

?

The experts aren't always right about what's wrong with you, and those errors can endanger your health—and even your life. SHAPE investigates why a growing number of people are being misdiagnosed and uncovers what you can do to stay safe.

BY KAREN ASP | PHOTOGRAPHY BY TRAVIS RATHBONE

Four years ago, Erin Morrissey, 25, was walking to class at Syracuse University when she sensed something was seriously wrong. Her heart began pounding, her head was spinning, and she felt a stabbing pain in her back. “I thought I was going to pass out,” she recalls. Morrissey managed to keep it together until she reached the nearby student health center, where the nurse took one look at her and summoned an ambulance.

At the ER, doctors determined that Morrissey was having an allergic reaction to antibiotics she was taking for a sinus infection. They gave her IV fluids and sent her back to her dorm, assuring her she’d feel better after a few days of rest.

But instead of improving, Morrissey’s condition continued to worsen over the next several weeks. Her joints ached, she felt confused and forgetful, and she suffered dizzy spells. She was also constantly exhausted. “I was too tired to socialize or study,” she says. “I mostly stayed in bed.” When she actually tried to sleep, however, it was difficult to drop off.

Feeling so drained quickly took a toll on her schoolwork. As she got sicker, Morrissey frequently sought refuge at her parents’ house in Connecticut. There she consulted another doctor, who said she had a severe case of mono. In January she made the difficult decision not to return to school for the spring semester.

“At that point, I was almost completely bedridden,” says Morrissey. “I used to be so athletic—I played three sports in high school—and there I was, unable to even get dressed or walk down the hall without someone supporting me.” The inconclusive interventions continued: trips to the emergency room for severe heart palpitations and consultations with numerous specialists, including a rheumatologist who examined her swollen joints to rule out rheumatoid arthritis. “My life was completely taken over by this mysterious illness,” she says.

One day, musing about her seemingly endless list of odd symptoms, Morrissey remembered that a friend had once told her of being ill as a child with Lyme disease, a bacterial infection transmitted by infected ticks. On a whim, she contacted her and was shocked that many of their experiences were similar,

even though Morrissey never had classic signs like a “bull’s-eye” rash. She visited a Lyme specialist, who ran a blood test and gave her what she’d desperately wanted for months: an accurate diagnosis.

Morrissey still had a long recovery ahead of her, including two years on oral and intravenous antibiotics. “But I was able to finish college by taking online classes,” she says. “Most important, I was just so relieved to finally have an answer.”

ROOM FOR ERROR

Morrissey’s journey through a befuddled medical community might sound like something out of another century, but it’s surprisingly common. “With about 10,000 conditions that could affect the human body, diagnosing a patient is one of the most difficult things doctors have to do,” says Mark L. Graber, M.D., senior fellow at RTI International and founder and president of the Society to Improve Diagnosis in Medicine. Though research on the topic is murky, experts estimate that 10 to 20 percent of physicians’ diagnoses are incorrect.

“It took almost my whole life to get the right diagnosis because no one person had asked me enough questions.”

Recent survey results from the medical publishing firm Wolters Kluwer Health suggested that more than one in five Americans believe they’ve been misdiagnosed by their doctor. Some stats hint at even higher numbers, including those from Best Doctors, a global health organization, which found that 29 percent of U.S. medical cases have needed to be refined or corrected because the original conclusion was wrong.

Admittedly, medical misidentifications aren’t always critical—mistaking eczema for rosacea, for example, probably won’t inflict lasting damage—but often the consequences are far more serious. Each year, between 40,000 and 80,000 U.S. hospital deaths are directly related to a diagnostic mistake, and a similar number of patients suffer permanent injuries, according to David Newman-Toker, M.D., Ph.D., a patient safety

researcher and associate professor at Johns Hopkins School of Medicine.

Even more alarming, those numbers appear to be on the rise, says Newman-Toker, partly because the population is both growing and aging, creating more opportunities for missteps. But the reasons for the increase go beyond simple demographics, says Evan Falchuk, vice chairman of the Boston-based Best Doctors: “Misdiagnosis is a symptom of a deeper problem in the health care system. There aren’t enough doctors, information, or time.”

“A primary care physician might see 30 to 60 patients in a given day, and if he’s hurrying to move on to the next person, he’s more apt to miss something,” says Newman-Toker. And although the length of office visits hasn’t changed much over the past few decades—the average is less than 20 minutes—today doctors spend only about half that time focused on the patient, he explains. “The rest is spent filling out paperwork.” Medical records pose a further problem, now that most people see several specialists rather than one family doc, leaving the onus on the

patient to keep each provider informed.

Sheri Kippins, 40, spent more than three decades bouncing between a variety of physicians. As a child, her hands, feet, and belly began swelling—symptoms her pediatrician attributed to allergies. Over the years, other doctors suggested and then ruled out everything from lupus to rheumatoid arthritis. In her early 30s, when her face became bloated, Kippins saw an allergist who finally figured out that she had hereditary angioedema, a rare immune system disorder.

“It took almost my whole life to get the right diagnosis because no one person had asked me enough questions,” she says.

FATAL MISTAKES

The worst-case scenario, of course, is when a doctor’s failure to get it right involves a life-threatening illness. Cancer



Not getting better? Your doc might need a new strategy.

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is one of the most commonly misdiagnosed conditions (along with psychiatric and neurological disorders, partly because of the tendency to assume that symptoms are all in your head). “Abnormal findings related to certain types of cancer are missed initially almost a third of the time,” says Hardeep Singh, M.D., chief of the health policy, quality, and informatics program at the Houston VA Health Services Research Center of Excellence. In some cases, imaging tests and biopsies are hard to interpret; in others, signs of the disease might be dismissed because they’re often associated with less serious complaints (blood in the stool, for example, can be a symptom of colon cancer or just hemorrhoids).

Figuring out when to investigate the less likely—but far more serious—scenario isn’t easy, and doctors sometimes get it wrong, as 28-year-old Tara McCarthy found out the hard way. She was only 16 when she developed a cough that plagued her whenever she was lying down. She was otherwise healthy and even played on the varsity tennis team, so her doctor blamed allergies. He prescribed a variety of meds, none of which helped. She returned to his office at least four times for more tests, but over the months her hacking only got worse, eventually waking her up every night. She also developed a walnut-size lump on the left side of her neck.

“I kept wondering about cancer, because my dad had passed away the year before from a brain tumor,” says McCarthy, an associate art director at SHAPE. But it wasn’t until she remembered the details of *Man on the Moon*, the biopic about comedian Andy Kaufman, that something really clicked. “He was a vegetarian and a nonsmoker, like me, yet he ended up with cancer.”

McCarthy returned to her doctor again and this time insisted on a chest X-ray. He ordered the test—reluctantly. “He kind of laughed and said, ‘I really don’t think it’s cancer,’” she recalls. But her hunch was spot-on: She had a huge mass taking up much of her chest cavity. A subsequent lymph node biopsy revealed it was stage 2B Hodgkin’s lymphoma.

McCarthy is convinced that she ended up needing much more treatment—including radiation, 12 rounds of chemotherapy, and a painful procedure that drained 10 ounces of fluid from

IT HAPPENED TO THEM



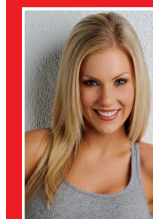
Erin Morrissey
Hometown: **Los Angeles**
Age: **25**
Original diagnosis: **Severe mono**
Correct diagnosis: **Lyme disease**
Time it took to get it right: **8 months**



Sheri Kippins
Hometown: **Atlanta**
Age: **40**
Original diagnosis: **Allergies**
Correct diagnosis: **Hereditary angioedema**
Time it took to get it right: **30+ years**



Tara McCarthy
Hometown: **Spotswood, NJ**
Age: **28**
Original diagnosis: **Allergies**
Correct diagnosis: **Hodgkin’s lymphoma**
Time it took to get it right: **7 months**



Shannon Ford
Hometown: **Miami**
Age: **36**
Original diagnosis: **Irritable bowel syndrome**
Correct diagnosis: **Celiac disease**
Time it took to get it right: **7 to 8 months**

around her heart—than she would have if it hadn’t taken seven months to get a proper diagnosis. She missed months of school and needed a blood transfusion, and even though she recovered completely, she must get yearly mammograms and MRIs because being treated for lymphoma has raised her risk of breast cancer. Like many victims of misdiagnosis, McCarthy contemplated suing her physician, but she ultimately decided against it.

PLAYING DEFENSE

Doctors can be just as concerned about getting it wrong, says Deanna Attai, M.D., director of the Center for Breast Care in Burbank, CA. “It’s an issue that many of us worry about.” And that is

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something you can use to your advantage in dealing with your doctor, says Kerm Henriksen, Ph.D., human factors advisor for patient safety with the Agency for Healthcare Research and Quality in Rockville, MD. He advises starting a dialogue with her: “As a patient, you have the right to question your physician,

gastroenterologist was ready to schedule an invasive and expensive colonoscopy for me when the blood work was quick and cost less than \$100,” says Ford. She cut all remaining gluten from her diet, and her digestive issues began to dissipate.

The lesson from Ford’s experience is to trust your instincts. Indeed, experts

Don’t hesitate to seek out a second opinion—particularly if your condition is serious or requires surgery. “You can’t ever un-operate.”

especially if you think something has been missed or if your ailment continues. You have to be your own advocate.”

That skepticism may have saved Shannon Ford’s life. She started to feel ill four years ago, just after returning from a business trip. At first she blamed it on stress; she worked as a human resources manager and had been traveling the country laying people off. “But I just couldn’t shake the fatigue,” says Ford, 36. She also felt gassy, often to the point of pain, whenever she ate bread or pasta, and was plagued by diarrhea and constipation.

Her doctor referred Ford to a gastroenterologist, who diagnosed her with irritable bowel syndrome. He told her to eat more fiber, which made things worse. Then a friend suggested she try avoiding gluten—a protein found in wheat, rye, and barley—and when she did, her symptoms began to subside.

Ford returned to the specialist and asked him if she might have celiac disease, a condition in which people are unable to tolerate gluten. Left untreated, celiac can interfere with nutrient absorption from food, damage the small intestine, and even lead to fatal complications. “But because I was gaining weight, not losing it like you normally do with celiac, he dismissed that possibility and didn’t test me for it,” she says. Instead, he suggested she undergo a colonoscopy.

Concerned that her weight gain could be a sign of hypothyroidism, Ford turned to an endocrinologist. When she mentioned her digestive issues to the second doctor, he ordered a test for celiac disease as well as thyroid function. The result: positive for celiac, negative for hypothyroidism. “I couldn’t believe the

stress that taking an active role in your health care can help keep you safe. The main strategies to employ:

MEET YOUR MATCH As with dating, you need a doctor you can talk to comfortably. If he makes you feel like a hypochondriac for asking lots of questions or discussing strange symptoms, dump him and find someone new.

GET PREPPED Don’t assume your busy doctor remembers everything about you, even if you’ve been seeing her for years. “Go armed with a clear, one-page timeline of your symptoms,” says Newman-Toker. You should also bring a list of any meds you’re taking, copies of relevant test results (including those ordered by other physicians), and some basic details about your personal and family health history.

EDIT YOURSELF Exam time is precious, so get right to the point, starting with your most pressing concerns. (Resist the urge to recount everything you’ve read on the Internet about your problem.)

GET EXTRA INPUT Even if you trust your physician, don’t hesitate to seek out a second opinion—particularly if your condition is serious or requires surgery. “You can’t ever un-operate,” Falchuk points out. It’s very common for patients to ask multiple experts to weigh in, so there’s no need to feel like you’re “cheating.” When you go for the supplementary consult, share only the info about your symptoms—and not your initial provider’s diagnosis, says Falchuk. “You want each doctor to look at your case with a fresh eye.”



RED FLAGS

A misdiagnosis can happen in any situation, says Elizabeth Cohen, senior medical correspondent for CNN and author of *The Empowered Patient*. But these three signs should tip you off that you could be entering dangerous territory and need to ask more questions or get another opinion.

1. The treatment that your doctor recommended isn’t helping.

2. Your complaints are common, but he diagnoses you with an obscure illness.

3. Your symptoms sound like they could match several conditions, yet your doc can’t explain why she chose one over the others as the root cause of your problems.

BE PERSISTENT If your doctor’s diagnosis just doesn’t sit right with you or you’re confused about it, keep asking questions: What else could this be? Are there any dangerous causes of these symptoms? What makes you think it’s this problem and not something else? If he can’t answer you—or if he’s so overconfident that he’s not willing to entertain any other possibilities—find another provider, says Newman-Toker.

In the end, standing up for yourself is key. Shannon Ford said she was initially afraid to disagree with her doctor, but she’s relieved she didn’t just accept his conclusions as fact. “If you’re not feeling well and you know something’s wrong, you owe it to yourself to keep pushing for the right answer.”

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