

Dx IQ #5: Top five things to do **before** you see your doctor

By Helene M. Epstein

Diagnosis is a journey. Over the next few months, this column will take you through the various steps of that journey, to help you get an accurate diagnosis. We'll show you where the pitfalls may be, how to be proactive, and how to partner with the care team to reduce them. [If you want an overall look at how misdiagnosis happens, [click here.](#)]

Welcome to Diagnosis Team YOU. Getting the right diagnosis is a team effort and **you** are the principal team member. This column shares what you can do **before** you see your doctor to help improve your chances of getting an accurate and timely diagnosis. These five steps are simple and practical and work for every body.

STEP ONE: Pay Attention to Your Body

Recognizing that you have a health issue is the first step. Whatever is bothering you, you know your own body and if something is off. We realize that some people find doctor visits stressful, expensive, or time-consuming. But if you have concerns about something you are experiencing, don't wait. Ignoring symptoms until they go away is dangerous. Take charge of your health by bringing your concerns to a professional.

Drake Sparkman, a former advertising creative director and an avid sailor, was the picture of health. At 57, he worked hard and played hard, with barely a cold to stop him. His wife Heather describes him as a "play-through-the-pain kind of guy." In the spring of 2009, he noticed something strange was happening to his vision. When he tried to read, it seemed as though words were "missing" from the page. He had never experienced anything like it before.

He might have waited, but his high deductible health insurance was about to reset. He saw the ophthalmologist on the last possible day before it did. The ophthalmologist told Drake, "Well, it's not your eyes," and ordered an MRI. The results showed he had a mass in his brain that was causing the visual disturbances. Drake had a grade four glioblastoma of the occipital lobe, a deadly form of brain tumor.

Due to his eye doctor's swift and accurate diagnosis, Drake was able to get the tumor surgically removed as soon as the following week, in early June 2009. According to his surgeon, had Drake waited even a month to see his doctor, he probably would have died before the appointment. Because he acted, he was given the gift of time — another 18 months — to work, sail, and be with those he loved.

If you experience a physical change that is concerning, take the first step and seek answers for your health concerns.

STEP TWO: Keep Your Medical Info Handy

Dr. Richard McClead, Associate Chief Medical Officer of Nationwide Children's Hospital in Columbus, Ohio, suggests the most common reason patients are misdiagnosed is that the doctor or nurse don't get all of the important facts. There are many reasons for that (See [Dx IQ #1: The most important medical issue ever](#) for more).

That's why medical practices give you a clipboard with sheets of paper and ask you a long list of questions. While not everything may be relevant to your current concern, the answers are important clues to what ails you. Rather than spend time in the waiting room trying to remember the name of that new medicine, or how often your symptoms occur, there are several easy-to-use tools available to help you be ready for the questions you will most likely be asked at the medical practice.

The Society to Improve Diagnosis offers a free [Patient Toolkit](#) specifically for preparing to visit your healthcare team. It helps you organize important health information necessary for an accurate diagnosis. It's something you can bring to every appointment. It covers many of the questions you will be asked so you can fill it out in advance, while you're home and able to check your medicine cabinet or find a test result. The goal is to help you tell your story clearly.

Most of us never leave the house without our smart phones. That's good because most smart phones have an app called Medical ID (click to learn more for [iPhones](#) and for [Android phones](#)). It's another convenient place to keep your most important medical data for your visits with healthcare providers. It's an easy way for you to list your medical conditions, blood type, medicines, allergies, emergency contacts, and more. It takes only a few minutes to set up. Just remember to keep it updated. (It also allows first responders to access in the case of an emergency in the event you can't answer health questions.)

STEP THREE: Record Your Symptoms

While your doctor may be an expert on diagnosing and treating your health conditions, only you are an expert on what your symptoms feel like and what your body is telling you. Start by writing your symptoms down and what's important about them. SIDM's [Patient Toolkit](#) has a section where you can describe your symptoms before you visit your doctor. It includes a drawing of a human body so you can mark up where it hurts. It also gives you an opportunity to answer the most important questions about your symptoms and list additional questions you may have. If your symptoms change, you'll know when and how.

Many of the questions in the Toolkit are based on the work of John Ely, MD, MPH, Professor Emeritus of Family Medicine at Carver College of Medicine. He taught medical students to ask patients eight important questions about their symptoms, in a Who, What, Where, When format. For example:

1. Where is the problem? Does it stay in one place or move?
2. When did it start? How long does it last? How often does it happen?
3. Is it changing? Has it been getting worse or better or is it about the same?
4. How severe is the symptom? On a scale of 1 to 10.
5. What makes it better? What makes it worse?

The answers will help your healthcare provider narrow down what could be causing your concern. Other important questions include – do you experience symptoms a particular time of day? Does it happen when you are sitting, standing, etc. The toolkit will help you note these differences.

You can print the Patient Toolkit and fill it out by hand or save it as a pdf and fill it out on your computer. (Just click Fill & Sign on Adobe Acrobat Reader, which is a free program.) If you choose to fill it out on your computer, you can save it to a file on your smart phone and keep it with you.

The Agency for Healthcare Research and Quality (AHRQ) also has a personalized question-builder available online and as an app to use before you visit any healthcare professional.

STEP FOUR: Learn More about Your Symptoms

It's not unusual to have to wait days, if not weeks or longer, for a doctor's appointment. Some primary care practices and specialists are booked months in advance. How do you know if you need to see your doctor immediately, need to seek urgent care, or if you can wait?

If your symptoms involve trouble breathing, chest pain or crippling pain anywhere, go to your closest hospital. If you have a choice, go to a hospital that's a trauma center.

For most other symptoms, you can use your time wisely by learning more about them. Many of us turn first to "Dr. Google:" looking up our symptoms online. According to Pew Research, nearly 80 percent of Americans have conducted health searches on the internet. We think that number has risen since the 2012 study was conducted. Back then only 35 percent of us had smart phones. Now, 81 percent of us walk around with a super computer in our pockets and 90 percent of us have access to the internet at home or work.

Of course, checking your symptoms online can be very helpful or terrifying, depending on how and where you do it. Type in "headache" on your browser of choice and the top three conditions that will show up are brain tumor, aneurysm, and cancer. That's enough to cause a headache.

Instead, search reliable, informative websites. There are many to choose from. Start with top healthcare websites like [Healthline](#), [National Institute of Health](#), [Centers for Disease Control and Prevention](#), [WebMD](#), and the [Mayo Clinic](#). For parents, the top websites are [Baby Center](#), [Kids Health](#) (plus [Teens Health](#) for your older children to visit on their own), the American Academy of Pediatrics' site [Healthy Children](#), and [Parents](#).

Doing so can help you describe your symptoms more accurately to your doctor. This kind of research can also help you put what you're experiencing into context for both you and your physician. And lastly, doing a little homework may help you prepare a list of questions to ask the doctor after she has examined you.

STEP FIVE: Be Prepared to Tell Your Story

It's common knowledge that one of the frustrations – for patients and clinicians alike - is lack of time for primary care physicians and patients to talk. [Over half of doctors report](#) they spend just an average of 16 minutes or less with each patient. Yet for every hour they can examine and listen and speak with their patients, [they spend two hours doing administrative tasks](#), like ordering tests, prescriptions, and filling out patients' electronic medical records. So, what can you do in advance to make the most of those 15 minutes?

You've written up your symptoms, you have your medical history on hand, and a list of questions. Your doctor will ask you why you've come to see her. What will you say? Dr. Ely says give them a short paragraph, not a novel.

Editors always tell writers, "Don't bury the lead." The same goes for your personal health story. What is your headline? What is your opening sentence? Put it into context.

Drake could have said, "For the first time in my life, what I'm reading isn't making sense because words are missing from the page." A parent might say, "My daughter usually is very energetic, but for the past week she is quiet and complains of headaches." [Lucy Reasoner](#) told her doctor, "Until a few days ago, I was in the best shape of my life but then I woke up with a heaviness in my chest, shortness of breath, a racing heart rate, and cough." (Click [HERE](#) for her story and several others.)

Many patient advocates will tell you to practice describing your symptoms. It might feel silly but grab a friend or a family member and practice your opening lines. Or do it in front of a mirror. Keep it brief; three minutes or less is a good goal. Emphasize why you are concerned and how is this affecting you.

Next Steps?

You've done the homework. You're ready to see the doctor. What's next? Our September column will focus on how to have the best experience at the physician's office.