

Dx IQ #10:

How to know if your diagnosis is right or wrong

By Helene M. Epstein

BOX COPY: *Diagnosis is a journey. Over [the past five months](#), this column has taken you through the [various steps of that journey](#) to help you get an accurate diagnosis. Last month we focused on [how to protect yourself against medical testing's dirty little secret](#). Each month we've shown you where the pitfalls may be, how to be proactive, and how to partner with the healthcare team to reduce your risk. [If you want an overall look at how misdiagnosis happens, [click here](#).]*

Michele (not her real name) was just 12 years old when she started to have severe stomach pains. Her pain level was high enough to interrupt school, sports, and parties. Her mother says she would come home and just “lay in a ball and shut out the world.” After about a year of on-again, off-again symptoms, she was brought to her pediatrician for an exam. Michele’s doctor ran some tests that didn’t indicate any problems. He reassured her that her bowels were fine.

Perhaps you’ve recently visited your healthcare professional because you’ve had symptoms that concerned you. Like Michele, you’ve been examined, perhaps your blood or urine was tested, or imaging tests were run. Finally, after several steps, your doctor diagnosed you and gave you a treatment plan. Perhaps you have medications to take or changes in diet and exercise or both. Or perhaps your doctor felt that your symptoms weren’t serious enough to require treatment, which is a diagnosis too.

If the treatment works, than perhaps the diagnosis was correct and you are on the right track. If the therapy doesn’t work, it could be a misdiagnosis or something else.

Thomas Westover, MD is an associate professor of maternal fetal medicine at Cooper Medical School and a New Jersey-based expert in high risk pregnancies. He explained his theory of why some patients don't get better after therapy or treatment. He offers eight possible reasons:

1. The diagnosis was wrong. This is different from the [“working diagnosis”](#) which is part of the normal process of identifying the source of your symptoms. There are [lots of reasons](#) why a diagnosis can be wrong.
2. The diagnosis was partially correct, for example the patient was diagnosed with a urinary tract infection. The first line of treatment is usually oral antibiotics that treat E coli, the most common bacteria. However, urinary tract infections can be caused by other bacteria, or even yeast, so the treatment fails.
3. The patient has a second condition that is now arising, for example an HIV patient who has also developed an infection due to his depleted immune system.
4. The therapy was correct, but the patient is experiencing side effects. Side effects of medicines are very common, ranging from minor to serious adverse effects.

5. The chosen treatment was correct, but it was prescribed or administered incorrectly; either by the doctor or the patient. For example, some people diagnosed with diabetes need to use insulin at home to control their sugar levels. However, administering insulin isn't easy. There are a lot of steps and the instructions can be very confusing. [So confusing that a "high percentage" of diabetics miss steps or don't follow them correctly.](#)
6. The therapy was not completed fully. This often happens when a patient is driven to stop taking a medicine or participating in treatment, perhaps because the side effects are too troubling or the cost is out of reach.
7. The therapy was never followed. There are many reasons why this may happen. For patients without good access to care or without insurance, certain treatments aren't easy to do, find, or afford. For example, in some communities wait times can be extremely long for physical therapists who accept Medicaid patients.
8. It was simply too late. "Some diseases are aggressive and swift," says Dr. Westover, who suggested a [massive pulmonary embolism](#) as an example. Also known as a [saddle pulmonary embolism](#), it happens when a very large blood clot blocks the [main pulmonary artery](#) (a source of blood flow to the lungs). Westover says, "up to 50 percent of patients die within 30 minutes of symptom onset." Sometimes medical help is needed far faster than the patient can get it. Many other diseases can be missed in the early stages. Cancer is the classic example; especially for patients who have skipped or were never offered recommended cancer screening programs, the disease may present at an advanced stage.

That's a long list of potential problems with a diagnosis and treatment plan. As the patient, you have control over some of them. You also have some influence over the ones that are not in your direct control.

What can you do?

You won't always know if your diagnosis is correct until you try the recommended treatment plan, pay attention to what happens when you do, and keep in close touch with your healthcare professional. Some health issues are urgent and this process will happen very quickly. For most of us, we will learn if our diagnosis is correct over a longer time period. There are four steps to doing so:

1. Follow the directions exactly:

Discuss the directions with your doctor or nurse before starting any medicines or therapy to make certain you fully understand what is expected. Ask questions until you do. It's perfectly fine to call the medical practice if you have any confusion about how or when to take a pill or go for physical therapy or get infusions.

All prescription medicines have some side effects. A side effect is different than an allergic reaction, which is rarer. [Minor allergic reactions may include a rash, or hives, but if you are having trouble breathing, or other serious symptoms, call 911.] However, often patients stop taking a prescription because a side effect is troublesome. Some side effects may become less taxing as your body adjusts to them. Some medications, like steroids and ‘beta blockers’ should not be stopped abruptly if you’ve been taking them for some time. Let your medical practice know if you want to stop taking a prescribed medication. Usually, they can offer an alternative or they may have suggestions for how you can reduce the side effects.

If the treatment is too expensive or isn’t covered by your insurance, tell the medical practice you need an alternative or their help in getting coverage approved, as soon as possible. The only way to know for sure how much your health insurance plan or pharmacy benefit insurance will pay for something is to check. Ask if there are any affordable, ‘generic’ alternatives that are equally effective.

Although Michele’s doctor had ruled out many potential issues and told her she was fine, her symptoms persisted. After a year of frequent but unpredictable stomach pains, Michele saw a pediatric gastroenterologist who suggested it was [abdominal migraines](#). He prescribed medications and then an elimination diet plan to identify foods that may have caused the problem. Michele’s mother helped her follow the pediatric gastroenterologist’s treatment plan carefully. She took the medications and stuck to the elimination diet but she still had symptoms.

2. Track and report your symptoms:

For most of us, the diagnosis will be correct and the treatment plan will work. How will you know if it does or if there’s a problem?

We explained how you can [keep a record of your symptoms](#) before visiting your doctor. Keep doing it throughout the therapy and after. It’s the only way you’ll know for certain if the treatments are working.

If your symptoms continue to trouble you, or if they get worse, it might be the wrong diagnosis or the wrong treatment.

Elizabeth Maloney, MD, a Minnesota-based medical educator, suggests contacting your doctor, “when you’re no longer making gains, when you make no improvement, or get worse.” She explained that doctors will review the treatment plan before they reconsider the diagnosis. Most will try a different medicine or therapy if they suspect the first one isn’t working. Sometimes all you need is a tweak or adjustment to a treatment plan, sometimes it is starting over with something new.

It is difficult for anyone to know without trial and error if new or worsening symptoms are due to a medicine that just doesn't work for you, a medicine that is actively working against you by causing serious reactions, or a misdiagnosis. "It is very tricky," Dr. Maloney said. She educates other healthcare professionals about how to properly diagnose Lyme Disease (LD). [Lyme is often missed](#) so Lyme patients who are misdiagnosed with something else usually experience treatment failure and worsening symptoms.

Every body is different. That's why not every prescription you receive is the best one for you. There's a new field called precision medicine that matches certain types of treatments, like chemotherapy, to a patient's genetic makeup. Also, sometimes the side effects are worse than the condition you're treating. Only you know if the cure is worth the discomfort. Finally, some medicines don't play nicely with other medicines; that's known as a relative contraindication. One drug can make the other ineffective or together they can create a new condition or symptoms.

You can help prevent this by telling the pharmacist if you are already taking any prescribed or over-the-counter medicines, before you start a new prescription. They can advise you if you need an alternative and can contact the medical practice for you. Ask the pharmacist if you have any questions.

Although Michele was careful to follow the pediatric gastroenterologist's treatment plan, nothing helped. Her pain continued, sometimes as often as three times in a week or as infrequently as once a month. However, her mother didn't report this.

3. Keep in touch with your healthcare professional:

When you are first given a treatment plan, ask when you should expect to feel better, says Maram Khazen, an Israeli pharmacist with a PhD in Health Communications. She is currently completing a fellowship study on communicating medical uncertainty at Brigham and Women's Hospital in Boston. Dr. Khazen encourages patients to remain engaged and actively follow up. For example, she recommends patients note the starting date of treatment in your calendar and circle back to the practice if your symptoms don't improve. This step is very important and yet it's not done often enough.

Some patients may give up and decide to live with the pain or discomfort of their symptoms, Khazen notes. At times, due to "bureaucracy, or long waits for appointments," we feel like it's too much trouble or we are uncomfortable with questioning the doctor's diagnosis or treatment. That may have been a factor in Michele's case. Her pain continued for over two years but it happened every so often. It's not unusual that a patient tries to live with pain.

Khazen stresses the importance of building a good relationship with your doctor. She notes that "improving communication between patients and physicians is key in improving health outcomes." Her mentor and a leader in reducing diagnostic error, Gordon Schiff, MD, emphasizes that doctors often assume that everything is fine if they don't hear from you

that it's not. He adds, "This assumption needs to be challenged. Clinicians (healthcare professionals who work directly with patients) need and often want to hear from you." Dr. Schiff, the Quality and Safety Director for the Harvard Medical School Center for Primary Care, feels strongly about this point. "Patients should feel empowered and have the mindset they're not bothering us. In fact, they are helping the doctor learn what is working or not, by "closing the loop" to give them feedback on their assessments and decisions," he says.

As Dr. Maloney pointed out, the first reaction of most healthcare professionals will be to review the treatment plan, not the diagnosis. For most of us, the doctor will try one or two alternative treatments before he turns his attention to reevaluating your diagnosis. Repeat the same steps: follow the directions exactly, track your symptoms, and communicate with the medical practice.

Dr. Westover says the exception might be if your illness is serious and your symptoms are worsening rapidly. Many conditions are easily missed at early stages. This is why we urge you to keep an open line of communication with your doctor.

4. Know when it's time for a fresh look:

What happens if the diagnosis is wrong, not the plan? Half of the eight reasons on Dr. Westover list for why a treatment may not work are due to a diagnostic error, #1, #2, #3, and sometimes #8.

Recognizing that the wrong condition was treated or that the disease was completely missed can be frustrating and maddening. However, you still need care and treatment. That's another reason why it's important to have a good relationship with your doctor. Finding and staying with a competent healthcare professional, who knows you and listens to you, is essential. That is called [continuity of care](#), which means seeing the same doctor over time. Having a doctor who understands your lifestyle and challenges, often helps him reach the right diagnosis faster, with fewer unnecessary tests and treatments.

Dr. Schiff says you should expect and get a medical team who encourage communication between visits. Look for practices who make it easy for you to ask questions and get answers in a timely manner. When you next meet with your doctor, ask him what the best way to reach him is. Ask if there is anyone available to answer a question or a concern after normal work hours. Schiff adds that if good communication is consistently difficult, you can "vote with your feet."

Getting a second opinion or changing medical practices are both good options if you believe you have been misdiagnosed and your current doctor is not actively working with you to fix it. If your doctor is unsure what is causing your symptoms, and is unwilling to keep looking for answers, ask for the name of a potential specialist for a second opinion. "Fresh eyes are

one of the best ways to catch mistakes,” says Dr. Mark Graber, founder and Chief Medical Officer of [SIDM](#). Often, your doctor will refer you to a specialist before you need to ask.

What was Michele’s final diagnosis?

Michele continued to have pain for another year. A soccer injury led to an [incidental finding](#) — information no one was looking for or expected to find — from the imaging test. She had a cyst in her ovaries. Her sports doctor said it looked fine but suggested they take her to a gynecologist to check. The gynecologist agreed that the cyst might be causing her symptoms but suggested that once her menstrual cycle became regular, the pain would end. And it did. Michele is currently healthy and in college.

Dr. Westover didn’t examine Michele but based on her mother’s report and her current good health suggests that what Michele had was a [“functional cyst”](#) (a common result of ovulation) which usually resolves on its own.

Michele and her mom did almost everything right. They followed the various doctor’s instructions and treatment plans. But like most of us, they never returned to the first doctor to let him know that Michele’s pain didn’t go away. Perhaps if they had closed-the-loop with her pediatrician, they would have avoided the unnecessary medicines and diet plan the pediatric gastroenterologist prescribed. They also didn’t follow-up with the gastroenterologist when they decided that treatment plan wasn’t working.

It’s unusual for a pre-menstrual girl to have an ovarian cyst, a key to how it was missed by two different doctors. However, letting the doctors know when a treatment isn’t working may have given them a chance to do further imaging or to suggest she see a gynecologist. Feedback is also one good way doctors learn; notifying the earlier physicians of the ultimate diagnosis might help the next patient with the same problem.

What would have changed if Michele’s ovarian cyst had been identified two to three years earlier when her pain first appeared? Dr. Westover says that the standard of care is to treat the pain she was experiencing with warm compresses, heating pads, over-the counter pain relief like acetaminophen or NSAIDs, and to tell her to avoid any activity that aggravates her pain.

Westover added that he would have had Michele return for regular follow-ups and ask her to report any new or progressive symptoms. Ultimately, paying close attention over time is the only way to know if your diagnosis is correct.