

Daughterhood the Podcast

Episode #69

Navigating A Scary Diagnosis with Dr Edward Rogoff

[Scary Diagnosis Navigating Fear, Finding Strength, and Securing the Health Care You Deserve](#)

[Daughterhood](#)

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SPEAKERS

Disclaimer, Dr Edward Rogoff, Rosanne Corcoran

Disclaimer 00:00

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Rosanne Corcoran 01:05

Hello and welcome to daughterhood, the podcast. I am your host. Rosanne Corcoran, Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson, who has worked on the front lines in the health care field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system, provide resources for you as a caregiver as well as for you as a person, and help you know that you don't have to endure this on your own. Join me in Daughterhood.

Rosanne Corcoran 01:53

My guest today is Dr Edward G Rogoff, an accomplished educator and advocate whose personal journey is nothing short of extraordinary. Diagnosed with hemophilia as a child, Dr Rogoff faced a lifetime of uncertainty until a liver transplant in adulthood led to an unexpected cure. His experience sparked a lifelong commitment to patient advocacy, organ donation awareness and reshaping how we approach chronic illness. He served on the boards of the Hemophilia Association of New York since 1980 and live on New York, the major organ donor organization for the New York City metropolitan area. And now he's sharing his wisdom in his new book, scary diagnosis, navigating fear, finding strength and securing the health care you deserve. In our conversation, we explore the power of building the right medical team, managing uncertainty, having tough conversations, staying resilient, and how to not let a scary diagnosis overtake your life and keep it all in perspective. I hope you enjoy our conversation.

Rosanne Corcoran 02:55

Caregiving happens sometimes over the course of years, but many times it happens with an accident, a stroke or a scary diagnosis, you mentioned six essential strategies for making a plan when that scary diagnosis is here. What are they?

Dr Edward Rogoff 03:10

Yeah, so I think there's a few things that people need to recognize as they begin this adventure, and one of them is you can't do it alone. You've got to build a team, and you've really got to have a thoughtful process of creating this team. So part of it is getting people with certain skill sets and certain availabilities who are going to be part of your team. Now maybe that's somebody who is going to say, I'm willing to call the hospital or the insurance companies for you and sit on hold and have these conversations because they make you crazy and you don't feel well enough to sit on the phone and do it. Maybe it's that. Maybe it's somebody who's going to come and cook for you a couple nights a week, and maybe it's somebody who's just going to be company for you. You really got to think through, what do I need, and what can various people give for me? And the other part about teams is, and this is a fellow who I interviewed, talk Don talked about this in the book, is that you should think about these. This is to use the term that you're you use is that there are circles, there are inner circles and medium circles, and that the people who are going to be a part of your team, are they going to be? Is it your spouse who's living with you, who's there for every doctor's appointment, or is it somebody who comes over to watch football games with you occasionally. So where are these circles, where? Who are these people, and exactly what are they doing? So number one, know that you need a team. Know that you can't do it by yourself, and begin to build that team. Another thing is create a toolkit if you're going to go into the hospital. Maybe it's just for a day for a test, or it's going in for something that could be three or four days or a week, you need to basically like you're going on a hike. You need to pack the things with you that are going to make this experience better for you. Maybe it's that book that's on the side of your bed that you haven't gotten to yet. Pack it in the bag and take it with you so you can read it in the hospital. Maybe it's clothes that are very comfortable for you that you feel this makes me feel like at home you're going to bring, it's your cell phone charger. How many people forget to bring their cell phone chargers? They have their cell phone, and after a day, they feel out of touch with people. So I think, to Give It Thought, to build this physical toolkit that you're gonna take with you, another thing is to

have a research program. So now the doctor says to you, you have X disease, and we're going to work on this, and you've never heard of X disease before, and you don't Is this serious? Is it treatable? How many people have had it? Etc. We live in a world where everything can be researched and studied in a way that's accessible to anyone. So obviously, there's Google, these AI tools like chat, GPT, they're incredible. They're amazing. They talk to you like a person. You can have an interaction with them and say that explanation is not really clear enough for me. Can you do can you explain something a little bit more fully, or can you give me more data on how many people have fully recovered from this after four months or six months? So you can begin to do this research, and then there's all these support groups like you who are out there. So if you got a diagnosis of a bleeding disorder, is a world I know there are at least a dozen organizations that have tremendous resources online, that have staff who are more than happy to talk to you and answer your questions and who understand what you're going through. So create this research program, because when all this is said and done, you're going to be an expert, and you have to be an expert, so that when doctors say things to you, you go, What do you mean by that? I don't think that's exactly right, or I read something over here. Now doctors may not like that. Get getting that from their patients, and you know what I say about that? Too bad, because you've got to be not important for the doctor to be knowledgeable, be able to explain things to their satisfaction. It's to your satisfaction. So you got to have this research program. You got to take a long view of this. I think people feel that the everybody would like to think, Okay, I got this diagnosis, I'm going to go in the hospital, I'm going to have surgery, and in two or three weeks, life will go back to normal. It may not go back to normal right away, and it may take a long time. And you need to be patient with yourself. You need to understand that you're entering something that's got a long process, and be patient, and that's where you find your resilience. And people think, I can't cope with this, you know what? Everybody can cope with it. And you'll find your resilience as you meet others who have gone through it, as you go through the process yourself over time, you'll say, Wow, when I started this, I didn't think I was going to be able to get through this, and now you're comfortable with it. I went through a liver transplant, and that's a sort of shocking diagnosis, scary, shocking diagnosis to receive, and I was totally overwhelmed by it, and I thought, How am I gonna cope with this? What I coped with it? Now, 13 years later, I'm completely comfortable with it, and so I think everybody can find that patience in themselves and that resilience in themselves. I don't know if I covered all six okay.

Rosanne Corcoran 09:21

That's okay. Build your team toolkit, research support, inner circle, take the long view, okay, yeah, all right, yeah, there we go. I want to circle back to to your story, yeah, because it's a long one and you

Dr Edward Rogoff 09:40

Sorry.

Rosanne Corcoran 09:41

No, no, listen, you. You brought everything from your own story into this book, and it's really a beautiful aside from the stress and the horror at times that you went through, you laid it out really easy to understand and productive and practical. So I thank you for that. But can you talk about that a little bit, where, how you started, and then where you came to through this whole process with hemophilia?

Dr Edward Rogoff 10:12

Yeah, so I was born Hemophilia is a genetic disease, and I was born with hemophilia, and it was not even though it obviously was in my mother's family. That's the way it's genetically transmitted from mothers to sons, and almost everybody who has Hemophilia is male. But I was diagnosed for whatever reason. I really wasn't diagnosed until I was, like, two years old, and at the time, when I was very young, this is like the 1950s there really was no treatment for this. And basically they told you do nothing. Just don't do anything. You're going to hurt yourself and get bruised and cause a bleed. And then when it happened anyway, then they would put you in the hospital and they would give you transfusions. And this was a world in which the transfusions were few and far between, because there's only so much liquid a person can take into their body. It was like we'll do a transfusion every day. In the meantime, we're going to keep you on this IV pole and keep you in bed for a week or two at a time. And so that was extra as a child, extremely difficult to be basically chained down in a bed waiting for these and then when finally you were ready to go, you have to lying down for a week or more, you could barely sit up.

Dr Edward Rogoff 11:45

So it was in so many ways. It was you felt diminished by it, you felt threatened by it. You were physically uncomfortable and and I was always afraid, okay, I got through this, I'll be back here in a week or two weeks. And sometimes I was sometimes I wasn't, but so there was fear of all of this anyway. So that was my childhood, and the I'll say another thing, which was at that time, my parents made a decision to basically hide the fact that I had hemophilia, because if the schools had known it, they would have put me in some sort of, what was the early days of special ed. It was no education. It was just being put as put to the side. My life would have been over if that had happened. And, but I was under stress of keeping this a secret and and I talk about this in the book, I think this is true for everybody, is that people need to decide, who are you going to tell if you have a you've been diagnosed with pancreatic cancer, and you're going to go through months of treatment? Do you want to tell the people you work with? Do you want to tell all your family members? And that's this process of creating those groups around you who's going to know and who isn't going to know. And so anyway, I went through that as a child. As I got older and treatment improved, and by the time I was 20, I could take a drug, an intravenous drug, home with me and use it myself to treat bleeds that totally changed my world and was a big, big step forward anyway, along the way, I got hepatitis C from a blood transfusion when I was about 16 years old. Today, there's a very effective treatment for hepatitis C. You take pills for two weeks and it's gone. This did not exist. And so hepatitis C, I had it for 30 years, 40 years, and over time, it destroyed my liver. And so that process of destroying my liver laid the groundwork for liver cancer, and the hepatitis C created cirrhosis, and the liver cancer on top of this, really, you know, left me with no alternative but to get a liver transplant. And so that started a whole other process. And where I live in New York, the list you get on, I got on the list for a transplant, but it probably was a year to get a liver. I probably didn't have a year though, I started to get on the list in other places. I got on the list at the Cleveland Clinic, Oh, wow. And which was a process that took a month or two, but once I was on the list, two days later, they called me and said, we have a liver for you. Get out. And they said, Can you get to the airport? We'll send a plane. And so they sent a plane, and my wife and I went to the airport and dodged thunderstorms on a this clear jet to Cleveland, and we got there, and three hours later I was in the operating room, and I was in the hospital for six days, which was amazing, and I went home, then stayed in Cleveland for a couple weeks, but basically, I was back at work a few weeks later. And anyway, the punchline to all this is, with a healthy liver, I could then go through a treatment for

hepatitis C, which worked. I had gone through other treatments which failed because my liver was sick, but now with healthy liver, I got cured of hepatitis C. And the most amazing things of all, thing of all is that this liver transplant cured my hemophilia. And so the clotting factor is the clotting factor that my body didn't make, that my liver didn't make, this new liver did make, and this disease that I never thought I'd live a day in my life without. All of a sudden, I wake up and they say, Oh, by the way, and I knew this would happen. And they said, Congratulations, Your Hemophilia is cured. So the odd thing is that this period of life has been the healthiest period I've ever experienced. I need to manage this. I need to go for blood work and blah, blah, blah, but it's amazing, and was obviously a great success story. It was not an easy path, of course, not an easy path. The surgery is difficult and frightening, and of course, all that preceded it was difficult, but also I was lucky to have great care. The Cleveland Clinic was an amazing place. I have some terrific doctors here, and I'm a happy story and and I think Rosanne, in a way, I think it's a story for everyone, is that you have to have some optimism about this. There was a time when some if somebody said you have liver cancer, you're dead. This is it. Somebody says to you, you have some type of lymphatic cancer, you're dead. Those stays are gone. One of the people I talk about in the book was being treated at the Sloan Kettering, which is leading cancer treatment center. And he said to me that one of his doctors, who was very experienced, said to him, 20 years ago, everybody who was in the waiting room at Sloan Kettering was dying. He said today, it's not true anymore. He said most of these people are people who are going to go through a process and they're going to be healthy and they're going to go home well. And I think that's something for everybody to keep in mind. We're lucky to live in an era when there is a lot of good treatment you. It's a lot of burden on you. You need to manage it. You need to figure it out. You need to get your head in the right place about it. But the truth is, there are many reasons to be optimistic, and you gotta find that optimism in this process.

Rosanne Corcoran 11:45

Yeah.

Rosanne Corcoran 17:58

Yes to carry you through all of that absolutely start to finish, and it's awfully it's hard also when you receive the diagnosis and then trying to move forward with that, with trying to find research, because the flip side of being in the world of we can cure a lot of things now, thank goodness yes, is we also have a lot of information that may not be accurate, and we might see it. We might see somebody on Instagram talking about something, and you're like, that's great, and then you take it to the doctor, and the doctors no. So how do we flesh all of this out?

Dr Edward Rogoff 18:37

Yeah, I think it's the it's a burden of doing research. And one of the things that I talk about is, how do you select the doctor? Yeah, and this is, and I'm related, related to the question you raise is that, is this doctor really knowledgeable about this? Is this doctor as experienced as anyone could be? And, and I say, Look, you want to find a doctor, in my opinion, who's been trained at a teaching hospital, because they have teaching means focus on truth. And are they all brilliant? And do they all know the answers to everything, no, but they're they've been raised in a culture that's focused on getting to the truth, not in coming up with quick answers that are often wrong. And everybody would like to find a quick answer. It's just like, you know, just get me there, and this will be over quickly, but you really need to be you

really need to get to that place where you're doing research, the people who are on your team are committed to finding the truth and are willing to do the work to do the sorting out of is this coming from a reliable source? Was it studied correctly? Was it studied with a large number of people? Was it studied with people like me, all of these kinds of questions that are going to tell you that you've gotten to the right answer? And I tell the story in the book, and always, anyway, I always think of this. Steve Jobs, yes, was you're that brilliant guy. He had all the resources in the world. He had pancreatic cancer that could have been cured. It spread to his liver could have been cured, and he decided to treat it with fruit juice. And now, at the end of his life, he would be Walter Isaacson wrote a wonderful biography of Steve Jobs at the end of his life, jobs knew that was a mistake, yes, but somebody like that can fall into that trap. Why can't you? You know?

Rosanne Corcoran 20:57

Exactly that's exactly, yeah.

Dr Edward Rogoff 20:59

And so you need to be hyper critical in a way of what you hear and what you think. And everybody would like to find the easy answers. And everybody I talk about denial, I've experienced plenty of denial in my life. What would we do without denial? This is what gets us through a lot of times is that I'm going to put it aside. I can't deal with it now, of course, we make mistakes because of denial. Jobs was in a state of denial about, I don't want to start getting all these medical procedures. I don't blame him, but that was what he had to do. And and he's and he's an example for he's an example for everyone.

Rosanne Corcoran 21:42

Yeah, and especially with that type of cancer, to have it and at the point where it could still be treatable, yes, you've got to move on that. And right? It's yeah, it's a shame, and it's for the sake of argument, in a cancer diagnosis, we strive to get a doctor that we jive with that we have a relationship with that we trust, and that we like, and all of those things. And then you get a cancer diagnosis, and it's like, you have to go down the street, and you're like, I'm starting all over. I don't know who this person is. I know nothing about them. I'm literally entrusting my life to them. Yes, how do you deal with that. How do you, I know, as you said, a teaching hospital and all of that. But how do you when you're there and if you go, I just don't like this person, and I don't how do you switch? Because then that takes time too.

Dr Edward Rogoff 22:33

It takes time. It takes courage, right? And people feel loyal to their doctors. Oh, she's been so good to me all these years and blah, blah, blah, but is she the right person today for you? I have a story of this little girl, Ava in the book, and Ava, at two years old, developed a very rare kind of kidney cancer. She lived in New Jersey, and the doctor, and this was a good hospital in New Jersey. The doctor at this hospital said to her parents, look, we love a vote. We'd like to do everything we can to treat her, but you need to go to a place that specializes that does so much more of this than we do. We hardly ever see this type of cancer here, you need to go to Sloan Kettering, because there's a doctor there who this is all he does, and that's the person they wanted to see. Wow. Now I don't think this guy was warm and fuzzy. I don't think but and these people went through, and this was in the middle of COVID. This was the horrible experience. This little girl was kept in a sort of comatose state for months. Anyway, it's a also very happy ending, but they had to go. They had to make that decision. The doctor in New Jersey,

their home doctor was had the courage to say, I'm not the best person to do that, but if he hadn't been, they still needed to say, Where else can I go? Right? And and that worked, and it's just an instructive story about the difficulty of coping with that kind of diagnosis?

Rosanne Corcoran 24:22

Yeah, you hit so many things that caregivers deal with when it comes to not wanting to share the story, not wanting to tell other people the stress of it, of trying to keep it all up, the denial of your care partner. How can you try to turn that denial into something to move them forward. Because, again, sometimes Time is of the essence. And then the flip side is you're not going to call and say, Could we come in tomorrow? It's going to be months before you get in, depending on what, yeah, what the specialty is, yeah. And how can you try to push that along a little bit?

Dr Edward Rogoff 24:58

Yeah. I think this is a job for your team. Okay? It's a job for it's hard to do yourself. It's really hard. Denial is so comfortable, yeah, absolutely. Because I'm just going to recede into this place, I'm going to binge watch, I'm going to I'll be happy. That's it. And somebody needs to tell you, Look, you're making a mistake. You need to face up to this now. You need to make an appointment now, and I'll go with you. I know it's tough. That's where these this team, these people who are close to you, who know you, who really are only motivated by helping you get well, that's where these people, no one else can do what they do. So I don't know any other way to do it. Somebody's got to beat you up in a loving kind of way to tell you it's you're not doing the you're not doing the right thing. Yeah, and I've seen, I've seen so many people. One of the things I didn't talk about with hemophilia. I never contracted HIV from a blood transfusion, but many people with hemophilia did, and I knew many of them, and it was interesting to see some of them could jump on it right away and let me see. Let me do what I can do, and others of them just recede. And boy, that's painful, painful to watch. And even now, when there are so many good treatments for HIV, people still do the same, they're afraid, and you got to face it, and you got to have somebody help you face it,

Rosanne Corcoran 26:41

Yup and it seems so long ago when we talk about blood safety, back back in the 80s, in the 70s and the 80s, we didn't know anything about blood that's right. And the amount of anxiety you must have felt during that time, how did you deal with that?

Dr Edward Rogoff 26:59

Denial? So two things, okay, obviously, no, there's no question. Yeah, I'm actually to give it a little bit more serious answer at the time, and I was seeing people get sick when they die quickly. So, yeah, this was, this was very real to me. I made a decision at the time to and there was clotting factor, was the treatment of choice at the time, and it was very effective, but it was not clear if aids had been removed. HIV had been removed from it or not. And so I made a decision at the time that I two things. One was I would not use clotting factor. I had not used it till I was 20 years old. I said, Look, you didn't use it for 20 years. Let's go back to that way of being careful and living without treatment. I'm saying I'm going to go back and do that for six years. I didn't use any blood products, and I was extreme. I was careful about not putting myself in a situation where I might cause a bleed, and I was lucky. Part of it was that was a good thing to do, and part of it was I was lucky that didn't happen. Yeah, and the other thing was, and

this, in hindsight, I don't know if it was right or wrong. I didn't get tested. I said, I don't know. This is one of these things, of do you want people to know that you have, you have HIV, or any other disease? And so I really made a decision. There was no treatment, and I said, let me not get tested, because if I get tested, I don't know where that information is going to go. I don't know what my doctors are going to say. And so I behaved as if I were positive. I hope that I wasn't. And after six years, there now was finally treatment which would have delayed the development of full blown AIDS, and so I guess you'd say I had a sort of a little mix and match of denial and managing the disease in a different way.

Rosanne Corcoran 29:10

Yeah, that's amazing. That's and because that was a scary time, it was a scary time.

Dr Edward Rogoff 29:16

It's thank God. It's thank god that's over. Hopefully, you'd like to think you'll never see something like that again, but who knows.

Rosanne Corcoran 29:24

There's so much that came out of that time and the stress that everybody was feeling. I give you so much credit for keeping your positive attitude that you have and your resilience through that time, because that was something it makes me wonder throughout these types of diagnoses. How do you try to keep yourself out of that fight and flight and freeze response, to maintain perspective, because there's so much coming at you, and it's all fear based at different weight, whether it's cancer or dementia or Parkinson, whatever it is it's a lot, how do you try to keep that response down and maintain your perspective?

Dr Edward Rogoff 30:05

Yeah, I think you really need to work at keeping a normal life. You've still got your family, you probably have work, you have other things, you've got your church, or you've got organizations that you're active in, you've got other things. You've got to hold on to the normal parts of life to the best extent you can, because you just can't allow this to eat you up 100% and it is a matter, I think, of realizing that you are bigger than this you which you are and that this is a piece of your life. It's not everything in your life. I've met a lot of people who make the disease that they have bigger than it needs to be, and I really think that you need a strategy that fits you for how can I maintain some normal parts of life while this is going on.

Rosanne Corcoran 31:07

That's very interesting. It make it bigger than it needs to be. What do you mean by that?

Dr Edward Rogoff 31:12

I think it's complicated. I think I think there are people, in a way, who enjoy the attention of being sick. I don't enjoy the attention of being sick, but I, but I've met many people who do, and they talk about their disease all the time. They talk about their experience with it, and it becomes this, becomes everything they do. Obviously, you need to focus on it. You need to do what you need to do, to treat it, to take care of yourself. But taking care of yourself is also a process of keeping those parts of your life that give you satisfaction, that engage you, that make you realize that you are bigger than this disease, and

everybody has those and whatever it is, you enjoy going to the movies with your friends. You enjoy going out to eat with them afterwards. Don't give that up. Maybe you can't work full time, but you can work part time. Maybe you've always wanted to take up painting watercolors. Maybe this is something you can do at home. You don't feel like you can go out and have a lot of energy, but maybe this is something you can take on, find your creativity, find the joy in doing that, and balance the scary diagnosis with the parts that are satisfying in your life.

Rosanne Corcoran 32:51

I love that. That's great, and that's, I think that's that can be used across our entire life. Scary diagnosis or not, right?

Dr Edward Rogoff 32:59

That's right. No, that's right, yeah.

Rosanne Corcoran 33:02

It's interesting too, because you bring up in the book that we have our own individual biases and prejudices that that can interfere with us making the best decisions, obtaining the best diagnosis. Can you tell me a little bit about that?

Dr Edward Rogoff 33:16

Yeah, this is I talk about a few of these. These are well studied in psychology and absolutely exist. This is what's one of them is attribution bias, which is you start with a certain attitude, and then everything you interpret in a way that confirms your bias. So this is you think doctors are just there because they want to make money. Some of them do not. All of them so. But then every time you go to the doctor, and the doctor doesn't spend as much time with you as you'd like, you interpret it because the doctor is he's not making enough money with me, and therefore he's got to go to another patient where he can make more money, maybe, but probably not. The doctor has patients waiting. The doctor has a boss who's telling him you got to see more patients more quickly. There's other things going on. The doctor feels that he's accomplished with you and your visit what he or she set out to do, you know, and then your bias gets in the way of that, and now you're misinterpreting what the doctor is doing. So we use these prejudices to confirm our own biases. I tell the story in the book of a woman, and her attitude was, she lived in Brooklyn. She was raised in Brooklyn, New York, and she would tell her son, and she lived to be 104 years old, and she told her son that she would never see doctors in Brooklyn. She said, Only the best doctors are only in Manhattan. Oh, my goodness. Now, with a lot of these things, there's sometimes there's a seed of truth in this. So Manhattan is the home of these high level medical institutions. There are many more doctors there. Yeah, okay, maybe that's true. But you know what? Brooklyn has a million people who live in it. It's got a lot of hospitals. It's got a lot of doctors, and chances are some of them are pretty good, and they can do what you need them to do. Anyway, as she got older, this became a bigger and bigger problem for her caregiver, right? So she he'd say, Look, I'm going to find the doctor nearby. No, she didn't want to go nearby. She was, she said, you find the doctor in Manhattan. Was like, oh my god, how am I going to get her there? Yeah, deal with all this, right? Yeah. And it's hard to identify. We will all have these biases, right? And you see somebody of a certain age, you make assumptions about them. You see somebody who dresses a certain way, you make certain assumptions about them. Somebody says, Oh, I went to Harvard. Now you think, Oh, this

person's a genius. You know what? Not everybody who went to Harvard's a genius. And so you And anyway, I think it's a very common thing, and when we're dealing with health care, something that's so important to us, I think these biases come to the surface even more. Yeah, and again, you have to think about it. You need to talk to other people about it. I know, I know I've seen plenty of doctors, and I know I have biases about them. It bothers me when doctors don't stick to their appointments at least in a reasonable period of time, or they're way late. I had a doctor who I saw, who he was running. He always ran late, so I said, I'm just gonna make the first appointment of the day. Every day he still ran late.

Rosanne Corcoran 36:45

So it was just who he was.

Dr Edward Rogoff 36:47

And that's who he was, yeah, and so now I made all kinds of assumptions about him, because of that, I'm compulsively early, so I don't want a doctor who's compulsively late, but anyway, but we all have these, and part of having some getting some insight into yourself and bringing these out into the open, I think, helps you to minimize them or realize which ones are worthwhile and which ones are distractions.

Rosanne Corcoran 37:16

Yes, very good advice on that. Can we talk about the hard conversations when doctors are sometimes a little reticent when it comes to the facts of the disease progression and the treatments for said disease, sometimes they're a little hesitant to say, we're at that point that this really isn't going to help you, or it's not going to bring much to your life. We can still treat you, obviously, but it's really not going to either cure or help you. How do you interact with doctors like that when they're hesitant in that area?

Dr Edward Rogoff 37:51

Yeah, I think it's up to the patient to establish the culture of the conversation you want and those values in that culture about honesty and bluntness, I think you need to tell them that. You need to say, look, I don't want to get bad news. I don't want to hear about complicated, difficult, side effect ridden treatments that I need to go through, but I need to hear about it fully so I get the sense, and you can tell them this, I get the sense from you that you're minimizing what this treatment is going to be, how long it's going to take, and how successful it's probably going to be. I need you to be blunt with me about it. And if you can't do that, is there somebody else, maybe who we can bring into this conversation, who's more comfortable with that? And this is where nurses, other doctors, patient advocates, can be very useful to you. They there understand the positive role of honesty, and they see that as a bigger part of their job, often than the doctor does. I think the doctor can be focused on writing prescriptions and giving treatment, and the other person can be more focused on a little bit more holistic view of where the patient is. You're hoping for patient centered care. You're patient centered. You're absolutely and not everyone gets that, no, and not by a long shot. And so it's up to you or to your team members who are with you, maybe your spouse or a child or somebody, to be the person who's frank about that with the doctor.

Rosanne Corcoran 39:46

Because they're trying to decide on the treatments or treatment plan, and it's is this business as usual for them, or is it because you're at a teaching hospital and this will benefit the research that they're doing? And I hate to say things like that, but that's really the reality that comes in sometimes, if you're not, if you're if you don't have that relationship, and if you don't have that ability to say, Give it to me straight here.

Dr Edward Rogoff 40:09

And I think also to to ask them, Are you do? Are you working on any studies related to this issue? Yeah, I think to ask them right out front, because once they're working on a study, this changes their goals, and it puts in place a goal that's in conflict with making you better. Yeah, maybe participating in a study or being with a doctor who's doing a lot of research is the right thing for you, but you better figure that out. But I think it absolutely can interfere with with it. When my mother's health began to decline, she had a Doctor Who, and I think this, I think she felt she was doing the right thing. My mother would go in, and I went with her to appointment. So my mother would come in and she would have the latest complaint, and she was in her early 90s, and you get complaints. I think the doctor felt like she had to do something right. There really wasn't anything to do, but the doctor started writing prescriptions every time she went to the office. And then one day, I'm at my mother's house, and I see, oh, my God, there's so much. And she really had nothing wrong with her whole row of jars of pills and everything. And I wrote down what they all were, and I looked, and I found, I looked it up, a lot of these were pills that had conflicting purposes, and it was because the doctor wasn't considering everything else that had been done, and she just wanted to do something for my mother. She was she liked my mother. She was trying to be nice to her. No, and my mother could never have done this on her own. She needed somebody with her to do it. Yep, in the final analysis, we reduced the number of pills she was taking from like 15 to three. Oh, my goodness, but there's, there's that role that the caregiver fills, that no one else could fill, nobody else could do it.

Rosanne Corcoran 42:13

Yes, absolutely, because you're the one that's there every day, or however often you're there. Yeah, you're looking at this. Wait, what is this for? And it's important to be able to talk to the doctor about these things.

Dr Edward Rogoff 42:24

Yeah, the doc, when I taught the doctor, didn't like it when I talked to her about it

Rosanne Corcoran 42:28

I'm sure she didn't, I have no doubt what, how did that conversation go?

Dr Edward Rogoff 42:35

I i decided to have that conversation without my mother there, and so I called the doctor and I said, Look, I think we've fallen into a pattern here. Of my mother has a new complaint. You have a new treatment, and this has now gotten out of hand, and did you know that you're giving her X and she's already taking y? And the truth is, the doctor had lost the perspective on it, and she was not reading the chart carefully anymore, and so she took it as criticism, and then she she became hostile with me. And I said, Look, I'm not trying to pick a fight with you. I'm just trying to keep it simple and effective for my

mother, etc. And I said, she loves you. She really loves being in your care. Helped was to reassure the doctor that the patient was like her friend, which I don't think that's the job there, but that was her attitude.

Rosanne Corcoran 43:36

And it's amazing that you're trying to stand up for your mother, and then you have to be like, but we love you, yeah, we love you. It's all good. I'm just asking questions. Yeah, it's, that's the that's the caregiver's plight right there.

Dr Edward Rogoff 43:50

Yeah, no exactly.

Rosanne Corcoran 43:51

Yeah. Do you have any advice for a caregiver who's in this situation with their care partner, be it their mother, their father, their spouse, their cousin or whoever, do you have any advice that you could give them for maintaining this or for going through this scary diagnosis and then going forward from that?

Dr Edward Rogoff 44:12

Yeah, I think is to appreciate number one, it's a privilege to help someone, and this is someone you love, so it's a privilege to help them, and it's a great responsibility to take that on. And you need to get in touch with your gratitude that you're able to be in this position if you lived 1000 miles away and you couldn't go to appointments with your mother or your friend or your whoever you wouldn't have be have that opportunity, I think you gotta, you gotta see it as a way to provide service to someone whom you love, and to that extent, it's you. It's a privilege, and that should connect you with your gratitude. And so it stops being a responsibility and it becomes a an opportunity.

Rosanne Corcoran 45:15

A big thank you to Dr Rogoff for his time, his wisdom and his heart, his book, scary diagnosis, navigating fear, finding strength and securing the health care you deserve is available now wherever books are sold.

Rosanne Corcoran 45:28

Want more Daughterhood? We are more than the podcast. We are a community that offers free, nationwide virtual support groups we call circles. These circles allow you to connect, learn and receive that much needed support through your caregiving journey. You can find more information@daughterhood.org where you can register for a circle, sign up for our newsletter, find our founders blog, and, of course, the podcast. Remember to also follow us on Facebook and Instagram @daughterhood.

Rosanne Corcoran 45:57

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discover our various circles and subscribe to our newsletter for updates. Feel free to message me on any of these sites and let me know what issues you may be facing and would like to hear more about, or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song, Mama's eyes from her album, Lessons In Love. I hope you found what you were looking for today, information, inspiration, or even just a little company. This is Rosanne Corcoran I hope you'll join me next time in Daughterhood.