

Episode 134: Lex couldn't stop bleeding

On a Friday afternoon in 2022, Lex was at home, just doing some routine work on her laptop. It seemed like just a normal day.

It did not turn out to be normal. In fact, what happened that day started Lex on a journey she never could have predicted.

And by the way – the story you're about to hear does not include any violence. But there is blood. A lot of blood.

Scott

As you listen to my conversation with Lex, you're going to get to know her pretty well. Even though she was very young, she knew what she wanted to do.

Lex

I grew up with my mom, dad, and two sisters in Cambridge, Massachusetts. I knew from really early on that what I wanted most in life was to be a mom and have babies. Then, I also figured out pretty early that I wanted to be a midwife. Like, I wanted my whole life to be about, sort of, procreation and raising small humans.

Scott

But then as a teenager, things got a little confusing.

Lex

Then, when I was 15 and I figured out that I was gay, the hardest part for me about that realization was wondering, like, "How will I have babies?" That was my focus for my teenage years - so, not a typical adolescence in the sense that I always felt like, if I had been straight, I had, like, high risk of becoming a teen mom because it was all I wanted to do.

Scott

So she graduated high school, left home, and started looking for a life partner, and things happened pretty quickly...

Lex

I met my first wife during my first semester in college. I was 18. She was my first girlfriend. She was older. She was a senior. Somehow, I convinced her to marry me. So, all of my dreams were going according to plan so far. It turned out that I was pregnant with twins. So, I had twin babies right out of college. They were born nine months to the day from my college graduation. Then, a few years later, I had another baby. Then, my wife carried our fourth son. Soon after that was when our marriage started to fall apart.

Scott

And that's when she met Meg...

Lex

Meg and I actually met at a support group for nursing mothers - her first baby was 4 months old while I had twins who were two at the time - and we became friends. I wouldn't say we became,

like, excellent best friends. There was always some amount of distance, but I was enamored with her from the get-go. We were both married to other people and our friendship grew over the next few years. Then, we accidentally fell completely in love. It wasn't a conscious choice in any way and it wasn't something that we really realized was happening until it was already completely established of this, like, intense mind-blowing feeling that I had never experienced, that I didn't even know was a way a person could feel.

I'd still say that falling in love with Meg was, like, the best thing that ever happened to me, even though it was also incredibly challenging because, at that point, I had four young children and she had two young children. We were both relatively happily married to other people. Like, there wasn't any fighting or it wasn't as if we had bad marriages that we were leaving. It was just more like we hadn't had this intense love with the other with our first partners. Ultimately, we made the decision to leave our marriages and be together. When that happened, our kids were ages 1, 2, 3, 5, and the twins were 7.

Scott

Now, Lex and Meg had to figure out how to make this work including deciding on careers.

Lex

We had both been primarily stay-at-home mothers up until then. We had to figure out a way to support ourselves and navigate sharing custody with our exes and all the traumas of divorce, so the early years were really challenging.

Scott

You work as a lactation consultant?

Lex

Yes. Do you know what that is? I help people feed their babies.

Scott

Right. You see a lot of boobs?

Lex

I do. I see a lot of newborns, a lot of boobs, and talk about milk all day.

Scott

And what does Meg do?

Lex

Meg is a high-school English teacher.

Scott

Overall, Lex felt like she was in pretty good health except for a particular pain that started in the early part of the pandemic.

Lex

I had been having this intense pain on the left side of my torso, sort of, under my ribs that would come and go, and it was very intense. I previously had appendicitis, an ectopic pregnancy, and a burst ovarian cyst. So I had been through some painful - like, going to the hospital for emergency surgery - situations previously in my life. When I was first having this pain on the left

side of my body, it felt like that level of pain. Like, I should probably go to the hospital, but I didn't. It was, like, the early days of the pandemic and going to the hospital wasn't a thing you'd do. So I didn't go to the ER. I just, like, lived through it for a few hours and the pain subsided. But when it kept happening, I did go to the doctor about it and, ultimately, I had an upper endoscopy and colonoscopy, and everything looked clear. My GI doctor at the time told me that it was possible that it was, like, in my head and that I was just stressed out, being home with all these seven kids during the pandemic. He suggested that I start taking SSRI, so I felt incredibly dismissed. I did start taking SSRI, which I enjoyed.

Scott

What is that?

Lex

SSRI is, like, an antidepressant anti-anxiety medication. I was like, "Well, yeah. It wasn't effective. I was still having this, like, probably once a week painful, kind of, spasm that would last a few hours. I felt like I had done everything I could to investigate it by going to a doctor and having these tests. So yes, I thought I was in good health and that it was just something I had to work through. Like, maybe it was caused by anxiety or I don't know.

Scott

And then it happened on a Friday afternoon. You were at home just doing some work, just sitting at your dining room table...

Lex

Yes. I was sitting at the dining room table. I was doing some charting for my job on my laptop and texting a friend, and I felt fine. I was totally comfortable and wasn't in any pain. Then, I thought that I just had to fart, so I did, but it felt like what I assumed was, like, diarrhea coming out with the fart. What do the kids say? I sharted.

Scott

There's a word for everything now.

Lex

Yeah, there is. So I quickly rushed into the bathroom, sat on the toilet, and had diarrhea. I took my underwear off to rinse them in the sink and I saw that it was blood that was coming off of them, but I just assumed that I had gotten my period. It wasn't enough of a shart to get in my underwear, but I had gotten my period and that's why they're wet with blood. I was sitting there just, like, having this really intense cramping and diarrhea - like, liquid diarrhea. Because I had been in such a rush to get to the toilet, I hadn't brought my phone with me or anything, so I was just kind of on toilet lock and I couldn't do anything. But I felt this intense sort of heat that started in my head and, like, rushed down through my body like I was fainting and everything. I lost my hearing and everything went sort of black. I had fainted before at a concert as a teenager, so it felt like that. It felt like fainting. But then, I waited for it to end and it wouldn't really end - like, the feeling of fainting - and I was just still having diarrhea. I couldn't really come back to consciousness. I really had no idea what was happening. I don't know how long that has been going on.

At some point, I heard one of my kids got home and I was able to call out to her and say, "Can you get me my phone and just put it under the bathroom door?" And so she did. As soon as I had my phone, I called Meg, my wife. She had been working close by that day, which is

unusual. Usually, she would be 45 minutes away at her job, but she had the day off, so she was just at a cafe close by. I called her and I said, "I don't know what's happening, but something is wrong. I am having diarrhea and I can't stop fainting." She said that she could just tell from my voice that all she needed to do was just get home immediately, and she kept me on the phone.

She had me try putting my head between my legs. Eventually, she suggested that I lie on the bathroom floor. I guess I wasn't having diarrhea anymore. And I remember the cool tiles felt really good. Like, I felt really hot. She was home within five minutes. So, when she walked in the door, she said it looked like a murder scene. Like, there was just blood everywhere. It splattered, like, in the entirety of the toilet bowl. I smeared it all around. I was just passed out on the bathroom floor and she was saying, "It's all blood. There's blood everywhere." I was like, "I think I got my period" and she was like, "No. You are bleeding from your butt." I was like, "Oh." She said, "I think I have to take you to the hospital." I said, "Yeah but I can't move." And she was like, "Okay, I'm calling 911."

Scott

You were out of consciousness in and out enough that you didn't even realize all that blood was there.

Lex

No, I still thought it was just like diarrhea. Yeah. I hadn't looked at it. It felt like having liquid diarrhea. I couldn't really see.

Scott

So you couldn't get up and, obviously, that's the time to call 911.

911 Operator

911. Where is your emergency?

Meg

(Hidden information)

911 Operator

Is that an apartment number or is that a single-family home?

Meg

Single-family.

911 Operator

Can I have your phone number, please?

Meg

(Hidden information)

911 Operator

And can I have your first name?

Meg

Meg.

911 Operator

Meg. Tell me exactly what happened.

Meg

My wife called. She said she was not feeling well, that she kept fainting and didn't know why, so I just came home as fast as I could and found her on the bathroom floor. She's in and out of fainting and she's pooping blood - a lot of it.

911 Operator

Okay. Is she unconscious right now?

Meg

Not exactly - in and out.

911 Operator

Let me ask you a few more questions. You said you were there right now?

Meg

I'm right here right now.

911 Operator

How old is she?

Meg

41.

911 Operator

Okay. Is she awake or is she unconscious currently?

Meg

In between.

911 Operator

Okay. She's very pale. She's not good.

Meg

Is she breathing? Yes.

911 Operator

Okay. Let me ask you a few more questions. Is she breathing completely normal?

Meg

It looks like it.

911 Operator

And you said she's still unconscious or in and out of it?

Meg

Yeah, in and out.

911 Operator

Okay. I'm going to start the responder. Stay on the line. I have a few more questions. Okay?

Meg

Okay.

(In the background) Keep breathing, babe.

She's really getting pale.

911 Operator

They're going to be on their way, okay? Just stay on the line with me. Is your door unlocked?

Meg

Yeah, it's unlocked.

911 Operator

All right. I'm setting the paramedic to help you. Now, I'll stay on the line and tell you exactly what to do next, okay?

Meg

Okay.

911 Operator

Are you right by her right now?

Meg

Yes, I'm right here.

911 Operator

Okay. How's her breathing status?

Meg

She's breathing, but she's starting to tremble, getting paler and talking about how thirsty she is.

911 Operator

So she is able to respond to you and talk to you, correct?

Meg

I wouldn't say it's responding.

911 Operator

Okay. So is she altered?

Meg

Yeah.

911 Operator

Okay. All right. And you said there's someone else home with you?

Meg

Yes. Kids, not adults.

911 Operator

Oh, okay. All right. I want you to just keep updating me on her breathing status, okay?

Meg

Yeah. That part is okay.

911 Operator

Okay. Does she have any kind of underlying medical condition that would cause her to do this?

Meg

Not that we know of. In the past, she had a burst ovarian cyst that was very severe and involved a lot of internal pleading.

911 Operator

Was she complaining about anything earlier?

Meg

Not today, no.

911 Operator

Okay. You said she was passing bloody stool.

Meg

Yeah, a lot. Not bloody stool. Just, like, liquid blood.

911 Operator

Hold on one second, please. 41-year-old female, in and out of consciousness, not completely alert. She is currently awake and breathing. Meg, do you have any pets in the residence?

Meg

Pets? Yes.

911 Operator

Yes. Are your kids able to put them away so that, when the responders show up, they won't run out?

Meg

Yeah, let me call the kids right now. Hang on. Kids! I need you to be right with me on this, okay? An ambulance is literally coming. I need you to put the dogs away and I want to take Edith upstairs. Take Edith upstairs after that. Thank you.

911 Operator

How is she doing?

Meg

Same. Okay.

(Mumbling)

911 Operator

Is that her mumbling in the background?

Meg

Yes, it is.

Yeah, I know you are, baby. I know. They're coming.

911 Operator

Do you see the responders?

Meg

I don't know. I can't stare out the window right now because I'm with her. Hang on.

911 Operator

Okay. They should be arriving now. Are the children old enough to go open the door for them?

Meg

The oldest one is taking care of the youngest. It's fine. I can go.

911 Operator

Okay. They're up there pulling down the street now.

Meg

Okay. I'm going to go let them in.

911 Operator

Alright ma'am. I'll let you go.

Meg

Okay. They're here. Am I hanging up with you?

911 Operator

Yes, ma'am.

Meg

Thank you. Thank you very much.

911 Operator

You're welcome. Take care.

Lex

It didn't take long for the paramedics to arrive. I remember they first strapped me into, like, a wheelchair kind of a stretcher, and then brought me outside down the stairs and onto a regular stretcher.

Scott

The bathroom was upstairs?

Lex

No, it was on the first floor, but there were some stairs up to the front door of our house.

Scott

So I think EMTs often have what's called a stair chair. They can put you in it - one's on behind you, one's ahead of you - and then takes you downstairs pretty easily.

Lex

Yeah. That must be what it was. I remember - I think the first time in all of this was when I opened my eyes - like, seeing that I was in the back of the ambulance and seeing my feet in front of me. They were starting an IV. We lived really close to a hospital, like, half a mile away, but they decided that they needed to go to the bigger hospital, which is more of, like, 15 minutes away. I had been in an ambulance once before with my son. He was transferred from one hospital to another. When he was nine, he had meningitis. So I had been in the back of an ambulance in that capacity. I remember we got into Boston at that time and we were in bad traffic. I remember saying, like, "Well, can't you just put the lights and sirens on? Like, we're in an ambulance. You don't have to be in traffic." The paramedics at the time were like, "Oh no. We only do that if it's a real emergency, so we'll endure the traffic." So, when I was in the back of the ambulance this time and they put the lights and sirens on, I thought, "Oh fuck. That's not good. If they're thinking we need to have lights and sirens to get to the hospital, I know that means they think it's a pretty big deal."

Scott

Even though they didn't say that directly to you, of course.

Lex

No, they didn't. I mean, obviously, there was urgency. I think they had gotten one bad blood pressure reading. My pulse was high. They had no idea where or why I was bleeding, and we didn't know if it was going to continue or what was happening. It was just random. I had an experience previously. I mentioned other times I'd been in pain. I had a burst ovarian cyst when I was in college and I lost about half of my blood internally, so I remembered that feeling and this felt familiar to it. I was like, I just need blood. They just need to give me some blood. So I arrived at the hospital being like, "They're going to give me blood." Like, that's what I was thinking - they'll give me blood and I'll be okay. They didn't though.

I remember the lights and sirens all the way to the hospital, I was wheeled in and left in this ER room and left there completely alone. I didn't have a nurse. The paramedics didn't stay. I didn't have any way to reach anyone. I wasn't hooked up to any monitors. I felt like, "I can't move and they've forgotten me. Where's Meg during this?" She was trying to secure all the kids and then she drove in her own car. So, she was actually the first person who came in before a nurse had even come in to see me. She arrived and I was like, "Oh, thank goodness. Someone is here. "

Scott

Someone knows you're there, even if it's not one of the medical people...

Lex

Yeah. But I was like, "Wait, we light-and-siren all the way here and now I'm just alone in a room. Yeah. That part was very disconcerting." Then, nurses came in and, eventually, a doctor. I was on an IV, but they did not hook me up to blood. They wanted to see what my levels were first. And then they sent me for a CT scan to sort of check what was going on.

Scott

A CT scan basically creates an image of the inside of your body, right?

Lex

Yeah, right. From the early times, people would come in and be like, "So you had some blood in your stool?" I hadn't seen it, but Meg had, so she would be like, "No, there was no stool. It was just blood. There was, like, so much blood." Because they were definitely thinking, like, "Okay, I had some blood in my poop as opposed to like, "Blood had been gushing out of my butt."

Scott

What really would've helped is if Meg took a picture of the toilet when she discovered you. Right? That would've painted a better picture for them.

Lex

I definitely had that thought. Instead, I think the first thing she did was flush it. So, I was still bleeding a little bit in the ER. They would have, like, a little commode for me to sit on but, at that point, what I was pooping out was, like, blood clots, so it wasn't liquid anymore. Every time, a nurse would come in and we'd be like, "There was more." And she was like, "Yep, okay." Like, no one was that worried about it.

Scott

That just seems odd. I mean, I know it's the ER - they see blood all the time - but this has to be somewhat out of the ordinary though.

Lex

Yeah, I mean, I think ultimately it was very out of the ordinary. But at the time, they were still thinking this is the ordinary way where sometimes people have, like, hemorrhoids that bleed. That was definitely the language they were using - like, "Do you have hemorrhoids? Could it be an anal fissure?" Things like that.

Scott

The ER doctor read the CT scan and what did that tell them?

Lex

That was when everything shifted because, in my experience, probably, many people who aren't in the medical profession know what it's like to be doctors from watching medical TV shows, right? So it was very much like that where the doctor comes in and has sort of, like, the grave expression, sat down next to the bed, and said, "So we've seen your CT scan and you have a large mass on your pancreas. You have other lesions on your liver. You have a dissected celiac artery. Yeah, it is very grave. Most likely, you have pancreatic cancer that's spread and advanced."

It just felt like it came out of nowhere. I mean, obviously, I thought about that pain I've been having, so I guess that could have been my pancreas all this time. Then, we were like, "Okay, so what? How is this related to the bleeding?" They still were like, "Oh no, probably you have a hemorrhoid or an anal fissure, and this is an incidental finding." They thought it was totally unrelated to the fact that I had this huge loss of blood out of my butt. I guess they thought that, sometimes, the way pancreatic cancer is diagnosed is an incidental finding on a CT scan.

Scott

It still seems too coincidental though.

Lex

Yeah. To me, it seemed like, "What? I'm not a doctor and this doesn't make sense unless, like, my whole body is ravaged with cancer and things are just, like, liquefying into blood. I don't know. But it didn't make sense in terms of how healthy I was and I didn't have any systemic symptoms of cancer, but they were very grave. There wasn't room for, like, "Maybe it's not a big deal." In fact, they really wanted to make sure we understood that this is not a cyst. This is a mass. This is a serious advanced giant mass that is, like, squishing all your other organs.

Scott

I know when you hear news like that, you try to - even if it's reading between the lines - hear some little bit of positivity. Like, maybe it's not going to be so bad. But it sounds like they weren't giving you any of that.

Lex

No, they really weren't. I remember saying to Meg, like, "I don't want this to be happening. I don't want this to be this story of what happened next in our life and for our kids. I immediately went, like, "Okay, they're going to lose their mom." Then, for their whole life from now, it'll be like, "My mom died from cancer when I was little." That's exactly where my head went. Then, I also felt like, "Get me out of this hospital. I do not want to be in this hospital in Western Massachusetts. I want to go to the big-deal good hospitals in Boston. So I was immediately advocating to be transferred. At that point, it was pretty late at night - I don't know, after 10, I think - and they were not open to transferring me. The only option, if we were going to leave, would be to sign out against medical advice.

I decided to have Meg call my dad. He had worked at Dana-Farber Cancer Institute in Boston. He has since retired, but that had been his job. So I knew he was, like, connected to all of that stuff. I felt like I didn't want to be the grownup. Like, I want to call in the grownups now to make this decision. I don't want it to be on us. I didn't want to call my mom because she had our kids and I didn't want to freak her out. So, we called my dad and he talked it through with Meg and decided that it was too risky for her to drive me for two hours to Boston in my current state. So, we would be admitted and go from there.

Scott

So you stayed in the hospital, at least, for then. What was the dialogue between you and Meg like at that time?

Lex

It felt like we didn't have to say much. I felt very much like we both were thinking the same things. We held each other and cried. I really didn't want her to have to leave but, because of

Covid, she wasn't allowed to stay with me. I didn't have anything. I didn't have a phone or anything. I had just come in the ambulance. So, I just was then brought up to this room and left alone to, sort of, think about dying. That's really what I did. Let's just think about, "Okay, I'm dying. What are the things I want to do? I want to write letters to my kids to open at different special events in the future. Somehow, I want there to be enough information so that my little one—" Edith was just turned four at the time. I was like, "She's not even going to remember me. What can we do to make something that she'll remember me and know how much I loved her?" So that was pretty much how I spent the night just thinking about that and feeling all the things I didn't do that I wanted to - I loved my job so much and the books I wanted to write.

I just started this photography project. I also work as a photographer and I was so excited about it and just thinking like, "I'm not going to get to take any more pictures. Why didn't I take more pictures? Why aren't there any pictures of me with the kids? Because I'm always the one behind the camera." I was thinking about these things. I also did have a moment even that first night of being like, "Okay, but I've also lived this beautiful life. I got to fall in love in this way, and Meg and I made it through. We created this beautiful family. Maybe that can be enough. Maybe that can be what I did, what I was here to do and it can be enough. So there was already, like, a little inkling of that coming through.

Scott

A little bit of self-consoling, even though you were only 41 at that time.

Lex

Yeah, I was 41.

Scott

At that age, you don't really think about your own mortality voluntarily anyway.

Lex

Right. But I guess, when people get bad news, there can be a reaction of like, "Why me?" I feel like, in general, in life, I've always had more of, like, "Why not me?" So I didn't feel like it was unfair or something I didn't deserve or anything like that. It just felt really sad that this is how it would all end.

Scott

You were in the hospital for a few. Did you get transferred to the other hospital or did you stay in this one?

Lex

I didn't, no. I was still there at the terrible hospital, as we call it. It was just the way I imagined it would be because I've had interactions with this hospital before mostly through my kids, and the communication between departments there is really lacking. So, there was a lot of talk of, like, the tests they were going to do. They wanted to biopsy the mass. They wanted to get an MRI with better images. They had decided I did not qualify for a blood transfusion because my level was 8.0 and you had to have it be lower than 8.0 to qualify because there was a blood shortage. So I felt incredibly depleted. It was hard for me to keep my eyes open because I was so lacking in blood. People had very few questions about the bleeding that had happened. The whole focus was about this mass on my pancreas and also my dissected celiac artery, which, I still honestly don't totally know what that means, but I know it means that the celiac artery is in poor condition in some way. So they had vascular surgeons coming in but everyone just be, "Yeah,

no. We should monitor it, but it's obviously nothing compared to this mass on your pancreas. So just focus on that.”

Scott

And from a medical standpoint, I guess that kind of makes sense. You have to triage what's the most important and urgent issue, and that big mass on your pancreas - I mean, pancreatic cancer - is typically not something you'd survive, right?

Lex

Yeah, definitely not. So we had put in for a transfer, but it kept being like, “Well, if they have a bed for you. Because of Covid, a lot of more routine surgeries had been delayed. So all the beds in all of Boston were somehow taken. They kept being, like, “Yes, we've approved you as a transfer, but we don't have a bed for you yet.” So I spent the next few days mostly in that hospital bed waiting for someone to come in and say, “We're transferring you” or to come in and say, “We're taking you for the MRI or we're taking you for the biopsy.” But every day, it kept being canceled - all the things. So, like, the whole time I was in the hospital - I think I was there four nights - no testing ever happened. They were testing my blood, but that's it. So I didn't have any more scans. I didn't have the biopsy. I didn't get transferred. They wouldn't let me eat because of, like, all of these things were maybe about to happen. So I could only have ice chips. It was really pretty horrible. I was like, “I'm trapped here. I've lost all this blood. I'm maybe dying and this is where I am. The longer I stay there, the less urgent it becomes for them, it seems.”

Scott

So it doesn't seem like there was any point for you to continue staying at that hospital?

Lex

Yeah, that's how we felt about it. So eventually, we got them to agree to discharge me because the biopsy wasn't going to happen until Monday. It was a Wednesday when I went in, and it became a weekend when nothing had happened. So then, I was like, “Well, the people who can do the biopsy aren't going to be here over the weekend. Well, if it's not going to happen till Monday, I can go home and wait until Monday at home.” Then, we got one doctor to agree to discharge me, and then his shift ended and whoever came on overnight was like, “No, I'm not discharging anybody.” So, it was a huge battle to get out of there. We were ready to sign the against-medical-advice waiver but, ultimately, they did discharge me and then I went home not knowing anything.

Scott

I understand you had another M R I that gave more information.

Lex

Yes. So what ended up happening after that was really just all of the next steps because of the connections we had. I don't know how it would've been if we didn't have these connections. I happened to have a lactation client, who was a GI doctor, and she was able to pull strings to get me in for the biopsy, which they then threatened to cancel again. So I think it was on the Monday or Tuesday when I did get in for a biopsy, which involved, like, an upper endoscopy with an ultrasound. So I had to be under and everything. It wasn't just, like, poke a needle in me. We had the biopsy and the surgeon said, “It's really good news. I took a couple of blood out of this thing on your pancreas,” which he was now calling a cyst, not a mass. He said, “You have a cyst full of blood. I think it's just going to dry up at some point. No follow-up needed.” That's what he said to me and I was like, “Well, okay. So 10 minutes ago, I had pancreatic cancer and

now I don't need any follow-up. We still don't know about what happened where I nearly bled out.

Scott

That just sounds like good news you want to grasp onto, but those are still not really complete answers though.

Lex

Yeah, exactly. No answers at all and I still felt horrible. I was still, like, way under the blood quantities one is meant to have, but it was good news that he didn't see abnormal cells and he just saw blood. That's not what cancer would look like. At that point, we had already started the process of getting in to see specialists in Boston. So we kept that appointment and we went in through a cancer diagnostic services clinic there at Brigham and Women's in Boston. Because I had this mass, they were willing to proceed and do more diagnostic work even if we had this biopsy that showed, probably, it wasn't cancer. So that's where I had an MRI.

The MRI still didn't show anything really different from the CT scan. It was like, "Yep, there's this huge cyst we now know coming off the tail end of the pancreas and there's this dissected artery." At that point, they thought the lesions on my liver were not something to be concerned about. So everyone was like, "Yeah, you can have follow-ups with this pancreatic doctor in a few weeks and we'll see if there's anything more to do about that." And I just was like, "Okay. But I had this really scary thing happen where blood came pouring out of my butt and I still have this really big bloody thing inside me and we just don't know what happened and how do we know that it's not going to happen again."

Scott

Yeah, that would be a big concern - you living day to day, thinking like, "Oh, is it going to happen again?"

Lex

Exactly, at that point, I already know that my blood levels are as low as they can be, so I was thinking, "If it does happen again, I don't have the blood to lose and live." I just really felt like it could just happen and I would bleed out.

Scott

Is there a way to supplement your blood levels or anything you can do on your own?

Lex:

Well, I was taking a lot of iron and blood builders. Because I work at a birth center as a lactation consultant, I work with midwives who are used to seeing people have postpartum hemorrhages. So they were helping me build my blood with supplements.

Scott

Were you concerned at all that you might still be bleeding internally?

Lex

Yes, I was. I was concerned. I think, now, in retrospect, I definitely was still bleeding and pooping out blood, but I didn't, because— actually, because of the supplements I was taking, a lot of them had a lot of bee powder in them, so I was like, "Well, maybe my poop looks red because of that." All along, I was getting my blood levels tested every week during this time, and

I could see that they weren't going up. Sometimes, they would go up and then they would go down, and that was like, "Well, does that mean I'm bleeding more?" Then, they'd be like, "Oh, well it's a different lab. It depends on how hydrated you are when they draw it." So there wasn't clear evidence that I was bleeding. But now, in retrospect, I know that I was.

Scott

How were the children handling all of this? You seem like the type that would want to be honest and open with your kids. Like, a four-year-old isn't going to understand what's going on. How do you handle this with the kids?

Lex

Well, we mostly tried not to tell them about it, especially at first when we thought it was cancer. I didn't want to freak them out until we knew. Obviously, I was going to tell them. We had this whole plan. If it had been cancer, then we wanted to rent a big house by the ocean and get all the kids there and just— if I had a few months to live, that's what we would do - live at the beach with them. So we had that plan, but we wanted to wait and make sure that's what it really was before we freak them out. I think they were freaked out. I'm not sure that our approach was ideal.

Scott

Even if you're not saying it verbally, kids can pick up on cues and body language.

Lex

Yeah. I mean, they knew that I was unwell. I was on the couch. I had no energy to do anything because I was really, like, living with the minimal quantity of blood. Like, my blood wouldn't circulate to my extremity. So, my hands and feet were just, like, white and numb most of the time. I had minimal color anywhere in my body and I was really tired, and they knew that we were still trying to figure it out, but there really wasn't anything to tell or not tell them because nobody knew what was going on.

Scott

Right. You still didn't have the answers yourself.

Lex

No, I didn't.

Scott

At what point do you say, "I'm going to go back to living my life?" Did you go back to work? How soon did you go back to work?

Lex

I was probably out of work for two weeks. Then, I had gone back, but I was doing just sort of, like, a limited day where I would only see a couple of clients a day, but Meg was upset about this. She wanted me to just be home. But the truth is my job is not physically taxing. I'm, like, sitting on a couch watching people nurse their babies. So I felt like I could do that and it would be good for me to be doing that. Obviously, like, we need the money and I don't want to lose my job and also my mind, so the distraction would be good. So I went back to work and then it happened again. I was at work and I was seeing a client in my lactation office and I remember feeling some intestinal cramping, like you'd have to have diarrhea. At that point, I was still scared to fart ever from that first time, so I didn't do that. I didn't fart, but I felt like, "Ugh, that's

not good." Then I started to feel that fainty feeling coming over me. It wasn't, like, a moment that was easy for me to step out - it was sort of an intense lactation visit - but, ultimately, I was like, "I have to go. I'll be right back." I got out of my office, went to the bathroom, sat on the toilet, and had diarrhea, and I knew the same thing was happening, so I checked. This time, I did take a picture of the toilet full of blood.

Scott

And incidentally, we won't have that picture on the show notes.

Lex

We will not. I did not send that one to you.

Scott

How long after this was it from the first time?

Lex

It had been almost exactly four weeks. The first time was a Wednesday and this time was Tuesday.

Scott

So 27 days.

Lex

Yeah. I managed to get my pants back on and walk into the office where the midwives work on their laptops between seeing people and it just so happens that my best friend forever from college works at the birth center as the program director. Usually, she's in there at her desk doing billing and everything. She was not in that day, but what I did was sort of collapse under her desk. There was a midwife there and she was like, "What's going on?" And I said, "It's happening. I'm bleeding. It's happening again." I called Meg and I said, "It's happening again. I'm bleeding." She wanted to talk to one of the midwives. She wanted one of them to take me to the close-by hospital, not the terrible hospital where I had been stuck. The birth center is really close to where we were living, so it was also like half a mile from that local hospital. The midwives were like, "We can't just drive her. We're going to call 911."

911 Operator

911. What's the address of your emergency?

Female 1

Hi. I'm calling from (hidden information). One of our employees is having some heavy bleeding and is fainting.

911 Operator

Okay. Bleeding from where?

Female 1

Rectal, at this point.

911 Operator

Okay. And what's the address?

Female 1
(Hidden information)

911 Operator
Okay. And your name?

Female 1
(Hidden information)

911 Operator
Okay. Can you just verify the phone number you're calling me from in case we get disconnected?

Female 1
(Hidden information)

911 Operator
And you said this was an employee, not a patient?

Female 1
Right.

911 Operator
Okay. And are you right there with the patient?

Female 1
Yes.

911 Operator
All right. Just a few more questions while I get some help on the way, okay?

Female 1
Yep.

911 Operator
And how old is the patient?

Female 1
How old are you? 41.

911 Operator
41. Okay. Has anybody tested positive for COVID-19?

Female 1
No.

911 Operator
Okay. And you said it was rectal bleeding. Do we know what caused it?

Female 1

No, she's got a bleed. We know this. Yeah. The Pancreatic cyst.

911 Operator

Is there a room number there that she's in?

Female 1

Say it again. I'm sorry.

911 Operator

Is there a room number there that she's in?

Female 1

We'll have somebody right at the side door. Just come in the side door to the office.

(In the background) She has Meg on the phone.

She's awake and she's breathing as of now. She's awake. She's pretty fuzzy.

911 Operator

Okay. So would you say that she's completely alert?

Female 1

She's not completely—

911 Operator

Is she breathing normally?

Female 1

Breathing normally, yep.

911 Operator

Any stroke-like symptoms at all?

Female 1

No. She has a low hematocrit. This is another bleed.

911 Operator

Okay. All right. We'll have an ambulance set up that way. From now on, don't let her have anything else to eat or drink. It could cause her to be sick or have further problems and just have her run to the most comfortable position, okay?

Female 1

She's on the floor, under the desk.

911 Operator

All right. They'll be there shortly.

Female 1

All right. Okay, great. Yep. Bye-Bye.

Lex

Meg was worried that if they called 911, they would insist on taking me to the bigger, farther away terrible hospital. But luckily, when the paramedics arrived, I was in such a rough condition that they said there wasn't time to take her to the faraway hospital. So that part was sorted out. But meanwhile, when I was lying on the floor of my office, all of the midwives were in there around me and I was like, "Okay, I have to have more diarrhea. More is coming." They had already called 911, so I knew help was on the way, and I was like, "Can get to the toilet?" And they were like, "We are not letting you get up." My blood pressure was, like, almost bottoming out and so I just had to poop in my pants on the office floor in front of my bosses, which was hard. Then, I just sort of gave myself over to it, I guess.

Scott

I know - we've talked about this - you're not the type that is easily embarrassed, but this had to be pushing your limits even.

Lex

It definitely did. I mean, it just feels wrong. It feels wrong to ever, like, release your bowels in your pants and then to do that while you're surrounded by your bosses at your place of employment. I think any feelings I had about that were quickly replaced by just fear that I was going to bleed out.

Scott

Embarrassment takes second place to "Am I going to survive this?" So one of the midwives called 911.

Lex

Yes, they did. At that point when she called, I had reported that I was bleeding and I was lying on the floor, but I wasn't continuing to bleed at that point. Things got a lot sketchier after that because my blood pressure nearly bottomed out and blood just started pouring out of me. It turns out that being forced to poop in my pants was actually one of the best things in terms of, ultimately, getting me a diagnosis and getting healed because, instead of all the blood going into the toilet, where it was just, hearsay of like me saying, "This had happened" and then being like, "There, there. Maybe you have a hemorrhoid." All of the paramedics and, ultimately, the doctors could see the quantity of blood and that it was not bloody stool, it was blood. It was just everywhere, I think, spreading out like a big puddle of blood around me. I was lying on my back. One of the midwives was telling me, "Just stay with us. You think of all those kids. You have to stay alive."

The paramedics got IVs going in both of my arms to try to dump fluids in me, and then it was lights and sirens to the closer hospital. They said, "We don't have time to go to Baystate." This time, at the ER, it was like what I imagined would've happened the first time where I was immediately surrounded by doctors and nurses. They hooked me up to blood transfusions, basically, as I was wheeled into the hospital. So I was finally getting that blood I've been wishing for. They immediately sent me up for a CT scan. The first time, there had been a delay of a few hours, I think, by the time I actually got the CT scan. So this time, I was still basically bleeding while I was in the CT scan, and that is what gave us the diagnosis. They could see on that scan that my splenic artery was connected to this cyst on my pancreas. The artery was pumping blood into the cyst on my pancreas. Then, my pancreas had created a fistula, which is like a

little connection into my intestines. So that is how blood was pumping from my artery into my intestines and then out of my rectum.

It was something that, when it first happened, I didn't understand why everyone was so confused or skeptical about what I reported in terms of how much blood I had pooped out, but that's because usually there isn't a way for blood to get into your intestines. If you've bled somewhere higher in your GI tract, by the time it would get to your intestines, it would be, like, black and digested blood, but this was fresh red blood. Usually, they would only see someone pooping out fresh red blood if they have a hemorrhoid or an anal fissure or something in their colon, which I didn't have.

Scott

So this was arterial blood?

Lex

Yeah, it was arterial blood and it was just coming directly from an artery into my intestines by way of this pancreatic cyst fistula.

Scott

It's ironic that the big hospital couldn't figure this out. It took the little hospital to kind of get to a diagnosis.

Lex

It did, unfortunately. Once they have the diagnosis in that small ER, they are freaked out. They do not want anything to do with me. They do not feel like they have the capacity. They're like, "We cannot keep you for one more minute." Like, basically, I'm a ticking time bomb, which is also frustrating because I had, like, just been at home for a few weeks in this state, and now they're scared to keep me in the ER because they didn't have the ability to stop me from bleeding from my artery. What I needed was interventional radiology. Those are sort of, like, the IT people of the doctor world. They go in through your arteries using, like, a CT scan to watch what they're doing as they like wind through your arteries to fix things.

Scott

Yeah. What amazed me— I know you were in ICU for a week and they went in through your wrist to get to your splenic artery. That just seems like a long way to go. I'm sitting here questioning why did they do that? But obviously, they're the medical professionals. They knew that's the best way to do it.

Lex

Ultimately, I got out of the local ER. I felt actually better than I'd felt in a long time because I'd gotten those blood transfusions. I was transferred to a hospital in Boston at last, and I was in the ICU there. They tried to do the interventional radiology. Their goal was to just block off my splenic artery, so I wouldn't have one anymore by filling it with coils. That was the only way to repair it without opening me up completely, which they said would be a very risky surgery, so they didn't want to do that. They actually went in through my groin the first night I was in the hospital. They spent five hours trying, but they could not get to the damage. Ultimately, it was an aneurysm in my artery. They couldn't get to it that way, so I was just in the ICU waiting for them to decide if they were going to try again or if they needed to instead open me up and do this riskier surgery. It was much better than my first time being in the hospital where I was just eating ice chips and everyone was delaying everything and nothing was happening. But it was not

entirely different. It was sort of a similar feeling of, "The longer I stay there and don't bleed out, the less urgent my case becomes." And the interventional radiologist kept having to bump me because something more emergent would happen.

Scott

But eventually, they did put the coils in your splenic artery...

Lex

Yeah, eventually I bled again in the ICU and then they prioritized me. They went in through my wrist and they fixed it.

Scott

And that resolved the issue completely?

Lex

Yes, it did. I mean, I still had the cyst of blood on my pancreas, and I still have this dissected celiac artery, which I just have to have monitored every six months. I have a CT scan to check on it, but it's been fine. But yeah, I haven't bled. I haven't had any pain. I lived.

Scott

This story is, obviously, partly about the really weird medical thing, but it's more than that. You went from thinking you were literally dying on the floor, especially the second time at your workplace. From that, you went to thinking, "Okay. Terminal disease." Then, "Wow, I'm going to be okay." That's got to be so stressful - like a rollercoaster of emotions. What did that look like in your mind?

Lex

Well, I really just feel that— ever since I came out of the hospital after they had blocked off my artery and we knew what was wrong and they had fixed it, I just felt euphoric. I feel like I've been given the most amazing gift of, like, getting to live - something that I was just taking for granted before, obviously, like most people do.

Scott

Like we all do. Yeah.

Lex

And that is what has stayed with me. So I don't even have hard, bad feelings about any of it, really. I just feel euphoria about getting to be alive. Every day, I feel very much, like, in the moment in a way that— I think a lot of us try to learn how to live in the moment and it's really hard with meditation and everything, but now it just happened to me - like, that's the only way I know how to live right now and it's delightful. I wish there was a way for people to get to feel this way without nearly bleeding out twice.

Scott

It seems like some people would go from, "Well, we think you're dying. You think you're dying. We need to make plans. What's all the things that you would want to do?" But now, "Oh, I'm okay." And some people would go back to living their normal life. Like, wow, that was a close one. But you didn't do that.

Lex

No. I mean, a little bit. I did go back to work and everything like that. I thought a lot about the time of thinking when I was going to die, we were going to rent a big house by the ocean and all our kids would come to be with us, and I felt like, "Why is that only what we were going to do when I had a few months to live? Shouldn't we live our best life every day not knowing if next week, you're going to bleed out from your splenic artery? Like, we just never know what's about to happen. Let's live our best life right now because we can." So yeah, that led to me doing some Zillow searching for a big house we could buy somewhere nearby the ocean.

It also just so happened that, during this time, which was last spring, early summer, the housing market was insane in the town where we had bought our house, which has, like, an extreme fixer-upper 6.5 years earlier. The value of our house had more than doubled. So, we had all this money in our house that we could buy a house. That is so much more of what we want, that we would fit in because we didn't really— with 7 kids, it's hard to fit in any house. We were so squished that, once the twins had gone to college, we didn't have beds for them anymore. We had to, like, take over that space because the kids were just stacked in there. So they could come home and, like, sleep on the couch for the night. But mostly, they had to be evicted from our home, which just felt terrible to me, especially in thinking, like, "Who knows how many days we have, ever?" So, it turns out that we couldn't actually afford to buy a house at the ocean - that part couldn't come true - but it did just get me thinking about what we could do. So we ended up finding this house that we now live in that is a very giant house. It had been a bed and breakfast for about 40 years, so it has 9 or 10 bedrooms - I lose track. We could afford it because it's in, like, a less fancy town, but it's actually more convenient to my wife's work and everything.

So yeah, right after I survived everything, we decided to sell our house, move, and start living our dream. We've always wanted to have farm animals. So, now, we have land. I just feel like, "Why would we ever delay the things we want to do?"

Scott

Yeah, it would be interesting if there was some way psychologically to put yourself in that state without having the big tragedy happen and the big scare, but I don't know if that's possible.

Lex

Yeah. I don't know either because I think you can say the words of knowing. Today is the moment we know we have, but unless you felt it, it's hard to really believe it.

Scott

From that first incident to when you moved into your new house was five months. You're an action-taker.

Lex

I am, Yeah. Well, when I want something, I make it happen, which was part of the humbling experience of that. You don't get to call those shots when you're trapped in a hospital bed and maybe going to die. Like, sometimes, you just have to surrender, which was good for me. But in my regular life, if it's something within reach, I try to go for it. I do a lot of DIY stuff because I'm not going to wait for someone to come fix this for me. I'm going to learn how to be a plumber or whatever it is. The other day, Meg put her foot down about me doing some electrical work. She was like, "Yeah, no, you're going to call the electrician."

Scott

Speaking of maybe dying, that's what would happen if I tried to do some electrical work.

Lex

Yeah.

Scott

Going through something like this, you think about all of the things that you wish you would've done. What are three things that are on your bucket list today?

Lex

Well, there's a book I really want to write. For me, creative work is what I want to do. So there's a book I want to write. There's a book I want to make with photographs - a few photography projects I have because I also work as a photographer. I want to turn my house into some sort of, like, a retreat center. I want to build a barn and have big parties with dancing and live music. But mostly, when I think about, like, what were the things I felt so disappointed I hadn't done when I thought it was all over, and it was things that would outlive me like the books I wanted to write or the pictures I wanted to take - something that would have stayed beyond me. So those are probably the things I am now most motivated to be working on whenever I have a free minute because you want to leave something. You don't want it to be like, "I lived and then I was gone." You want it to be like, "I lived and then I was gone. But look at all this work I left." I put my ideas somewhere so that they could stay. That's how you live on. I love my work so much. I love my job. I love just getting to be with my family. I hope I never lose this feeling of gratitude, euphoria, and gladness for being here. That's part of why I want to keep talking about it so I don't forget and get dragged down in the mundane of, like, "I have to take the recycling out." It's like, "I get to crush all this cardboard because I'm here and alive!!"

Scott

One way that you are creating your own legacy is through your photography. You mentioned that you do photography and it's kind of a side hustle for you. That's one of the things that I was fascinated by when we first met online. I went and looked. You have a full blog that has pictures of your kids and photography projects that you've done, and I think people can look at that blog and feel like they get to know you, Meg, and your kids just from the pictures. Looking at those pictures just exudes love and family.

Lex

Oh, I'm so glad to hear that.

Scott

Yeah. If people want to see that, your website is lexbeach.com. And if they want to, they can go through that site and contact you by email. Is there any part of this that we haven't talked about that we should include?

Lex

I don't think so. It was a crazy thing that happened and crazy things happen every day that we don't get to know about. I now walk around life looking at people and thinking about their insides, like, "Gosh, all those arteries just going where they're supposed to go. That's lucky." Go. I hope people can hear this story and feel glad for all their inner workings working.

Scott

If you'd like to see the full transcript of this episode, or if you want to see pictures of Lex and Meg and their family, you can get all of that in the show notes for this episode, at WhatWasThatLike.com/134.

And in the show notes you can also watch a video, made by two of their sons, Luke and Jasper. It's a mini-documentary about their family – and their rabbit, Shirley. You'll enjoy it.

And as I was putting together this episode and thinking about Lex's story, I learned a new word that relates to what happened to her. The word is lachesism. This has to do with disaster interrupting the regular flow of things. Just like with what happened to Lex – everything seemed normal and going along fine, then she went through this terribly stressful time where it seemed like the worst case scenario and she might be dying, and then she got through to the other side. By going through that, her life is better now than it was before. That's lachesism. There's another interesting example of that in today's Listener Story, and I'd love to hear what you think about this. I'm sure there will be lots of discussion about this in the Facebook group, so I'd love to hear what you think – you can join us at WhatWasThatLike.com/facebook.

And now, a voice mail –

Phoebe Judge voice

Hi Scott. My name is Phoebe. I wanted to call in and let you know that I love your show. I discovered "What Was That Like" about a year ago. After hearing a couple of the recent episodes, I went back in and downloaded all of the past episodes. I just can't get enough of these stories. I especially enjoyed the story about the man who ate his own foot. I'm actually a podcast host myself, and I think I should try to get him to tell that story on my show. Anyway, I just wanted to let you know that I'm really enjoying "What Was That Like" and I hope you never stop. I'm Phoebe Judge. This is Criminal - oh, wait a second. I said that out of habit. Just edit that part out.

Scott

Wow – I can't believe Phoebe Judge sent me that message! No – I mean I literally cannot believe it. Because it actually didn't happen. That voice and that audio was all created by AI. Pretty cool, right? It's just something I've been playing with for a while. And it's a little scary how realistic it can be. If you don't know who Phoebe Judge is, she's the host of the popular true crime podcast, Criminal. She also has the best voice in podcasting. So, no, she didn't actually send that voice mail. But Phoebe, if you happen to hear this, you're welcome to send me a real audio message any time and I'll play it here on the podcast.

And one more thing – the newest Raw Audio episode is now live. This is Raw Audio 31. These are extra, bonus episodes, all including 911 audio, that you can access and binge just by supporting the podcast for \$5 a month. In this episode, we have a theme – alligator attacks. And of course, these all happen here in Florida. This episode includes 5 different stories. Here's a clip from one of them:

911 Operator

911. What is your emergency?

Male 1

Yeah, I'm out at this park over in Davie. I think an alligator got this lady.

911 Operator

You think an alligator got the lady?

Male 1

Yeah.

Scott

You can hear that episode, and the other 30 episodes, by signing up to support the podcast at WhatWasThatLike.com/support.

Graphics for this episode were created by Bob Bretz.

Full episode transcription was created by James Lai. And I highly recommend both of them if you need those services.

And now we're at this week's Listener Story. As you might know, this is how we end every episode – with a short story sent in by a listener. If you have something interesting that you can tell in 5-10 minutes, email it to me at Scott@WhatWasThatLike.com. This week, we're hearing from a friend of mine, Jack Rhysider. Jack is the host of the hugely popular podcast called Darknet Diaries, which I've been listening to for years.

Stay safe, and I'll see you in two weeks.

(Listener Story)

Jack

When I graduated high school, I was 18 and I wanted to see more of the country. I live in the US so I bought a 30-day unlimited Amtrak ticket. It was just me going alone. I got on the train. I was nervous and excited. My first leg was, like, a four-day train ride. I just wanted to get to the other side of the country far away from what was possible right away. I just had a seat on the train - no bed - and I had to somehow figure out how to sleep on the seat.

The guy sitting next to me was writing a book about how to ride on trains, which was like the perfect person to be sitting next to. Right? He knew all the tricks of riding on the train. It was just a fantastic traveling companion. There was a nice family riding in the seats in front of me. Behind me was a sweet couple who was funny and generous - like, they were passing on wisdom to me through stories and parables. Behind them was the porter - the guy who worked on the train and took care of any issues in our car and stuff. Those were who I was going to be traveling with for the next four days.

This was like my little traveler pod. The first day was great. I got to know the train and the people on it, and it was just super. I had plenty of food and things to do. Actually I had a good night's sleep that first night, which was kind of surprising. So, the next day, I was there feeling more safe and comfortable than I could have ever imagined. I could have easily sat next to someone who was, like, a horrible person, but everyone around me was just so wonderful and the whole experience was great.

But this made me start to worry things were going too well. I started to think, "Oh no. Does this mean something awful is going to happen to me? Why am I being so lucky right now? I don't want to be lucky now. I want to be lucky when the going gets tough or when I'm in some sort of weird situation. If I exhaust all my luck now at the beginning of this trip, is there going to be any

leftover luck from me in the other 28 days that I have on this train? These thoughts swarmed my brain and they started burning into my soul. Somehow, I started getting nervous about it. Then suddenly I felt lachesism. Just recently, I learned what this word means. I didn't know what it meant at the time, but I saw it and I was just like, "Oh my gosh, that reminds me of this time that I felt this way. Lachesism is a feeling you get when you want a disaster to happen to give you some sort of clarity in life - like when the arc of your life is just going too smooth and you want to be kinked a little bit just to give you a sense of purpose and a new direction that you can focus on.

I was feeling lachesism because my opportunities just seemed unlimited. Whatever I wanted to do, I could do, and that made me start to really worry that maybe I'm not going to make the best choices - if there's anything I could do, I can do - and I need something to guide me a little bit here to put me in a direction, and a disaster is exactly what I need to happen here because I've just been way too lucky on, like, the first two days of my trip. I decided I needed to create my own disaster. I was looking out the window drinking from a water bottle, and I made a split-second decision. I threw the water bottle into my huge backpack upside down with no cap on, soaking everything in my luggage - my clothes, my food, everything I had in there. Then, I acted, like, "Oh no, I just spilled my water and it's everywhere now".

And I even got the guy next to me wet a little bit by accident - I didn't mean to do that. Well, now I had a really big problem that I had to deal with. You can't just ignore this. I had to figure out a way to dry everything in my backpack when all I had was a seat on a train as my space to do it in. There were no washers or dryers on the train. It was wonderful to deal with this disaster. It was glorious and it absolutely forced me to focus on this problem, which helped me pass the time, and it gave me clarity and it got me over that lackadaisy feeling. Obviously, I have no idea if causing a disaster made me not have any other disasters on that trip or if it gave me more luck in the future - it probably didn't do any of that. But the rest of the trip did go great and that trip helped shape me into the person I am now with new perspectives and experiences in life.