Contents

Proem 00:00

People are stressed, tired of the pandemic, more focused on vaccines, fewer people are getting tested. Almost a year later we're hearing the same questions about COVID-19 testing. We heard:

- *Who needs a Covid-19 test?*
- *Which test should I get?*
- *What do the results mean?*
- *What if I have a positive test?*
- *Do I need to stay home after I have a test?*
- *Who will do what with my test result?*

Although I spend many hours every week learning about COVID-19 and its personal and societal impact, I can't say I know that much about testing. I'm not a scientist, a virologist, an epidemiologist. Although, I am a pretty smart, curious person with my ear to the ground, I'm nervous about tackling the topic of testing. It feels no less complicated than ever. Still, here goes.

Following my person-first approach to health, let's start with people's circumstances and life flow, put testing into a context of managing the risk of COVID-19. Then let's tackle what testing even means, what to expect from testing, and then circle back to the person – how do the results impact our circumstances and life flow?

Circumstances and life flow 02:33

How does it start? A person feels poorly – flu-like, cough, breathing difficulties, altered taste and smell, or suspect they may have been exposed to someone. OMG, do I have COVID-19? I need to know for sure, right now. My life's routine flow has been interrupted. Wait, what if I have it? Can I go to work? Who else have I or could I give it to? Do I even want to know? Do I even want to know? Do I want anyone else

to know? Will I lose my job? How will my family survive if I can't work? Fear, uncertainty, confusion. Reactions vary depending on age, living situation, work life, other illnesses, who depends on you, your history with illnesses, your specific normal.

Managing risk of COVID-19 03:34

Personally, we manage the risk of COVID-19 somehow every day whether we pay attention or not. We wear mask or don't or sometimes do or don't. We physically distance and wash our hands or we don't or sometimes do or don't. As communities, we manage risk the same way – masks, distancing, rules, customs. We are all part of many communities that may have different rules and customs - our family, our neighborhood, our workplace, town, state. Communities react differently to suspected COVID-19, as well. The constellation of community risk management can include testing, tracing, treating, isolating. See testing is only one piece.

Introducing ME Cortizas 04:44

I asked my friend, Mary Ellen Cortizas, ME, to join us to help us better understand testing. ME has been running labs for about 25 years. While she isn't a lab tech, a pathologist, or scientist, she and I have spent many hours mulling over the 'so what does this mean for regular folk' for many topics over coffee and at meetings since we met and began working together at Boston Children's Hospital in 2008.

Health Hats: ME Cortizas, welcome. I'm so glad to be talking to you. Everybody, ME and I are old pals. We worked together at Boston Children's Hospital. I led the Patient Family Experience initiative. ME ran the lab. We actually got into some trouble together.

ME Cortizas: Yes, we did. Danny. Some of my favorite times at BCH was getting into trouble with you.

Don't understand COVID-19 testing? You're not alone. 05:46

Health Hats: Yes. Anyway, I wanted to talk to you about testing. It seems like such a mystery. Talking about testing is just too big. People talk about it. I want to say stuff like, I don't think they understand it, but I don't understand it enough to be helpful myself. I just know that they're not right.

ME Cortizas: Yes. The fact is the whole realm of testing, particularly for infectious diseases. Is really complicated. And, and, you know, I'll just comment that I, you know, I'm not a laboratorian, right. I run, I run operations. I've been fortunate in that. Although I do have a science degree and a background, I've been able to learn a lot and understand that testing is complex. And yet people, people want this to be sort of be the end all of any disease. It gets challenging to try to explain to someone, all of the complexities of how tests get built and what they're built for and what they're not built for. I've watched in my time, very common diseases that despite years and years and years of research don't have defined laboratory tests that give people an answer. And that's a real challenge for folks. I think.

Health Hats: It seems that testing puts you in a ballpark. It may help with uncertainty, but it doesn't solve uncertainty. Each test will come up with a value. But then somebody has to interpret it. What does it mean? So what for people in general and so what for me?

ME Cortizas: Exactly. Most lab tests - aside from pathology tests where a pathologist looks at a tumor sample and can make a diagnosis. Lab tests on their own contribute to diagnoses, but they're not the be-all and end-all, and everybody's a little different. Sometimes when we test, you're testing against yourself, how levels in your body change for certain things. Sometimes it's a standard, there's a general population number and you create a reference range for the normal population, but again, it's really complex.

Health Hats: Let's go really simple. My sodium is a certain number, my glucose is a certain number that may be fairly objective. But then what is the range of normal and what is the range of normal for me?

ME Cortizas: Exactly. Laboratories set a normal range built on sex, age, other illness or hereditary history that you might have. All of those things get built into a result and it's highly regulated. It starts with a baseline. Most of us know about our cholesterol levels. Those are all contingent on where you are in the process, your age and who you are. All of those variables have to be taken into consideration by your doctor. And your doctor makes those final decisions about what that result may or may not mean.

Screening, not diagnosis 09:27

Here we are talking about Covid-19 testing – a screening test. Do you have it or don't you, right now? With some genetic conditions, like Sickle Cell, results don't change. Repeated tests give the same result. They're diagnostic. But in the case of an infectious disease like COVID-19, timing matters, many factors matter. Test results inform a diagnosis, they're not a diagnosis. An experienced clinician needs to interpret and make a call. You likely have it now or you don't.

ME Cortizas: Screening tests generally are built to catch everything under the rainbow, because in the case of an infectious disease, something very contagious, you don't want to miss anybody. So, you'd rather have a few cases where you need follow-up to confirmed. The gold standard test in COVID land is the PCR, the molecular test that you really rely on for the most specific results.

Health Hats: That's the deep nasal pharyngeal where they go in your nose and take a swab.

ME Cortizas: Generally, the most reliable tests are those for nasopharyngeal swabs, NP swaps.

Health Hats: Okay. Sometimes the test is done and it's positive, but there's always a few people that aren't positive that come up positive. So, that's the false positive. And if it comes up negative, but they're really positive, that's a false negative. So, they're trying to balance that.

ME Cortizas: And you have to understand in the whole testing cycle, which has so many variables from where the samples collected, how well it's collected, how it's labeled. How it's stored, how it's sent. All of those things can contribute to a false negative, or even a false positive. It's a complex process to get a test done. In my early years when I was actually collecting samples, how you collect it matters. There are certain ways to collect every test under the sun. Either you can get a false positive or a false negative. So, all these variables impact testing. And the reality is that, although we certainly want it to be perfect, it's not a perfect system. I think that makes it hard for people. In terms of my conversations with my

friends and family, it's hard to go down the rabbit hole of why it's so complex. The other thing, Danny, is that most tests are a point in time.

Health Hats: So, that means that if positive now, that doesn't mean that five minutes later you might not be positive if you were negative. Now five minutes you could be positive if you did it again.

ME Cortizas: Probably a little more than five minutes.

Health Hats: Okay. So, the next day.

ME Cortizas: The next day. It is a point in time. When you're measuring biochemical markers or other things that are not genetic, those things change. So, you have to be aware of that as well.

Health Hats: Wow. What we're talking about right now is a diagnostic test. Do I have something or don't I have something.

ME Cortizas: I would call it a clinical test because the diagnosis, the diagnosis will come.

Health Hats: So, that's not a good thing calling it diagnostic?

ME Cortizas: Remember it's a clinical test which is subject to federal regulations, so that it's performed very well. The diagnosis will come when your doctor sees it.

Health Hats: The PCR test can take a while to get the results. If they're testing millions of people, there's only so much load a testing facility, a lab can manage. So, it could take longer to get results.

ME Cortizas: Yes, that's true. Running the test is probably not the gating mechanism. It's receiving all the tests, running them, and then, Danny, the informational interface of getting that result into the hands of the person who needs it.

Health Hats: That could be the patient. It could be the doctor.

ME Cortizas: It's similar to vaccines. You have the vaccine in your hand, but how do you get it into the people? All the logistics that surrounds it.

Do I need a test? 15:13

Health Hats: I want to think about the everyday person, you and me, who are concerned about our lives and our families and going to work, whether we're a professional athlete or, or a stay-at-home person or

whatever, right. What do I need to know about testing? What are the questions I should be asking either when somebody says we need to test you, or when I think I need to be tested? It seems like that's only the first question.

ME Cortizas: Yes. The question is understanding why you're getting tested and what you should expect from the results? Whoever recommended you get the test should be able to tell you that. The most important thing is that testing should never, ever, stop us from being safe. Testing's important, particularly if you're someone who is at risk and may have been exposed to try and get a handle on what needs to be done to keep someone safer. But first asking your provider what it's for, what you should expect and what it will, and won't give you, I think is the most important thing.

Health Hats: It seems that there's a lot of people who feel I need to get tested haven't had a conversation with their provider. They're worried about themselves. They're worried that they've been exposed, or they want to go visit somebody or they're going to travel. It's originating with the person. Until you can buy a test at the drug store, like a pregnancy test, you don't need a prescription for a pregnancy test, getting a test either comes from an order from your doctor or nurse or prescribing person, or you go to a clinic that has walk-in testing. Those people should be asking you, why do you want to test, and information about your circumstances? Because what you're saying the circumstances are important.

ME Cortizas: Yes. I think people get tested for all sorts of reasons. If I want to go visit my son at school in Vermont, I've either got a quarantine or get a test within a certain timeframe. People may have been exposed to other people. So, you go get a test to see. Again, listening to your public health guidelines, going to the CDC site and trying to learn about that. And understanding that all of these tests are point in time and you want to make sure that you do it, you do it in the right timeframe to make sure that you've covered yourself.

Health Hats: So far, one of the most important things I'm hearing you say is, first having good habits, physical distancing, wearing a mask, washing your hands, then if you suspect or have symptoms you consult, you get a test. Somebody interprets them that you trust. Now people are all trying to get vaccinated. Does testing change after vaccination?

ME Cortizas: I think that's still a question to be answered by the researchers.

Health Hats: Okay.

ME Cortizas: Sometimes with vaccines, you'll get an immune response, but it'll often be different than what you might get from an infection. I think that what's really challenging is that all of this testing, all of this work that's going on in research is happening as the disease unfolds in large numbers.

Health Hats: It's so real time, isn't it?

ME Cortizas: It's so real time. And there's so much work to do to really understand what is the best testing? A lot of other diseases that have been around longer have much more well understood testing

responses. As we develop the vaccines, what is the right testing to see if you are immune as opposed to exposed. That's still being worked on.

Getting tested 19:42

Health Hats: People have questions. If they are self-seekers, the CDC and the local health department are places to get information.

ME Cortizas: And your doctor. I would imagine most doctor's offices have informational places you can go right to their website, get the best information and follow that. It's complicated. For myself, there's no magic bullet here. It's hard. I've come across a lot of people I know that have great anxiety in this. It's something we've never, ever seen in our lifetimes and the anxiety and the need for answers is sometimes overwhelming. It was funny, there was someone I was talking to a while ago who had been very tangentially exposed, probably not a risk of exposure, but was completely distraught about this exposure. If you've ever worked in healthcare, you become an expert on all things healthcare, which I always say I'm not. I know enough to not be dangerous. But I said, look, if you're asking me my opinion on what I think, I can give it to you, but it's really not about my opinion. It's about how you feel. And let's say they give you the level of comfort. If you think you want to go to go to an urgent care center and get a test, then go get a test. It's really challenging. It's very complex. If a person will feel better, if they go to the urgent care and get a PCR test, and two days later get a negative result, that's what they got to do for themselves, even if they've been as safe as possible. In my family alone, my sister has a progressive type of lateral sclerosis, my brother-in-law has severe MS, my mother-in-law is elderly. I mean, I'm NOT particularly worried about myself, but I'm mostly worried about my friends and family. If I were faced with the potential of having to expose someone, I would certainly go get a test that my doctor recommended.

Health Hats: Some people are afraid to get tests because they feel like if they get a test, they'll get a positive test and then they won't be able to work or something. That adds a whole other layer.

ME Cortizas: There's a lot you could add to it. But I think your point about people who are afraid to get tested is of particular Importance to the people who are most affected. I would say, Danny, the people that can least afford to not work and how much they're struggling. You and I have the luxury of controlling our own fates a lot more than some people do. Just think about how frightening that is for them.

Circling back to the person 23:08

On that note, let's wrap up this challenging topic by going back to how COVID-19 testing results impact our circumstances and life flow? We got a test, or we didn't. It's a threshold of life, like getting married, the day we first locked down from COVID, or received a diagnosis of cancer, something scary, disruptive. There's a before and after. If we got the COVID-19 test, we wait for the results anxiously. What do I do while I'm waiting? Go about business as usual, quarantine? Depends on whether you've been vaccinated or not. Again, things change so fast. New guidelines come out every day. I'm reluctant to say what you

should do. Ask your doctor. Can I quarantine if I should? What if I live in a place where I can't isolate? Guidelines have limitations because they assume an average situation. There is no average situation.

I get my results, a doctor, a clinician, tells me I'm positive or negative. Negative is such a relief, but there's still tomorrow. What would the results be if I were tested three days later, a week later? If the doctor says you have COVID, well that's another episode.

I didn't get tested. What does that mean?

OK. What's the bottom line here? Some things aren't so complicated (to me). As always, I'm speaking for myself. I am not every person. For me, wear a mask, physically distance, get vaccinated. Designate a health partner to help you when the shit hits the fan. You will need help to manage, think, stay relatively sane. If you can, think ahead. What doctor will you call? Where can you get a test? Jeesh, I'm already into complicated.

What makes me crazy is that most of these complications existed before COVID. Our leaders could have invested in the defense of our health, our communities' health. We could have expected our leaders to invest. But we didn't. We can now. We can also help one more neighbor going through these complications.

Let me recommend a few resources. Listeners can find links in the show notes. Readers see below.

Stop Covid in Its Tracks. Test Treat, Trace – Graphic from Involution Studios

CDC Overview of Covid-19 Testing
American Academy of Pediatrics Guidelines for Testing

Potential for False Positive Results with Antigen Tests for Rapid Detection of SARS-CoV-2 - Letter to Clinical Laboratory Staff and Health Care Providers
What it's Like to be Tested - Video

Rethinking testing for COVID-19 -Healthcare Triage Video

An Introduction to COVID-19 Testing – FDA Video

COVID-19 Testing Explainer: Sensitivity, Specificity, and Predictive Values AACC Video

Coronavirus Testing HHS.gov

Interpreting a covid-19 test result from the British Medical Journal