# Wrong!

Doctors misdiagnose 1 in 20 patients, with consequences that can be deadly. Find out why these mistakes occur—and what you can do to make sure they don't happen to you.

BY ROCHELLE SHARPE
ILLUSTRATIONS BY ANDREA DE SANTIS

DENISE CORNWELL had felt the lumps for years. Solid and small, about the size of tiny olives, they popped up from time to time inside her upper thighs, just below her groin.

Mostly minor annoyances, they bothered her enough that she mentioned them at her annual checkups. For 7 years, her doctors dismissed the complaints, saying she probably had a minor infection that had caused her lymph nodes to swell.

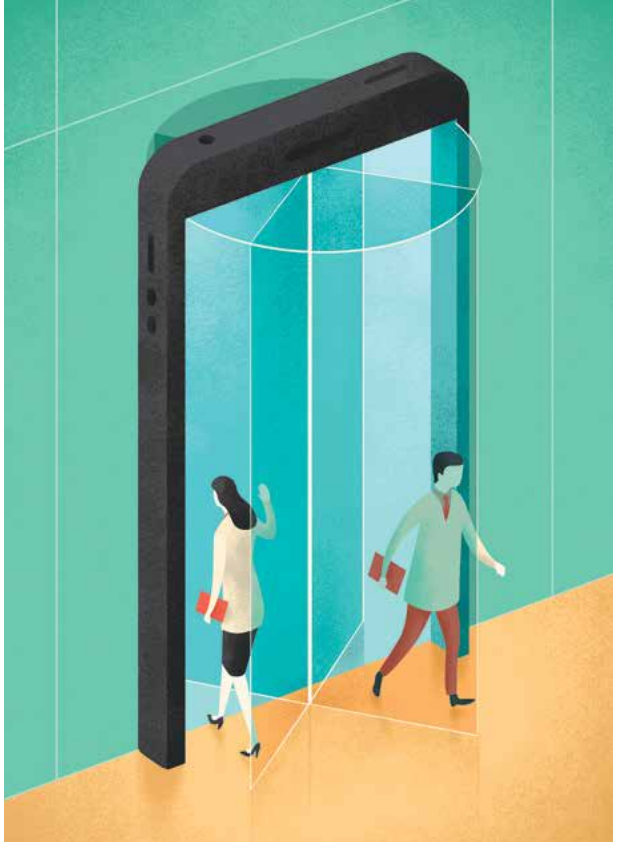
Then, in 2010, Cornwell discussed the nodules with her gynecologist, who diagnosed her with syphilis and gave her a shot of penicillin. Shocked and angry, Cornwell confronted her partner, who immediately got tested and learned he was negative for the sexually transmitted infection. As Cornwell started to question her diagnosis, she was confronted with a new symptom, a rash on her neck, which doctors then incorrectly diagnosed as eczema. The rash was actually an allergic reaction to the penicillin. But developing the rash had one positive result: It made Cornwell look more closely at her neck and notice the enlarged lymph nodes near her collarbone.

Cornwell went to yet another doctor and finally received the correct diagnosis: non-Hodgkin follicular lymphoma, a slow-growing cancer that had, over the years of misdiagnosis, advanced to stage 4. Even so, Cornwell was lucky. After treatment, her cancer went into remission. "The syphilis misdiagnosis actually saved me," says Cornwell, 48, who lives in a small town 50 miles from Chapel Hill, NC.

It's rare for a misdiagnosis to aid a patient's recovery. At best these medical errors result in a delay of needed treatment. At worst they can kill. And misdiagnosis is distressingly common. "Most people will experience at least one diagnostic error in their lifetime," the Institute of Medicine concluded in a landmark report in 2015, which stated that improving the diagnostic process was "a moral, professional, and public health imperative." Twelve million adults are misdiagnosed every year in doctors' offices and other outpatient settings, the report said. That's about 1 in every 20 patients.

"Everybody's got a story," says Gordon Schiff, quality and safety director at Harvard Medical School's Center for Primary Care. He has four himself, including his bout of food poisoning, which was misdiagnosed as appendicitis, and his collapsed lung, with symptoms that were misconstrued as medical school anxiety.

The most common mistakes involve the most common conditions. Cancer, heart attacks, and infections like sepsis and pneumonia are missed most frequently, patient safety experts say. In one large study of malpractice claims, nearly a third of all diagnosis-related complaints involved cancer. Yet only recently did misdiagnosis become the focus of the nation's burgeoning patient safety movement, which for years had concentrated on medical errors that are easier to correct, such as drug dosing mistakes and hospital hygiene.



**The Doctor's Not Listening** Miscommunication is one of the most common reasons for patients to be misdiagnosed.

Now researchers, educators, patient safety advocates, and a wide variety of health care professionals are banding together to tackle this seemingly intractable problem, discovering how complicated the issues really are.

Sometimes diagnostic mistakes have less to do with medical knowledge than with the way doctors think. Mounting workloads, harried interactions between doctors and patients, the load of electronic medical records, and the increasing complexity of the health care system all add challenges.

## DEADLY MISTAKES

After a misdiagnosis, not all patients are as fortunate as Denise Cornwell. Diagnostic errors are the most common type of paid medical malpractice claims, with one of every four paid claims involving such mistakes.

Last fall, an Ohio jury awarded $1.9 million to the family of Lisa Born, a 31-year-old woman who died after a misdiagnosis. According to court documents, she had gone to University Hospital's health center in suburban Cleveland in October 2014, complaining about excruciating pain in her leg and chest as well as shortness of breath. A doctor briefly examined her and diagnosed her with sciatica, recalled her mother, Linda Born, who had accompanied her daughter to the health center. Linda, concerned about Lisa's extreme pain, frantically questioned whether the nerve compression diagnosis made sense. Mother and daughter left the health center with

potent painkillers and lots of doubt, deciding they would seek a second opinion the next day.

But 4 hours later, Lisa was dead. An autopsy revealed she had died of a pulmonary embolism, after a blood clot traveled through her body and lodged in her lungs. She had the condition's classic symptoms and at least quadruple the risk of developing blood clots because she took birth control pills. Yet the hospital had not conducted a simple blood test that could have detected whether she might have the condition. "This didn't have to happen," said Linda, distraught that the doctors had dismissed her questions. "They didn't listen." (Linda spoke to *Prevention* last fall but has refused to comment further due to a recent court settlement.)

## COMMUNICATION SNAFUS

Many diagnostic errors arise from communication missteps, especially in hectic emergency departments and busy outpatient clinics where doctors are in such a rush that they can easily get distracted. The frantic pace may mean that doctors don't have time to listen to their patients' stories or to consult properly with other doctors when in doubt. And the medical system is so fragmented that doctors may never find out that a diagnosis they made was wrong, making it impossible to learn from mistakes.

The lack of communication also applies to abnormal test results that may get lost in the confusion. Studies have found that about 7% of abnormal lab results and 8% of abnormal imaging tests are not communicated to the patient or acted upon by the doctor within 30 days. "No news is not necessarily good news from the doctor," says Hardeep Singh, a leading patient safety researcher at the Michael E. DeBakey VA Medical Center and an associate professor at Baylor College of Medicine. When doctors don't talk with each other about a patient they're both caring for, it gets even more difficult to reach the correct diagnosis.

The problem is especially worrisome at walk-in clinics, where patients may see a different doctor every time they seek medical help, says Gary Nielsen, a medical malpractice attorney in Lake Success, NY.

One of Nielsen's clients, a roofer, went to such a clinic five times within a few months, the attorney says, and was told each time by various doctors that he had bronchitis. Until the man was hospitalized, none of the doctors had considered alternative explanations, Nielsen says. Tests showed that he actually had endocarditis, a dangerous inflammation of the heart lining, which had been left untreated for so long that he had to have a heart valve replaced. Nielsen says if the doctors had spoken with each other or even reviewed each other's notes, the condition would likely have been diagnosed earlier.

## TECHNOLOGY GLITCHES

As doctors and hospitals shift more medical records from paper files to digital ones, they're discovering both the benefits and the problems of new

# Help Your Doctor Get It Right

**Doctors have a wealth of medical knowledge and an arsenal of tests to help them make a diagnosis, but patients' input and participation are vital, too.**

### GET YOUR RECORDS.

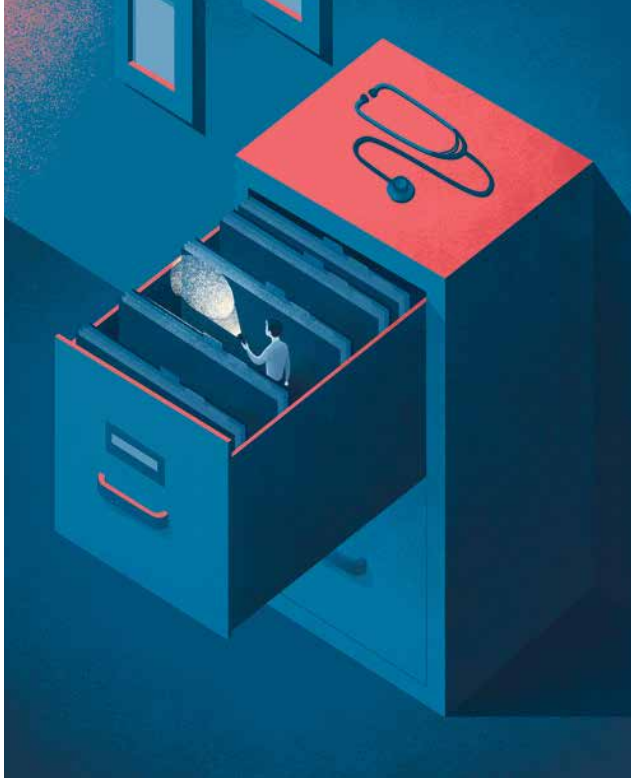
"We all assume the records are stored and doctors have access to them," said Mark Graber, president of the Society to Improve Diagnosis in Medicine. "Often, they don't." That's because patients may get their care in different health systems, which don't share records, even electronic records, with one another. Also, over the course of one illness, patients may change doctors and treatments. There is only one constant: the patient. Call all your providers and ask for your records so you have them all in one place.

### TELL YOUR STORY WELL.

You may get only a few minutes with the doctor, so use them wisely. It may help to jot down notes and practice what you'll say a few times in advance. Describe your problem succinctly and highlight your main symptoms, including what may exacerbate them, experts say. And try to be polite. Patients who are considered difficult—that is, too aggressive or demanding—have a 42% greater chance of being misdiagnosed than those who are more neutral, concluded a study published last year in *BMJ Quality and Safety*.

### ASK THE GOLDEN QUESTION: WHAT ELSE COULD IT BE?

With those five words, patients can sometimes prevent their doctors from making cognitive errors. "You're helping your doctor think outside the box," says Io Dolka, who recently launched GreyZone, a Seattle-based company that helps patients with difficult-to-diagnose conditions. It's also useful to ask the doctor if two things could be going on at the same time, she says. "Physicians often look for a unifying diagnosis, but sometimes two different disease processes could be at play."



**Looking for Clues in the Files** Paper medical records are going digital. That has its advantages—but can compound mistakes.

technology. The pluses are obvious and include faster updating, easier sharing with other doctors, and a decreased risk of lost records. But one problem stands out: If an error is made in an electronic record, it may be automatically carried over and added to new files, creating long-term repercussions.

Consider what occurred at Texas Health Presbyterian Hospital in Dallas in 2014, while the nation was on high alert for Ebola. When Thomas Eric Duncan walked into the hospital's emergency room, he had a severe headache, stomach pains, and a high fever. He told a nurse he'd recently spent time in Liberia, an Ebola hot spot at the time. But after 4 hours, he was discharged with a diagnosis of sinusitis and a prescription for antibiotics. Two days later, Duncan felt worse and returned to the hospital. Within a week, he was dead, the first person in the United States to die of Ebola.

An analysis by Singh and his colleagues suggests that the errors responsible for Duncan's initial misdiagnosis are endemic to many hospital systems and could have happened almost anywhere. In this case, Duncan's electronic medical records showed he had no fever or chills, probably because the doctor mistakenly clicked on the wrong box in a template, Singh wrote in a detailed examination of the incident. The man's travel history had been input but had been buried in electronic notes that included many other types of documentation, such as records that had been specially designed to show whether patients had received their flu vaccines. If the doctor had read the nurse's notes about the patient's travel history, or if the nurse had verbally communicated the red flag about that travel history to the doctor, it's likely that Duncan would have been diagnosed with Ebola earlier.

## JUMPING TO CONCLUSIONS

Diagnostic mistakes may also occur because of cognitive biases that cloud doctors' judgment, says Mark Graber, president of the Society to Improve Diagnosis in Medicine. Such biases happen when doctors, like all of us, make assumptions about people based on their own beliefs or past experiences instead of rational judgment. A doctor might not diagnose a fit, younger patient with heart disease, for example, but that might be the go-to diagnosis for an older, overweight person.

Doctors may also show bias in how they treat patients based on their appearance. Velma Payne, a researcher with the Department of Veterans Affairs, says that women, the elderly, and those who look disheveled report having a particularly hard time being heard when they complain of pain. And when she studied 35 people who had been misdiagnosed, she found that few of the patients felt they had been taken seriously by their doctors. An exception: "One woman purposely wore a business suit to every appointment so she would be viewed as competent and professional," says Payne. "Doctors may jump to conclusions," especially when they're under time pressure, adds Graber.

**In a study of people who'd been misdiagnosed, few felt their doctors had taken them seriously.**

Psychologists have identified other types of bias, too, and some may be at least partially responsible for the high rate of misdiagnosis. With anchoring bias, people place too much importance on the first piece of information they receive. Those with confirmation bias interpret new evidence as supporting their beliefs even when it may point to another diagnosis. It's easy to see how a misdiagnosis can happen if doctors hold on to an initial impression despite new evidence to the contrary.

Peggy Zuckerman, 67, of Long Beach, CA, says she almost died because of her doctor's biases. When she went to a California emergency room with severe anemia 13 years ago, the doctor, a gastroenterologist, found what looked like a tiny, scabbed-over stomach ulcer in one of her initial tests and said her anemia was caused by an ulcer.

Zuckerman took the prescribed medication, but her condition worsened. She underwent more tests, which showed no signs of an ulcer, she says, but the doctor thought her stomach looked red and stuck to his original diagnosis. Sicker than ever, Zuckerman then had an ultrasound of her liver, which detected a softball-size mass on her kidney. Six months after her original diagnosis, she was found to have kidney cancer that had spread to her lungs.

After recovering from intensive treatment, Zuckerman began combing through her medical records to figure out why she had been misdiagnosed. She made two stunning discoveries. First, the emergency room doctors had recommended that she be followed by a rheumatologist or a hematologist, not the gastroenterologist the hospital had assigned. More important, she saw that her pathology report showed that she did not have an ulcer. "If the doctor had paid attention to the report, he might have asked the golden question: What else could it be?" she says.

## QUESTIONING AUTHORITY

Now Zuckerman works as a patient safety advocate, trying to help others avoid misdiagnoses. Her advice: "Get all your records and read them," she says. "Failure to get them is harmful to your health." Patients may find important information that has been overlooked and may spot mistakes that, if not corrected, could cause problems with their future medical care.

Patients should also seek a second opinion when a treatment isn't working, advocates say. Finding a doctor who specializes in a different field can sometimes be helpful. "Boundaries are so distinct between specialties, it gets in the way of patient care," says Jeanne McArdle, 57, of Manlius, NY. She went to orthopedists on and off for 40 years before a rheumatologist told her she had Ehlers-Danlos syndrome, a genetic disorder that causes hypermobile joints and skin disorders. The orthopedists kept referring her to physical therapists, who gave her exercises that exacerbated her symptoms, she says.

"If you hear of a medical miracle, chances are the person was misdiagnosed to begin with," says Trisha Torrey, 64, a patient safety advocate who was told in 2004 that she had a rare form of cancer that would kill her within months. When her blood work and CT scan did not show evidence of cancer, she told her oncologist she wanted to get a second opinion before starting chemotherapy. "He told me I was wasting my time," she recalls. The doctor she saw for a second opinion arranged for her tumor tissue sample to be sent to the National Institutes of Health, where it was found to be benign.

Many patients hesitate to question doctors, who are often viewed as authority figures. But the Internet is changing that, as it makes medical knowledge more readily available, giving patients information to bolster their questions and concerns. When Torrey got sick, she "Googled the living daylights out of everything," she says. (Of course, the Internet is full of false information, too. See the sidebar at right for a list of resources—online and off—that provide trustworthy information for questioning a diagnosis.)

It's smart to walk into a doctor's appointment with a working hypothesis and a basis for conversation, says Helen Haskell, 65, of Columbia, SC, who founded Mothers Against Medical Errors. Adds McArdle: "I understand that they went to medical school and I didn't." But that doesn't stop her from reading medical records and reports. "They're my experts. But it's my life."

Hospitals, medical schools, and physicians are taking steps to reduce the number of diagnostic errors, too. For a start, many doctors are less dismissive of patients and more aware of the potential for harm, patient advocates say. More than ever, doctors see the value of sharing information and listening carefully to patients in this increasingly fragmented, fast-paced medical world. And they're more willing to examine their work habits for flaws, no longer content to keep the focus of the patient safety movement on errors like medication mix-ups.

The Institute of Medicine report on misdiagnosis highlights eight goals for reducing errors. These include professional education and training, more accurate use of technology, and working environments that promote effective communication and testing. But perhaps the biggest goal is increased collaboration—among health care professionals, patients, and families—so everyone works as a team to figure out what's wrong. "Doctors don't make the diagnosis alone," Schiff says. "The diagnosis is coproduced by doctors and patients working together."

## If You Think You've Been Misdiagnosed...

**Follow the advice of patient safety advocates: Trust, but verify.**

If you're questioning a diagnosis, these steps can help you get to the truth.

- **Talk with a librarian at a local medical school or contact one online.** The Society to Improve Diagnosis in Medicine has a free program called Expert HealthSearch that connects patients with medical librarians (*improvediagnosis.org/page/experthealthsearch*).
- **Search PubMed** to inspect medical publications from around the world (*ncbi.nlm.nih.gov/pubmed*).
- **Get a second opinion from Best Doctors,** a Boston-based company that connects people with medical experts.
- **Do an Internet search.** Even better, go directly to reliable websites, such as *medlineplus.gov* and *mayoclinic.org*. Helen Haskell, founder of Mothers Against Medical Errors, likes *uptodate.com*, an evidence-based site for doctors that's available to the public for a fee.
- **Join an online community,** such as Smart Patients or Inspire, where patients can learn from one another.
- **Resist the temptation of unreliable information,** such as that from drug advertisements and personal anecdotes, advises Gordon Schiff, quality and safety director at Harvard Medical School's Center for Primary Care.