

CC From Every Angle-Mark Lewis & Jonathan Bleeker

[MUSIC PLAYING]

How does a patient find his voice? Dr. Mark Lewis was one week into his oncology fellowship training when he self-diagnosed his rare cancer. In this episode of Your Stories, Dr. Lewis shares with his friend and colleague, Dr. Jonathan Bleeker, how the many roles he's played as caregiver, doctor, and patient help him navigate the cancer community.

So John, I'm thrilled to have a conversation with you. In fact, this is our 10th anniversary of a friendship, because I met you right as we were starting our training as oncologists. So I'm always curious, and frankly, as long as I've known you, I don't know your reasons for going into medicine.

When you are introduced to someone, and they ask you what you do for a living, and you tell them you're an oncologist, there's often a pause. There's often a furtive glance and a lack of eye contact. And almost, you can feel the intrinsic sense to say that they're sorry. Because they envision themselves in that role and feel like that's not something would like to do with their lives.

So as I look back, the why for me is twofold. For me, it's a, it's a desire to help people. But when I talked to high schoolers and I talk to folks who are thinking about going into medicine, I say, there's a lot of ways to help people.

Yeah, absolutely.

You can be a counselor, a social worker, a pastor, a yoga instructor. So is the science. And you have to love the science. And I'm the kind of kid who asked for a microscope for his 10th birthday, so I could look at the water in the puddles outside my house. And so I was always drawn to that. So I think it's about finding a way to help people and matching it with something that engages you and motivates you. And for me, that's science. So that's why I went into medicine.

We talked about this being our 10-year anniversary, so to speak, of starting fellowship. Certainly, know some of your backstory, your why and your how. Has your outlook on that changed over the past 10 years?

I thought basically my entire boyhood that I was going to go into the ministry. So I was a preacher's son. And not just that, I'm an only child. So this was-- you know, I was it. I was the only potential heir to the throne, if you will.

We moved to America when I was eight. My father's immigration X-rays showed a really large mass in his chest. And one of things we do as oncologists is break bad news. This was the case example of how not to break bad news.

I watched my dad go through treatment, and he died when I was 14 years old. So that's pretty much when I threw myself headlong into saying, OK, I'm going to be an oncologist. I just envisioned cancer as this monolithic foe, and it was like, coming for you.

And what really helped was my father's oncologist took me under his wing. So I was offered the opportunity to work in this clinic, which I'll be honest, at first was a little weird for me, because it was this place where my dad had been treated. But on the plus side, all the people there knew that and were incredibly kind. From there, I decided, well, I want to go into medical school. And so that was sort of the chain that led me to that particular field.

How did your experience with your father and his bad news shape how you present that to your patients today?

So I just-- I guess I just know how impersonal it can be. So basically what happened was we went down to the embassy in London. We lived in Edinburgh, Scotland. We went down to the embassy in London. We did the X-rays, and then we basically just got this sort of call that, oh, you know, your X-ray is abnormal, so you should get that checked out. There was no sense of urgency. And I carry that with me now, because I know a lot of the patients have gotten to my clinic through similar conversations.

In our 10 years of practice, have you felt like your practice has changed during that time?

I think social media has a lot to do with it. As you know, I'm a patient myself. I have multiple endocrine neoplasia type 1. It's a rare cancer syndrome. I found it, I think, maybe the day before I met you.

Which I had no idea at the time this was going on.

Right. So I had had horrible abdominal pain, that-- it goes to show you the folly of self-diagnosis. I thought I had appendicitis. I actually had high calcium. My father had had high calcium. There's only a few things that give you high calcium in successive generations. And that's when everything sort of clicked, and I had my Eureka moment.

And as you also know, I went to the internist, and I told him my concerns. And he quite literally thought I was a hypochondriac. I mean-- and in fairness to him, I went in there hot and heavy, saying, hey, I'm an oncology fellow in my first week, and I think I have a rare tumor syndrome. I mean, I understand--

It's the classic medical student syndrome, where you learn about something, and the next day you wake up in a cold sweat and having-- yes.

So I co-founded a Facebook group for patients with MEN syndromes, because we're very rare. So there's some incidence estimate that MEN1, my disease, probably somewhere around 1 in 30,000 Americans. I didn't know anyone else there that had MEN1.

And what happened, I think providentially, was I met an MEN1 patient who was coming there. And it's a wonderful woman. She's had, at this point, I think almost 30 surgeries between her pancreas and her parathyroids and her pituitary. And I was talking to my endocrinologist, and he said, you know, you really should meet someone. So we were introduced.

And it was fairly early days of Facebook groups, and we founded one. And what I've seen is that patients are more and more self-advocating. My point is, is that there's been this rise of patients having a voice in a manner that-- they had it before, but they didn't have quite the ability to amplify it.

And I was saying to someone yesterday, I sort of feel like social media is the second coming of the Gutenberg press. And if my father was alive-- my father never sent an email. He did not live to see email. He would be absolutely blown away by everything that's happened, not just in the last 10 years, but since 1994.

I think that's also echoed in even folks who are not as savvy in the social media world, which I would say most of my patients are not. Because my patients are elderly, from rural South Dakota, but expectations have changed.

Yeah.

It was not unusual when we started practice when a patient would come in, even with a very early stage cancer, and assume it's the C word. There's not much that can be done. I should sell the farm, quite literally. In 2019, that's not the case. I think that through social media, through the lay press, and to be quite frank, the progress that has been made-- a tremendous amount of progress has been made. Let's not short shrift that.

But now, the expectation is I saw this ad on television, and that's going to work for me. And you're right. We have to tap the brakes sometimes. We've had to change our mindset a little bit as oncologists. It's a tightrope that we have to walk. And the thing about it is the target moves, the goalposts move, in a very good way.

That's why when I think about my training and what we learned, it's not about the drugs. It's not about the surgeries. It's about the way you think. It's about thinking patterns. How do you deal with patients? How do you interpret new data? And that's what I think I've taken over the past 10 years, is if you think only about what you're doing today and that data and that drug, you're going to get left behind very quickly.

The last thing I wanted to be able to tell you is I learned a lot from you in fellowship. We sat next to one another in the room, in our Fellows room, our little cubbyhole. But I also got the chance from time to time to listen to you talk to patients. You just have a way about you. You have a great way of sort of reading someone and then sort of shaping the news to them.

Thank you for that. That's much appreciated. I've learned a bunch from you as well. What you experience as a patient and a physician and an advocate, it's very easy to not see that side of the table. And so to hear your experience and having heard you tell that story multiple times, it never gets old. There's always a new wrinkle. There's always something I can take away from that as well.

And really, I think this is what it's all about is we can learn about the next phase one drug, the next phase three trial, but it's working with, alongside our patients and each other, where we learn how to really care. I thank you for your help there as well.

Yeah. You got it, buddy.

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