

Stephen Calabria: [00:00:00] From the Mount Sinai Health System in New York City, this is Road to Resilience, a podcast about facing adversity. I'm your host, Stephen Calabria, Mount Sinai's, director of Podcasting.

On this episode of Road to Resilience, we're joined by Karen Rochester, a heart transplant recipient whose powerful journey reminds us just how far hope, strength, and community can carry us.

Karen was on the brink of heart failure when she was rushed to Mount Sinai Hospital, where her life was saved by a team of dedicated specialists and the gift of a donor heart.

Her recovery wasn't easy. There were setbacks and moments of doubt, but she never stopped fighting. Now, more than a year later, she's thriving and eager to share what helped her through. We're honored to welcome Karen Rochester to the show.

Karen Rochester, welcome to Road to Resilience.

Karen Rochester: Thank you.

Stephen Calabria: So you got your start as a nurse, is that right?

Karen Rochester: That's correct. I became a registered nurse in [00:01:00] 2001.

Stephen Calabria: Okay. And so as a result, you had something of a background in medicine. You knew how to handle patients, you knew what patients would go through when they were under significant stress.

Karen Rochester: Correct.

Stephen Calabria: And so when you were pregnant with your first son, Ani, you were diagnosed with a rare heart condition that's triggered by pregnancy. When did you first realize there was something wrong, and what were the findings?

Karen Rochester: How I first came to realize was I was actually gonna have a tubal ligation after his birth that morning. And during the procedure when they were prepping me for the tubal ligation, the anesthesiologist discovered that I was having some significant arrhythmias. And that's how I, that's how I found out. Prior to that, I had no symptoms.

And you couldn't feel it? You couldn't. No. No.

Stephen Calabria: And what was the diagnosis?

Karen Rochester: The diagnosis after they ruled out to see if I had some type of infection or [00:02:00] blockages, somewhere that will, leading to the heart. They ruled all of those things out and they determined it was postpartum cardiomyopathy that's directly related to pregnancy.

Stephen Calabria: And in 2004 there was a bit of a flare up again. What happened there?

Karen Rochester: So after the birth of my son and I was diagnosed with this illness, it I had recovered, meaning my heart function returned back to normal. So 10 years passed and I had another child, and after her birth, it came back. So it had reoccurred the postpartum cardiomyopathy.

Stephen Calabria: And as a result, you were at serious risk of what a heart attack...

Karen Rochester: No, I was at serious risk of potentially deadly arrhythmias, was the significant risk, because the heart muscle was so weak. So that's why I had to get a pacemaker and then defibrillator implanted.

Stephen Calabria: So fast forward to August, [00:03:00] 2023. You had something of a scare that led to a hospital visit, correct?

Karen Rochester: Yes, that's correct. So being that I've had the heart failure from the postpartum for so long, it's just something I've lived with.

I was still working. Going about my normal life as usual, even with the pacemaker defibrillator. But what happened that day that I got admitted the night before I had some stomach issues. I thought I had a stomach virus and I thought that's all it was.

So that morning when I got up. I became very short of breath and that's not the norm for me. So when I called 9 1 1, besides the stomach upset, I really called it as a respiratory distress because I was short of breath. That's what prompted me to go to the ED.

So after I called 9 1 1 because I was having some difficulty breathing, I felt very short of breath when the EMTs arrived at my home, the first thing they do, they

check your pulse ox, which tells [00:04:00] you how much oxygen you have in your blood.

So when they did my reading, they said it was normal and they didn't understand why I called it in as a respiratory distress. So I explained that you can't go by those numbers. I feel very short of breath and I can't even stand without feeling like I'm gonna collapse.

So the EMT and I went back and forth. He basically argued with me and said, oh, you, you're not in any respiratory distress. I don't understand. So I tried to explain my history to him and basically I had to force him, to convince him to please take me to the ED.

So once I arrived to the ED that's nearest to my home, because of my cardiac history, I came in complaining of the GI problems and the shortness of breath. But of course, they called the cardiologist, so routinely they would do an echo and cardiogram.

So they decided to do that at the bedside because my blood pressure is normally low because of the heart failure. That's nothing [00:05:00] new, but it was extremely low. I could hardly maintain a blood pressure without keeping my legs elevated.

So when the cardiologist came to the bedside to do an echo. They checked the right side of your heart and the left side of your heart. The entire time that I've had the heart failure, the right side of my heart was unaffected at all. It was just the left.

So when he checked the right first, he said, Wow, your right side of your heart is zero. It's doing nothing. It's not moving at all. So that was a shock to me. So when he checked the left, he said, I'll be generous.

Your heart is functioning the left side. I'll be generous and give it barely 5%. He said, you need a transplant like yesterday. So he explained the hospital that I was at, which is another Mount Sinai in Long Island.

They don't do transplants. So he said, we literally, we can't help you here. You're in the process of dying [00:06:00] now. That's what's happening to you. I have to be honest with you. And would you consent to go to Mount Sinai in the city? 'cause I think that's the best option for you.

Of course, I consented. So I was rushed there as an emergency. So when I reached Mount Sinai, the team was already waiting for me and they got me stabilized and I was admitted into ICU.

Stephen Calabria: What goes through your mind at a time like that when things are so uncertain?

Karen Rochester: It's very scary. The first thing I did, I called my mom to tell her goodbye. I thought I was gonna die, and I asked my mom to let my children know because I have five children. It was so many of them to call. And then the second person was, who's now my fiance.

I called him. He was there at the hospital, but he was in the waiting room. And I just panicked. I was afraid. I thought I was gonna die, because the cardiologist explained to me the severity and that there was a chance I wouldn't survive the ride to Mount Sinai from Long Island. [00:07:00] So it was very scary.

Stephen Calabria: And so in a moment where you're basically staring death in the face, did you make any more phone calls?

Karen Rochester: No. I, I, I couldn't at this point. I'm so weak. I'm feeling myself passing out. So one of the guys rode with that, rode with me in the ambulance, talked to me the whole time and said, whatever you do, don't go to sleep. 'cause all I wanted to do was go to sleep.

So, no, I didn't have any. At this point, I have no strength to make any phone calls, tech, nothing. So he just tried to engage me in conversation as much as he could and tried his best to keep me awake.

So, obviously when I got to here to Mount Sinai, it was just all confirmed and then that's when it would. That's when it was really, how grave my condition really was once, I mean, I knew it was bad, but when I got here, that was it.

And then they gave me something called ecmo, which I wasn't aware of, which is basically life support. That's what keeps the heart [00:08:00] pumping oxygenated blood throughout your body to all your organs and to keep my lungs oxygenated, because at this point they told me, the heart just basically was not working.

I wouldn't be able to have a blood pressure on my own or maintain any oxygenated blood flow to anywhere in my body without this thing called ecmo. So that's what they had to do, like immediately.

Stephen Calabria: Before you received your transplant, what kept you going mentally during those most challenging days?

Karen Rochester: I would definitely. My family, my children, but even before them, my children might get upset. My grandchildren, they were the really, the ones that really helped me keep a little bit sane because I was very afraid.

I didn't want them to, they call me Kama, not grandma, but Kma, since my name's Karen, and I didn't want them to lose their Kma.

Stephen Calabria: How do you prepare for something like that? Are there any kinds of role models you can look to or you lean on your [00:09:00] family?

Karen Rochester: I leaned on my family. I didn't really have someone that I could relate to that maybe had been through this or had even had the condition that I had because it's so rare.

So it, it was, I, it was, the weight was really on my family and my fiancé. Because it almost made it, for lack of a better word, worse because I am in a medical profession. So I understood everything.

Stephen Calabria: And you recognized better than perhaps the average person, the gravity and the risk involved.

Karen Rochester: Exactly, exactly.

Stephen Calabria: Then came the transplant. How did it go down?

Karen Rochester: Okay, so just because you need a transplant, it doesn't work like that. You have to have a whole workup. Like I said, I was admitted in August. The month before the transplant. So there's a whole workup.

You have to get a barrage of tests because your body has to be in a certain condition to even receive the organ or it's gonna fail. So you [00:10:00] get a barrage of tests from CAT scans to colonoscopies, breast exams, you name it, blood work.

And so you have to do all of those things first. And then what happens is they, I was told, once all of those things come back, quote unquote good, you put on a list and the medical staff has to go for bat for you, I guess, to like some type of board or something, for lack of a better word, to plead your case.

And they also explain that unfortunately, and unfortunately for me, the sicker you are, the higher you move up on the list. So I was that sick. So they told me I would be pretty up high on the list once all of my tests and everything came back.

So thankfully everything came back, for lack of a better word. Good. 'cause obviously I'm very, very sick. So they came and told me on September 4th that they had great news for me.

[00:11:00] They got me on the list. I've been in the hospital a little over a month. They said, we got you on the list. Now we wait. So I asked if I'm stable, can I go home and wait? They said, unfortunately with me, no.

I was too sick to go home because I still had to have that intervention. Explained to you about the ecmo, you can't be at home on that. So I said, well, is the ECMO like indefinite? They said, no, about 30 days. So I'm thinking, wow, 30 days.

Who gets the heart before 30 days? So there was another option called an LVAD, a left ventricular assisted device that they give people who need a heart transplant as well while they're waiting. It's a mechanical, but I was deemed not a candidate for that.

They said, unfortunately, you're not a candidate. Your body for some reason is making a lot of blood clots. Because of that, you can't even have an the LVAD. So I wait so fast [00:12:00] forward September 4th, they come and tell me, you're on the list. Great.

So they said, now we just wait. So three days later, the seventh, they said, oh, get ready. We're going to surgery. We got a heart. I couldn't believe it. Three days later, just after getting on the list and they said, it's a perfect match, your blood type, which is rare, and it your antibodies, everything matches.

So immediately I burst into tears because immediately I said, wow, someone just died. And I was so upset. So one of the doctors, Dr. Contreras, who I see now, she said, Karen, I understand.

You know, I understand how you feel, but if you think of it this way, this person wanted to do this. This is something they wanted to do. When she put it that way, then it [00:13:00] helped. And then I also had to recall, I have a son who passed away when he was 21 from a traumatic brain injury back in 2009. He was only 21, and I donated one of his kidneys.

And for years and years and years, I felt guilty that I gave his kidney away. It was just. Part of my grieving, and I felt like, oh my God, why did I do that? Maybe he would've survived. And then I heard my son like, Hey mom, see, look, you felt guilty.

You gave one of my kidneys and now to trade off this, you got a heart. So I looked at it that way and that helped me tremendously. Oh God, that helped me Tremendously song. But that was my initial reaction.

Stephen Calabria: And so you get wheeled into the OR. Now do you recall the moment?

Karen Rochester: Yeah. Uh, yes. I recall the moment 'cause, when I got to the, or my surgeon who was gonna do the [00:14:00] surgery, he greeted me at the door and when they opened it, so he welcomed me. He said, oh, I heard somebody got engaged, because the same day, on the fourth, I got engaged before they told me that I was gonna have a transplant.

So it's like everyone in the OR knew that this happened. So that was nice. So that's one of the first things he said, Hey, I heard you got engaged. He said, so we're gonna, we're gonna fix you up good.

And I said, okay. I was nervous and I was still very afraid. You don't know what to expect. So I think I, I tried to prepare myself that there's a chance maybe I, I won't wake up. That or, maybe it'll be too late or maybe I'll be the one where everything goes wrong.

You just, you just don't know. And, one of my biggest fears, too, was I didn't want to be aware and wake up and be on a ventilator, [00:15:00] so I'm glad that I don't remember it. I was, I mean, my family took pictures, so I, I do know what happened, but I'm glad, I'm grateful for that. I don't have any memories of being on a vent.

I thought it would be something that would give me anxiety and make me panic, but I have no recollection of being on vent.

Stephen Calabria: When did you wake up?

Karen Rochester: I'm not exactly sure because I was told that surgery was eight to nine hours. So when I woke up, when I woke up, I wasn't on vent. So obviously my condition and all of the tubes, and I obviously, I know I had the

surgery, but I don't remember exactly when I woke up because they had to get me off of the vent so we, we knew off of the vent.

So I don't know exactly when that happened. I just remember waking up and I'm in ICU, but obviously there was days before that that I had had the surgery by the time I came to realize. But I don't recall how many days that that was.

Stephen Calabria: Your hospital stay lasted four months. What happened in that time? [00:16:00]

Karen Rochester: That was rough. Most of the time was in ICU. And I was just helpless, completely helpless. I couldn't do anything for myself. Absolutely nothing. I couldn't even if the call bell was literally not by my hand, I couldn't turn to look forward or reach for it or anything.

I couldn't feed myself. I, I, I could do nothing for myself.

Stephen Calabria: Were you aware?

Karen Rochester: Completely help. Oh yeah. I was a hundred percent aware. Yeah. I was a hundred percent aware.

Stephen Calabria: And you could feel your new heart beating.

Karen Rochester: Yes, I could. I could feel it. Yes, I could feel it.

Stephen Calabria: How did that feel?

Karen Rochester: Felt great. It felt great. By no means though, was an a easy journey through that process, it was very difficult. Extremely painful. Some depression set in. I I was questioning that I'm make the right choice because prior to my transplant [00:17:00] I never felt sick.

I felt tired, but not sick. Now I feel sick and I'm helpless, and I never felt like that in one day in my life. So that was hard. The recovery process. Was very hard and I had to go through rehab.

And even after you go home, they told me it could take about maybe 12 months to maybe start to feel like your old self. It took me 18 months to actually feel better, to feel like my regular self.

Stephen Calabria: Could we drill down into that depression thing or what more. Someone might think. Look, I am so much healthier now. Even if I do feel laid out, things are going to get that much better.

That's the optimist's point of view. But when you're laid out in that hospital bed, you're saying that your mind works a little differently.

Karen Rochester: It works a lot [00:18:00] differently, because you're not out of the woods. Anything can go wrong. You can have rejection any moment. From that moment until the rest of your life, until it's your last day on earth, it's always a constant threat of rejection.

It's always a constant threat of some type of infection, because once you get the transplant, your immune system has to be suppressed, and that's for life because you'll run the risk of your body rejecting the heart, so they don't want your antibodies to attack the new heart.

So it's still, it's very, it's still risky. It's gonna be risky for the rest of my life. But, I had to learn how to walk again. I had to go to, I could not walk, I could not stand without at least four adults helping me just stand or sit up.

So I would lay there in ICU and turn my neck a little bit and watch people walk and other patients. And I used to just cry saying, wow, I'm never gonna walk again. I [00:19:00] literally could not walk. I had a feeding tube I couldn't eat. It was rough.

Stephen Calabria: Sounds like, though, you were blessed with a strong support system. Who would you say played a pivotal role by your side during the recovery?

Karen Rochester: It's hard to really single someone out because I had lots of support from all of my children, including my mom who's in her eighties. But I would say my sister was the greatest asset because I made her be my healthcare proxy.

She works in health records administration, and so she's familiar with a lot of the medical terms and procedures, so I felt she was best and my family all agreed. To let that be her responsibility.

So without her, it would've been a way more difficult for me because she spoke for me most of the time when I couldn't. She did most of the [00:20:00] speaking for me. So I would say the most would if I had to choose, but it, I

really had a village because it wasn't just my sister, but she was my healthcare proxy.

That's why I say that, but it was my fiancée, my children, my children's spouses. It was constant. So, it really took a village. I couldn't imagine going through something like that and have absolutely no support.

And unfortunately some people, that's their experience. But I'm thankful that wasn't mine.

Stephen Calabria: What would you say is the biggest contribution, someone like that, who's serving in a supporting role can make in that situation?

Karen Rochester: The biggest contribution, I feel like my sister, she would listen to me. She didn't just try to make decisions haphazardly. She still asked for, you know, my opinion or my thoughts, that was important. So [00:21:00] I would say that was very, very important.

And then, like I said, her being able to speak for me when I could not, was extremely important. 'cause there were many days, I, I just, I just couldn't, I didn't, I just didn't have the energy, I didn't have the capability or the pain is so overwhelming. You just, you can't do anything.

Stephen Calabria: So there was a lot of pain, too.

Karen Rochester: Lots of pain. Lots of pain. Lots of pain. Mostly the surgical site for obvious reasons. Yeah.

Stephen Calabria: Having gone through what you went through, how do you think facing a life-threatening illness changed your outlook on daily life and gratitude?

Karen Rochester: Wow. How can you even put that into words. I've always been grateful. For my life, because I've been going through these cardiac issues for so long.

I had the pacemaker and defibrillator before the transplant, and that device literally saved my [00:22:00] life at least 12 times before the transplant since I had an implant. So I've always been very grateful for that because the arrhythmia.

I was susceptible to is called ventricular fibrillation, and the layman's term for that is sudden cardiac death. That's the deadliest arrhythmia you can have. So without the defibrillator, I would never be revived.

So I've been grateful for my life, but I feel like I was given another chance to prolong my life because even though the defibrillation is good every time, it shocks your heart. It also does damage to the heart, because of the electricity it takes to shock the heart at a deadly arrhythmia.

So it's good because it saves your life, but it does damage, and I've been shocked multiple times throughout the time that I had my device implanted. So the transplant, it just gave me a [00:23:00] new lease on life. I don't have a pacemaker defibrillate anymore. Yay. That's great.

I can go through security devices now. That's great. I couldn't have magnets near me at all. Couldn't talk with my phone on that side. So those seem like little things are big things to me. Now I can just be like a normal person.

Stephen Calabria: Did it also affect how you view your life's meaning and purpose?

Karen Rochester: Yes. I feel like I'm so grateful to even do this interview. There's not a place that I go that I don't share my story. It's usually my fiancé. He starts off first. Hey, you know, she had a heart jazz point, I'm happy to do that because I feel like I'm a living, breathing survivor.

Of this terrible heart disease that I had, and now I received a new heart and I'm an example that you can [00:24:00] survive it, where I didn't even think I could survive it. So every day that I wake up, I'm reminded, Hey, I, I survived this. I survived it.

So that's, it's very important to me to share it. Maybe it's gonna help someone.

Stephen Calabria: And the fact that you went through something so huge. I imagine places a lot of life's problems into perspective.

Karen Rochester: So many things are so petty, so insignificant. People don't get it. Things people complain about.

Stephen Calabria: Well, it must be difficult to hear.

Karen Rochester: I it. Yeah, it is, but it's human beings, so, you know. But I get it. And you know, I guess it also helps too, my medical background. I'm just a compassionate person. But I enjoy sharing my story. If it's gonna help someone, so be it. I just helped someone the other day.

Someone called me and said, Hey, remember we ran into each other at the supermarket a couple of weeks ago? I hadn't seen you, and you told me what happened. [00:25:00] They called me yesterday to tell me that he said his daughter just had a baby last month and she has postpartum cardiomyopathy, and she's in ICU as we speak.

And she's afraid, can I speak to her? Because they said she needs a transplant like yesterday, they told her, and this is her first baby, and this just happened yesterday. After I spoke to her, she couldn't stop thanking me.

She said I helped ease some of her ex anxiety, and I shared everything that I'd faced, but I said there was a light at the end of the tunnel. Try to remain positive. You can call me anytime. I'm the survivor, so she just, rare thing too post, you don't hear a lot of it.

So it was just so weird. I just ran into her dad two weeks ago at the supermarket.

Stephen Calabria: And how would you say it altered and how would you say the experience altered the trajectory of your life? What things are you doing in planning you don't think you otherwise would've done had it not [00:26:00] been for getting sick?

Karen Rochester: Hmm, that's a good question. I'm trying to be more sociable. Not that I'm not a sociable person, but any event, or since I've been feeling better, because prior, a few months back, I couldn't really attend many things. So, for instance, my high school reunion.

I can't miss that. Things like that. The holidays with the family, 'cause I missed some when I was in the hospital. I couldn't be with them for like, Thanksgiving, Christmas was iffy. We, I just kind of kept my distance.

So I'm, I, I'm just trying to be more social. Just being around my loved ones more and making more phone calls to people. You don't wanna just show up at somebody's funeral like most of us do.

So when someone comes to my mind, I call them and instead of say, oh yeah, I should call, when they come to my mind, I call.

Stephen Calabria: Why? Because social connection now, you feel it being more important

Karen Rochester: I feel it being more important because [00:27:00] I look at it this way. It's going on two years that I had my transplant. It could be going on two years that I passed away, so that's how I look at it. It could be two years that I passed away.

Stephen Calabria: Another crucial part of resilience, we talk a lot about the on this show, is maintaining cognitive and emotional flexibility, so adapting to new circumstances with grace and as much ease as possible.

What were the aspects of your recovery that were the most challenging to cope with, and how did you ultimately manage it?

Karen Rochester: The most challenging was the pain. That would be number one, was the pain, and then number two would be the constant thought that, hey, you might die, still. Even though you got the heart, doesn't mean you're not gonna die. That was the second most challenging.

And then I would say the third would be, I really could not walk. [00:28:00] I could not walk to save my life. I couldn't walk and I didn't really understand why. I knew, obviously I've been through something traumatic, but prior to that I could walk fine.

And my body literally felt like I would joke around with the nurses. Did somebody fling me off of a bridge or something? 'cause why does my body just feel so beat up? I said, that happens with some people.

So that would probably be, the third thing, was that I really believed I could never walk. So even after the transplant, when I came home, I had to use a walker for a while and I could only walk a few steps and then I'd have to sit, I had a walker with a seat and still couldn't walk well.

Stephen Calabria: For someone currently navigating a major health crisis, what piece of advice or encouragement would you give them?

Karen Rochester: The first advice I would give as difficult as it may be, 'cause I have to [00:29:00] give the same advice to myself, is try your best to remain positive. Keep up the positive thoughts because there's so many negative.

Thoughts that you can have, which is understandable. So I think the first advice I would give is try as difficult as it is, even still for me, is try to maintain the positive thoughts and try to focus on, yeah, you could've died but you didn't.

You could've gotten more sick, but you didn't. You live in a place where this opportunity was available to you? There's some people where they live, this is not even an option for them. They don't have access to this type of healthcare.

So I would say the best advice is to try to look for the positives. The glass is not half empty, it's half full. 'cause that's been my issue. Oh, it's, it's half empty. No. Now I'm doing better with realizing, no, this is half full.

And then secondly, no such thing as a dumb [00:30:00] question. Something you don't understand. If you have to have it explained to you 10 times, have them explain it to you 10 times. Things like that. That's important, you know?

And then we live in an age where there's a of information just at your fingertips. Sometimes that's good, sometimes that's bad because then sometimes, you think you can self-diagnose or, you have to have trust in your team.

You have to have trust with your caregivers and I'm grateful. I had trust in my caregivers. They were the best. And I mean that. No, I mean that they were the best. From the top to the bottom, they were the best.

Stephen Calabria: If someone is unsure about the state of their health and thinks they might need a checkup, what would you advise them to do?

Karen Rochester: Go get that checkup. Yes, don't hesitate. It's always better to have things [00:31:00] ruled out.

Stephen Calabria: What do you want your story to teach others about resilience? Oh, or the power of community.

Karen Rochester: I hope that my story would ease someone's anxiety that might be facing anything that's life-threatening or just challenging to your health, whether if it's something cardiac or some other ailment. And I hope that I can always be an example. That you can survive these things.

Stephen Calabria: Well, that's it for my questions. Was there anything else you wanted to say?

Karen Rochester: I just wanna say I'm, I'm rich. I mentioned it earlier, but I just wanna re mention it. I'm very grateful for this opportunity to share my story. I really appreciate that my doctors thought of me. and I'm just grateful. [00:32:00] I'm grateful. Very grateful.

Stephen Calabria: Well, we're grateful to have you here. Karen Rochester, thank you so much for coming on Road to Resilience.

Karen Rochester: Thank you.

Stephen Calabria: Thanks again to Karen Rochester for her time. That's all for this episode of Road to Resilience. If you enjoyed it, please rate review and subscribe to our podcast on your favorite podcast platform. Wanna get in touch with the show or suggest an idea for a future episode? Email us at podcasts@mountsinai.org.

Road to Resilience is a production of the Mount Sinai Health System. It's produced by me, Steven Calabria, and our executive producer Lucia Lee From all of us here at Mount Sinai, thanks for listening and we'll catch you next time.