

Dx IQ #7: Ask these key questions when you get a diagnosis

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 and timely diagnosis. Last month we focused on [how to navigate the doctor's visit when you have a health concern](#). Each month we'll show you where the pitfalls may be, how to be proactive, and how to partner with the healthcare team to reduce them. [If you want an overall look at how misdiagnosis happens, [click here](#).]

It can be intimidating to sit with your primary care physician after he has listened to your input and examined you in your paper gown. [See [last month's column](#) to learn more about presenting your symptoms.] Perhaps your heart is beating a bit fast as you wait for his pronouncement of what is causing your symptoms. What can it be? Is it serious?

At some point during the visit you will hear the *working diagnosis*, the healthcare professional's (doctor, nurse, or physician assistant) best analysis of what may be the source of your concern. It may turn out to be the final diagnosis or it may lead to the answers you seek.

Which is why your job isn't done, yet. As the most important member of Team Diagnosis YOU, you need to discuss what happens next. Your healthcare professional may suggest one or more of these next steps and you have the right and the responsibility to ask questions, take notes, and actively participate in each of them. They are:

1. Tests
2. Treatment plan
3. Referral to a specialist

Tests. Tests can help you identify what is causing your symptoms or rule out the most dangerous possible causes. There are a lot of moving parts and people who order tests, take samples, and analyze results. Errors during this process are a common cause of missed or delayed diagnosis. Questions to ask include:

1. *What kind of test(s) will I have?*

There are so many different ways to identify what is bothering you. Knowing what kind of tests you are taking will help you prepare properly. There are tests that require samples of your blood, urine, saliva, or feces (stool samples).

Biopsies are tests that take a sample of tissue from your skin or your internal organs to identify possible infections, autoimmune disorders, or cancer. For example, your dermatologist may biopsy your skin to check for psoriasis or infection or skin cancer. There are [imaging tests](#) that look inside your body to

view bones, muscles, organs, and brain function like x-rays, CT scans, MRIs, ultrasounds, and [PET](#) and [SPECT](#) scans. There are also endoscopes (viewing tubes) which look into the available spaces in your body, like your nose, throat, anus, or vagina to identify issues with breathing, speaking, eating and digesting, and more. If the doctor suspects your heart may be involved, she could order tests where your heart function is observed by attaching electrodes to your skin like an EKG, an echocardiogram, or a stress test.

2. *Why do you think I need this test?*

Each test can have several purposes. Some are to screen you for common diseases, some are to rule out serious conditions, some are exploratory. Don't be afraid to ask questions while you're in the medical office so you understand why they think you need this. Not every test is essential and some may be invasive, have side effects or be expensive. You have the right to ask whether the test is necessary, if it's costly, or if there's an alternative.

3. *What do I need to do to prepare for this test?*

Not every test requires special preparation but many do. Some require fasting or avoidance of specific foods or drinks. Some ask you to temporarily alter a personal habit. For example, before you have a mammogram, they ask you to avoid using antiperspirant. It's such a little thing that it doesn't seem important. But the aluminum in most antiperspirants can look like calcifications that would lead to more tests for breast cancer. If you are scheduled for a colonoscopy, a procedure where a camera looks inside your large and small intestines, you need to follow step-by-step instructions so your colon is clean enough for the test.

Otherwise, they may need to reschedule the test for another day.

4. *Are there foods or supplements I need to avoid beforehand?*

Blood and urine test results can be inaccurate if you have certain supplements in your blood stream. Last month we explained the issues with gingko biloba. Biotin (B7), a vitamin present in most multivitamins and products for improving hair, nails, and skin, may interfere with many blood tests. It can cause false high and low scores and lead to treatment for the wrong condition or no treatment at all. This is why we urge you to tell your doctor and the people conducting the tests about all of the supplements you take.

5. *How do I schedule these tests?*

Sometimes the practice will schedule the test for you and sometimes they give you the lab or facility's phone number so you can schedule it yourself. Check if you need to get precertification from your insurance for certain tests. The medical practice may help you with that or you may have to do it.

6. *When will I get the results?*

Use the answer to set a reminder to check for test results. Patients may think no news is good news. It's not true. [No news is no news](#). You can read story after story about patients whose test results were never reported back to them so they didn't get timely treatment for serious conditions. [Jessica Barnett](#) died at 17 because of lost and misread tests. 12-year-old [Rory Staunton](#) died of sepsis in part because the blood test results weren't read.

7. How will I get my results?

Every practice has their own way of sharing test results. Some have a staff member call, or post it on the patient portal, or only contact you if the test indicates a medical problem that requires you to come in for another appointment. Ask how they prefer to communicate results and then make certain you hear from them. If you don't, then call the practice to follow up. As we keep reminding everyone, no news is no news. We also strongly recommend you get a printed result for every test you've taken, from the doctor, the portal, or directly from the testing facility. Keep a copy to share with other medical practices, or if you see a specialist, or seek a second opinion. It's easier to do this one test at a time than to scramble for copies when you need them.

Treatment Plans. If your healthcare professional has confidence that she has enough information to act on the working diagnosis, she may just recommend a treatment plan. That plan may consist of a combination of diet, exercise/physical therapy, medications, and/or at-home therapies, like ice and elevation for a sprained ankle or gargling with hot salt water for a sore throat.

Sometimes, a treatment plan is employed to test a working diagnosis. If these simple interventions work and you feel better, that may be the end of the process. However, before you begin any treatment plan, there are several questions we recommend asking:

1. What do you think it is? Can you explain the diagnosis?

Most doctors will automatically explain what the diagnosis means and put it into plain language. Some will give you literature or websites to visit. Others will sketch the body system affected and diagram the problem. For those who don't, or if you have more questions about what you've been told, ask them specifically for a detailed description. It is perfectly fine to say you don't understand a term or ask him to avoid using medical jargon.

2. What else could it be?

This could be the most important question you can ask any clinician when first given a diagnosis. It serves two purposes; to allow the doctor to share her thinking about why one diagnosis over another and it reminds her to consider a diagnosis that may have been overlooked or discarded earlier in the process. That is called a differential diagnosis.

3. About those prescriptions:

If you are given a prescription for a new medicine, ask these four questions. Pay close attention to the list of possible side effects and read the pamphlet that comes with new medicine. If you need more information, ask your pharmacist who may know more about the potential complications of your new prescription. Of course, remind the doctor which medicines have caused allergic reactions, so she can double-check this prescription doesn't contain the same ingredient.

a. What side effects should I watch for? Which side effects mean I should stop taking this prescription and call you?

b. Are my current medicines and supplements alright to take with this medicine?

- c. *Should I stop taking it if my symptoms subside?*
 - d. *What if it isn't covered by my insurance? Or what if it's too expensive?*
- 4. *When should I start to feel better?*
This is an essential question for any new diagnosis. If you are told that the treatment plan or the new medicine should help you feel better in two weeks, then pay attention to how you feel in two weeks plus a few days. If you feel better, continue to follow the instructions or finish the prescription as directed.
- 5. *What if my symptoms get worse or stay the same?*
If you feel worse or have new symptoms instead of feeling better, or your pain or symptoms are the same, contact the doctor's office to discuss what to do. If you are feeling significantly worse and the treatment plan isn't working, make an appointment to be seen as soon as possible.

An alternative treatment plan might be no active treatment at all. Instead, a wait-and-see approach may be suggested. Depending on the potential condition, it is also known as watch-and-wait, active surveillance, or active monitoring. This requires your full participation because your healthcare professional is counting on you to keep track of your symptoms, note any changes or new health issues, and get back to her on a regular basis. You may be asked to do this on your own or you may be instructed to come in on a regular basis to be checked or tested. Make certain you understand what is required of you and ask questions if you're uncertain of any aspect.

Referral to a Specialist. Your primary care professional is probably a general practitioner, an internist or a family practitioner. If they think your symptoms require a specific kind of expertise, they will suggest you make an appointment with a specialist. There are specialists for every part of the body and every bodily function. Some common referrals may be to a cardiologist (heart), orthopedist (bones, spine & associated structures), gastroenterologist (digestive system), neurologist (nervous system including brain function), or oncologist (cancer). You may be asked to see more than one specialist if your symptoms are common but the cause is hard to pin down. There are over 10 thousand conditions but only a few hundred symptoms. Not every specialist will require a visit. Your doctor may request a consult on your case, an expert who will review your records and discuss it with your primary care professional. He is supposed to get your consent for this in advance.

Many of your questions may be unique to the type of specialty. Here are a few that apply to all referrals:

1. *Does this mean that you think I have X?*
Just because you're sent to a specialist does not mean you definitely have a condition that falls within that specialist's area of expertise. Often, it is to ensure that something serious gets ruled out, or crossed off, the list of possible problems. For example, know that a [referral to an oncologist](#) doesn't necessarily mean you have cancer. However, your doctor is acting with caution because it doesn't help to wait-and-see when cancer may be the culprit.

2. *Do you have a referral for me?* Many insurance plans require that you are given a prescription for a specialist visit. At that time, if the healthcare professional doesn't recommend a particular specialist, you can ask for the name of one. If the specialist isn't in your insurance network or is too far away, ask for an alternative.
3. *What if I can't get an appointment?*
Call your doctor's office and ask them for help or for additional names. Or both.
4. *When should I come see you again?*

What if I'm told they think it's nothing at all? This can be a perfectly appropriate answer. Perhaps it's a normal part of aging or a new condition is still in the very early stages and can't be detected. That's why we strongly recommend everyone keep track of their symptoms and return to the doctor if things worsen. It is also worth [requesting a copy of the doctor's notes](#) to ensure everything you said was captured correctly.

If you feel your concerns are not understood, you have several choices. If you wish to have a fresh set of eyes on your symptoms, go see a new doctor for a [second opinion](#). Choose a different medical group, if possible. Use the tools we provided you in [Dx IQ #5](#) to make certain your information is presented in a clear, factual, and concise way. If you are feeling dismissed, however, it raises other significant questions that we will cover in next month's column.

Close the loop. No matter which scenario you have been given, your most essential next step is to follow the plan you've agreed to. Get the tests. See the specialist. Follow the treatment plan. One of the most common causes of delayed diagnosis or error is the patient doesn't do what's they've agreed to do. So have your calendar available when you visit your primary care provider so you can schedule the tests or the specialist that day.

Then, without fail, circle back to the healthcare professional with feedback. Get your test results (never assume [no news is good news](#)). Discuss them with a trained staff member at the practice, let them know how you're doing with the treatment plan she proposed or the specialist proposed. If you need to be seen again, make the appointment and follow-up. This provides your doctor with essential information that helps you and the rest of the practice's patients. If every patient made sure to close the loop, diagnostic error would be greatly reduced.

These are just some of the possible questions you can ask. Two highly respected organizations also have their own tools to help ask questions of your healthcare professional: [AHRQ Question Builder](#) and the ABIM Foundation's [Choosing Wisely Campaign](#). Please use the links to see what they recommend.

What's next? In December, we will take a deeper dive into when you know something is wrong and you feel your doctor isn't taking your concerns seriously.