Ted Meyeru2019s illness and art journey

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Then at 52, enough people said to me, well, you have this interesting life. You were sick. Now you're healthy. It's the reverse of most people. But then I started doing this series of people's scars and I started doing monoprints of people's scars.

And I would listen to their stories about how healthcare was good or bad, and doctor's bedside manners were good or bad, and how they navigated the medical system, but also their survival stories, because everybody with a big scar has survived.

This is Doctor Talks, real talk from real doctors on the issues that matter to you most. Welcome to the Two Curious MDs podcast. This is Surya Raman, and I'm here today with Ted Meyer of Art and Med, patient artist and patient advocate, who's also a friend of the podcast.

And we're excited to have a really big conversation about some big topics here and also maybe have a little bit of fun. So with no further ado, I'm going to welcome Ted to the podcast.

Welcome Ted. Hi. Hi. Good to see you. Good to see you. Yeah. I'm just going to read a little bio. One curious MD. One curious MD. And I'm just going to read a little bio here from your website at tedmeyer.com.

So if anybody's looking for Ted's work, everything is www.tedmeyer.com. Ted Meyer loves bodies. He loves to paint them, photograph them, even print off them.

He loves healthy bodies, but also bodies in states of trauma and healing. He creates puzzles of bodies that celebrate sexuality and survival. Through his art making, photography, design, curation, and publishing projects, Ted portrays the beauty and humor of physicality while exploring narratives of the human condition.

Ted is an artistic patient advocate. When he started working with bodies years ago, Ted never imagined that his work would be shown in venues as diverse as the United Nations, the National Museum of Health and Medicine, UCLA, the Broward Museum of Art, St.

John the Divine, and galleries in Asia and Europe. It continues to be an exciting, evolving, and rewarding journey. It is exciting and rewarding. And always changing.

You're on your second TED Talk. I've done two Ted Talks. Well, they have to let me do it because I'm a Ted. You're a Ted. That's a shoe in. You have a new book that's just come out this year called The Room Sinatra Died In and Other Medically Adjacent Stories, which I have to say is hilarious take on from the point of view of the young Ted, the Ted that spent a lot of time.

Speaking to different audiences

Mostly young, some old, but I think they're all looking back. It's as an adult looking back at the young Ted trying to understand the medical world. Yeah, absolutely.

I'm done with such humor and I think a real love for images, for the people, the characters that you meet, and just how sometimes these interactions that happen in healthcare can leave us feeling a lot of different emotions.

And sometimes those emotions are absurdity or just kind of… annoyance, and I love how you've captured that and

expanded the range of emotions and perspectives that can be available.

When we talk about patient illness narratives, yeah, thank you for being here. So to start with, how do you decide what's going to be in a talk when you start to give a talk?

Well, a lot of it depends on who the audience is. So I have a base talk. I have base information because I do art about illness or I curate other people's work about illness.

So I have a lot of the same slides for all the talks. I have a little starting because it all starts from the same place of that I was sick when I was a kid and I did art about illness.

But then if I'm talking to doctors, I get much more technical. I talk about my symptoms. I talk more specifically about the illnesses of the people whose artwork I show.

And if I'm talking to artists, I tend to show a lot of the same work, but I talk about it, the images a little bit more. Do they look like other artists?

What are the techniques they've used? And I also am a big believer in doing art about something rather than just making pretty art. So I talk to them about that.

And sometimes that is met with a good reception and sometimes it annoys people. Well, synthesizing all these different areas. I love how you've described that the same story, right?

That's part of what we talk about in narrative medicine is sometimes we tell the story a little differently based on who our audience is. And you've had a chance to tell this story on so many from platforms, large and small, to patients, to artists, to physicians.

And you've seen that depending on where you're located and what your experience of illness and wellbeing is, the story can be received differently or experienced differently.

Tell me when you're speaking to the patient advocates. When that story goes out and you're talking about what you've done with bridging the divide between patients and their physicians, for example, and how that goes back to those seminal moments in your childhood where you notice that something was off.

Well, as you know, you read this section of my book to a group a long time ago. Well, when I was a kid, what I have is very rare. And as a result, when I was a child and I would be in teaching hospitals, I was the textbook.

The doctors would come in, there'd be a group of interns. They would all poke me and prod me and tap my stomach because I had a very enlarged spleen at the time, but they would never talk to me.

They would just talk about me. They would say things like, oh, he's going to die, he's going to get cancer, he's going to have necrosis, his bones are going to fall apart.

Then they would leave. I say in the book, this is not a conversation you should have in front of the seven-year-old having therapy afterward or at least access to a therapist.

From childhood illness to patient advocacy

So that talk, first of all, I outlived them. I'm still alive, so screw them. But that memory of these just being an object, just being, you know, and other people see that too.

Women get that as sex objects. I got it as a patient. Whereas it was my illness that thrilled the people because they hadn't seen it before. It wasn't me as a person.

And that just always stuck with me. So later on in life, I had been doing graphic design for years and hit a point

where I just hated it. And I just always thought about how badly these experiences at different teaching hospitals went.

And I thought, well, how can I do something about that? And to do it, I needed to be around doctors in training so that I could give them a good what for and say, you know, you guys need to think of us as people.

So I approached UCLA and I got I started a little program there, but they never really fully embraced it. And then you and I had sort of this odd meeting and you brought me into Keck and there the programs really worked out well.

I think I have, you know, we have a gallery, we've developed a lecture series with the artists and patient advocates. So I don't know, it's all been serendipitous.

Beautiful. Yeah, I love that because when we're medical students and we're looking at, you know, the diagnosis of gauches, for example, or other rare illnesses, you're right, most of us won't see a case of a rare genetic illness.

And so that fascination that physicians can fall into and that kind of intellectualizing versus actually seeing the patient in front of them. And I recall one of the first pieces of art that I saw that kind of really got that aspect, you know, and described it and transmitted that felt feeling was this, I was in residency in New York and it was this play that came out called Wit.

by Margaret Edson. And that's another example of how art can really explain to us, hold up the mirror and say, well, this is how you're behaving. And is this what you think medicine should be about?

And what would it be like if you were on the other side? of this equation. And I think there's been this really beautiful awakening in the last couple of decades that you have also and other artists and other creative endeavors have really tried to understand.

What is this illness experience? How do people not just experience it, but live with it? How do they transmit it? What meaning do they make out of it?

So when you were starting to first formulate this, I know there was a multi-step process. The first process was kind of one, actually having a life change, a life changing moment where all of a sudden you were going to live a lot longer and have different possibilities open for you and that pushing you to kind of rethinking what your art could be about.

Can you describe a little bit of that? Sure. And I think this experience that I'm going to talk about, a lot of my friends that have AIDS have been through it.

Even people lately that had cancer and the cancers are not treatable. But there's a point where you were told you're going to die. And you plan your life to die.

I always joke that my retirement plan was to die. I didn't have a 401. I didn't have a retirement set up. I never bought a house because I thought, well, if I'm going to be out of here by 30, I'm just going to go have fun and travel as much as I could.

And then a new drug was developed. And as a result, I I didn't know how many years, but I knew that I had the chance of a normal life. And at that point, you have to start taking life seriously, like maybe have a career rather than a job, maybe have a girlfriend rather than just run around, do different things.

And I know a lot of my friends with AIDS, when AZT came out, it was the same thing. They had sold their life insurance policies ahead of time. given up their houses and everything and all of a sudden there was AZT and the multi-drug cocktail and and A lot of them are still alive, but they had also planned to die and sort of you know So it's it's an it's an interesting thing when you have a life like mine Which where you're very sick young and then you get better.

It makes you Look at things a little differently. I think Yeah and I love how you've carried those those perspectives that you had as a child and really connected with those perspectives and valued them and not just pushed them aside but really gone back and understood yeah when the art cart lady was going around and you know giving you the materials that would become kind of the seedbed of your own artistic practice that that was not just getting your artist self to learn new tools, but also starting to tell your story from the perspective.

We should probably explain this story. I was about seven or eight years old and I might have been a little older. I was in the hospital. I used to have to be in the hospital multiple times a year, three to five times a year.

And I would go with my art supplies, and I'd bring a pad, and I would draw while I was in the hospital. But I just hated being in the hospital. And this volunteer at the hospital said to me, well, you can draw if you don't like it here, do a drawing about it.

And that was kind of revolutionary at that time. There weren't art therapists everywhere. There weren't child psychiatrists there. And the fact that this woman said, oh, well, I'm going to help you.

We're going to get some IV tubes. We'll get some bandages. We'll do something. but it gave me the feeling that it was okay to say, this illness sucks.

Being a sick kid is a very interesting thing because you're still a kid, you want to have fun. Adults want to treat you like a kid and they don't want to pity you, but you can't act real sick as your kid because they'll get sick of you really quickly.

Creating the Scarred for Life project

A sick kid who's Pleasant can manipulate everybody but a sick kid who's crying and whining all the time is a pain in the ass And I sort of learned that the way to handle that when I was at that age But anyway this woman she changed my life by just saying you can talk about what you have and my brother who had the same disease and Landed up dying from it.

He never talked about it. And when he was older college and afterward and he would have illnesses pop up or he would just not be healthy. He would never talk about it with his friends and as a result they didn't know how to relate to him and you know we would always have conversations about like Why don't you just tell your friends you've got something and that's why, you know, what's going on with you is happening.

And he just, he didn't want to do it. And I found that if you just, you know, if you just say to people, I've got something and don't burden them with all the minutia of it, so they feel burdened, they're going to be very accepting.

Yeah. And how important that is to tell the story, right? Because as you've told the story, each time you tell the story, it changes a little bit. It refines itself.

You start to see different layers of it. And I love how you've gone to the place where you're telling it to different audiences and it's coming out in a different way as well.

And now you're helping others to tell their story. I love what you described about the IV tubes and the band-aids. And you have patient artists right now who are actually doing exactly that, but as adults and as a way of describing their own illness experiences, and you're curating those art shows.

Talk a little bit about that. What led you to that path? Well, I had been a graphic designer for years, and when I was in my, I always tell people that I had never made a plan for my life until I was 52, because I never thought I'd have a life.

Then at 52, enough people said to me, well, you have this interesting life, you were sick, now you're healthy, it's the reverse of most people. And at the time, I was doing artwork about the fact that I was sick.

I should say earlier on, I was doing artwork about the fact that I was sick. So people just kept saying to me, well, you should talk about this. It's really interesting, which I had never thought about.

But then I started doing this series of people's scars. And I started doing monoprints of people's scars. And I would listen to their stories about how health care was good or bad, and doctors' bedside manners were good or bad.

how they navigated the medical system, but also their survival stories, because everybody with a big scar has survived. So this sort of gave me an anchor that wasn't about me, because by this point, there had been new drugs, I was very pretty healthy.

But I still have this, I can still listen to people who have been through horrible things, Having known what they went through, I could empathize. And I approached UCLA and said, I've got 100 stories and monoprints of people's scars that have been through horrible things.

And maybe I should come in and talk to the doctors and tell all these stories about good and bad medical care. So at that point, they were looking for some medical humanities in their program.

I met the dean of curriculum after calling up for months. I kept calling and calling and saying, I'm an artist, I want to work in the medical school. And the secretary kept saying to me, we don't want an artist, go to the art school.

And I kept calling again and again, like every two or three weeks I would call. This woman, heavy Jamaican accent, very funny. When I finally met her, she was great, but one day she was sick and I got the assistant to the dean of education and he said, let me call you back in 20 minutes.

This is a great idea. And about an hour later, I got a call. Can you come in tomorrow and talk to the dean? And that's sort of how it all started. But they didn't have much budget.

They didn't have much space. Persistence pays off. Can we just say that persistence pays off? Like you kept calling. Because I really didn't know what else to do with myself.

I was sick of doing graphics, and I just kept thinking. You know, I was a good graphic designer, I was a great graphic designer, but this is something where I knew my life experience was different, and it could lead me to something.

Especially when I started the Scar project, because I had this understanding of these people that had survived horrible things. It's like, it's very easy for me to talk to people.

I always say that I could walk into a hospital, lay down on a gurney in the hallway at any time because that's what I did when I was a kid. It was sort of my growing up was being around nurses and gurneys and that horrible smell of disinfectant that's in every hospital.

Smells of my childhood. Yeah. I feel really comfortable around this. Not that I want to be in a hospital, but when I walk in to visit people, I'm more comfortable than other people.

But the more of these stories I heard from these scarred people, the more it just became apparent that this is something I could do better than most people.

Not that there aren't other patient advocates out there doing fantastic work. But this little niche of retelling people's stories of their problems in the medical system was something I could do.

And then I decided, well, I'm going to look for people who tell their stories through art because I loved art. So medicine and art, I just combined the two, and it took a while for it to really gel.

It didn't gel so much at UCLA, although we had a couple of really great talks with artists, but it did gel at USC. What was great about USC is, first of all, there was a whole gallery.

It wasn't like we're going to put some artwork up in the hallway. There was an actual gallery. The first thing there, I had a boss there who was willing to kind of go to the mat and claim that gallery for me.

And I always talk about that gallery. It used to be the monkey gallery. And that was because all the professors would go to Costa Rica with their fancy cameras and they'd take pictures of monkeys and they would come back and they were all on the wall.

So it was a gallery, kind of a vanity gallery for the doctors and the professors. We got that gallery. It took a while explaining to people that this is space that would be better used as part of the curriculum.

And then we put up shows by these patient artists. And the first one, I think we got eight people. Now we get several hundred years later. But they didn't really gel.

It was a nice talk. People liked it. But there was one woman who came in and she was convinced that her cancer had gone into remission because of sort of new age medicine, not Western medicine.

And I didn't think I wanted her on stage. talking about her medical treatment and her prognosis without a traditional doctor on stage with her.

Why medical students need humanism

Not to argue with her, but just because this talk was for the med students and I didn't want them to hear things that wasn't going to be on their tests as far as treatment things.

And once we had the artist and the medical professional, the specialists from that field on stage together, everything sort of clicked. It became very magical.

And what's been amazing is the insight of the doctors into the artwork. So I guess we should explain here that the artwork, like it's not somebody who has an illness that does landscapes.

It's somebody who has an illness. They have to be doing artwork. about their life, their daily happenstance. And a lot of it can be pretty abstract in a way, it can be patterns or things, but it does relate.

To hear the doctors talk about it, I'm always sort of surprised by their insight by it. But let's get back to the whole idea of the bringing the art in.

The art is for me to show these first and second year students that here are a group of people who have terrible illnesses. They might die from them, but they are still people.

They are not their lab results. They are doing artwork about their illness. It is part of their life and they're using it creatively, to tell a story, to let people know what they're going through.

So don't look at this person who's come to you with a bad heart that needs replacing or cancer or something horrible and think that's all they are. Like they used to think about me when I was a kid.

Yeah, yeah, exactly. That danger of the single story is what we call it. And I think what we're getting at here is for physicians in training, for these medical students who, you know, they've worked hard, they're really smart, they're doing this for the right reasons.

They do have a certain level of interest and empathy, but it's the rigors of medical training and maybe just there's really no time. in which for them to learn that, oh, this is actually a thing, this is actually available to you, that you can get into a patient's experience and that that can be useful to you.

I remember as an educator looking up YouTube videos of kids who are living with maybe cystic fibrosis and when people start to first share their illness stories on YouTube.

And I think that the digital revolution has been amazing for allowing us to share our stories in that long form, where it's like, oh, what is the experience of living with something every day versus the little one-liner on your chart that might say, oh, you have cystic fibrosis?

And I felt that, you know, physicians, you know, we're not the expert on illnesses when somebody has lived with it every day and that there's so much expertise there that people are bringing, but also a perspective.

I remember seeing so many different pieces at these shows that you're talking about that are curated where it really not just humanizes, but makes us think about the illness differently.

and how that can open up when we're thinking about therapeutics and management and what's possible for a person and even making decisions, right? If I know what's important to my patient, it helps me to make decisions, better decisions about the choices that they have in front of them versus if I just treat them like this is the diagnosis, this is the standard treatment and you've got these three choices and the choices are just you know, a little bit different, you know, a little bit of information is known this way, that way, but I haven't thought through as a physician what the impact of this surgery or medicine or a therapy that I'm, you know, recommending is going to have.

And, you know, just, I think when we talk to students after they've been to some of these talks, they're really finding that what they're learning in med school comes alive.

really just kind of becomes more relevant, more immediate. I definitely do see that they come in very, you know, pulled in by the art. It really has even changed the kind of culture of that downstairs art gallery, where it just feels like there's an elevated experience.

you know, where we can maybe sit quietly with one piece and just be meditative about it and really take it in, which can be a real nice break from the way medical school usually goes, right?

Which is just at a high speed where you do this, do this, do this, move to the next thing. And that has really become kind of a cultural center in the basement of the Keck Medical School that has drawn in so many different people.

You even have an art show about researchers having their work kind of interpreted by artists and what that's like for them to kind of see that. And then art and medicine do go hand in hand.

It really helps us to engage with concepts in a different way. Yeah, I mean, I think I feel like I'm fighting a number of things and some of it is just human nature.

I mean, you and I have seen these first-year med students come in and they're really excited the first time they deliver a baby or the first time they cut into somebody or they see a cadet, like it's the first time.

But if they're going to you know, they can get bored just like anybody else. And I think that they lose their enthusiasm after several years of seeing the same things, the same cases.

And I would think a doctor who does a hip replacement five times a week, it's not a big deal for him. He might still like the skill, having the skill to do it.

He might still feel or she important because they've changed someone's life, but it's not a big deal for them. It's a routine thing. One of the things I always talk about is as things get routine for you, don't forget that it is a major life event to the person you've done it with.

It could be the biggest thing that's ever happened to them. And you've been through it five times this week, but they are through one time in their life.

So I think that that's really important. And then the other thing, which you've heard me talk about a number of times, is picking the right profession, making sure that your specialty matches your personality.

If you don't like talking to people, work in an ER. If you have an adrenaline issue, work in the ER. If you're somebody who wants to really get close to your patients, maybe watch someone grow up, be a GP, and if you're a neurologist and you want to see someone around for 30 or 40 years, start studying people with MS or specializing in people with MS and neurological things that are going to deteriorate over time because you'll be part of their life for decades.

And I think people make the wrong decision either because of money or pressure. It can be disastrous to them and their patients. No, I'm really being brought into this kind of realization or recognition that this has been such a kind of addition to the medical education field.

The field of medical education, which in the last 10 to 15 years, myself as a medical educator, we've realized that we're having to put back in these humanism aspects of medical practice that really overlap with ethics and humanism.

being attentive to, you know, having empathy and connecting with people because there's been such an erosion of it. Or the system, right, is, I mean, we barely ever get eye contact.

We, you barely get to know your doctor, you know, themselves. And this breakdown and this relationship is what we're really trying to get at. We're really trying to expand out.

Look at what goes missing. If you don't, just take a moment or develop that skill. I think when we view art and we go in there, we're developing a sensibility, an aspect of ourselves that the next time I have a moment where I connect with this patient and we're kind of connecting on a human level, oh, I can actually recognize that that's happening and I can slow down and I can just kind of be with the patient and it comes from a place of at least having done that once before.

What patient art reveals

or at least having encountered the idea that it's important, that there's value in it. There's nothing like when I was a kid and the doctor would come to the house in the morning.

He did his house calls in the morning and then he did his hospital rounds in the afternoon. It was very different than nowadays. So they would come to the house, they would get to know you.

There's a certain kind of element of setting that leads to people getting to know each other better. They would see your house and how you live. And I'm sure that a lot of things happen, interactions because of that and people seeing problems that you don't see just seeing somebody in an office.

Exactly, exactly. The actions or the tableau speaks louder than any words could, right? The image. Tell me a little bit about what impact telling stories has on the patients and artists who are doing this kind of storytelling.

What have you seen? What difference does it make to their lives? Well, first I'll talk about the Scar series. So this series called Scarred for Life. And every time I show this work, people are really moved by it.

So I'll give a little better explanation. I roll ink on people, I pull a print, and then I paint into the print with things that happen to them. So it sort of looks abstract.

And these people, they frame them and they put them on the walls. Two things happen. The first is that everybody comes up to me to tell me what they've been through.

And this is part of why I originally went to UCLA, because it was so apparent to me that there's a big duality between when patients feel they're healed and when doctors feel they're healed.

doctors feel they're healed when their test results come back and the people feel they're healed when mentally they feel they have survived it and they made it through and maybe their body is never as strong as it was before that

heart transplant or the car crash or whatever it was.

There's a big difference. I always say everybody knows the day they got operated on, but there's no actual healing date. So as a result, the expectations between the med students and the patients or the doctor and the patients, they can really be very divided.

So that's one thing that I learned from hearing all these stories. And the fact that so many people would come up to me and want to show me their scars and they'd go, this is what I went through.

Like they want to be acknowledged for this major thing that happened in their life and that they suffered and that they survived it. Like the whole idea of surviving cancers, surviving a kidney transplant, it's a major And that's what gets back to that idea.

This is the major thing that happens to most people in their life, but the doctor does it three times a week and couldn't remember these people's faces a week later.

which I think leaves us much the poorer for it that that is the way it is for physicians. You know, I think we talk about the burnout epidemic. We talk about how emotional kind of being in such a high stress kind of manufactured environment leads to some of these fractures, which I think doctors ourselves want to heal and change.

So just saying that we lose out just as much, I think, from not being able to connect. And I have a second point and I can't remember what it is. Oh, the impact of telling the stories when your patient artists have their art maybe for the first time being viewed all, you know, in that gallery way, like a curated way.

Yeah. So a lot of these people do like a lifetime's worth of art and it never gets shown because as I often say, nobody wants to see your colon reconstruction over their couch.

So the people do this work, they have sketchbooks full of things, but it never gets shown. It's not the kind of work that's going to get shown in the gallery.

So the fact that I can show it and give them a voice, and I also, when I show people, I talk to them ahead of time to make sure they can really verbalize what's going on with them and their care.

I don't want someone up there who doesn't really understand what's happening to them. What I always find amazing when I talk to these patients who are doing art is how knowledgeable they are.

It's just amazing to me. I have one friend who talked about going to cancer college when she had never thought about cancer, she had a double mastectomy, she had to learn everything about what her test results meant, what kind of treatments.

And it took her months to get up to speed on her treatment. And the knowledge, the sort of institutional knowledge of some of these people about their illnesses is just amazing.

We just at Keck had a young woman on who had sudden cardiac arrest syndrome. Her knowledge, she's become this huge activist and patient advocate to make sure people get tested, to make sure machines are available in public everywhere if somebody needs to get shocked.

And she's worked on bills. She just got a presidential award for her work. And when she was talking to the med students, I mean, I was just really amazed at her knowledge about care and treatment.

She knew every statistic about how many kids, how many adults, how many people die because there was no one around, how many people had already been to doctors, and because they were women, they were discounted.

landed up dying, you know, because no one takes female heart attacks seriously. So it's, it is really important to listen to these people. And if the only way to listen to them is by looking at their pictures, then that's what we have

to do.

And that's what I did. The impact can be not just on a personal level of, you know, kind of having their illness experience be witnessed, or just the lifetime of art that's actually gone into the meaning making.

Because each time a piece is made, it illuminates another part of the journey for the person themselves. And sometimes art can just really anchor experiences that feel so chaotic, right?

And that's what we talk about in narrative medicine is This is what I teach my residents and my students is when you go into a room and somebody says, well, nobody's been in to see me all day and the doctor only spent 10 minutes with me.

It's because that's what it feels like because the rest of their day was pretty empty. To you, it felt like, oh, you spend 10 whole minutes, 10 whole minutes on your very, very tight schedule of seeing X number of interactions may feel like it was a lot.

And so just even understanding that people who are in the hospital and are sick are going through what we call a chaos narrative. meaning hours could pass by and it feels like minutes and vice versa.

And hospitals don't do a great job of keeping track of time, right? I mean, it's not like you can see the days, the day passing through and enjoy it. They've all got these white lights and day and night kind of blend together.

So that's one of the things I try to teach and that this meaning making, this bearing witness that's part of this idea of narrative medicine. I mean, what you've been doing has been really transformative in this way to not just allow this idea that, oh, we can invite patients who make art, call them patient artists, even just the idea of what shall we call them?

Is it artist-patient? Patient artists. I mean, I think this is a point for, and you've heard me say this a million times, like all these people, they might have been doing art if they were healthy, but because they were sick, they did a different kind of art.

And the images they create would have never happened if they were healthy. They would have done other. they would have done a landscape, they would have painted their cat or something.

But because they were sick, they have artistically gone in a different direction. To me, a lot of that artwork is way better than had they been healthy.

Your story you were just telling, and I had this memory just now that I had not had for 50 years of being in the hospital and thinking, where is my doctor?

There's a lot of things when you're a little kid and you're in the hospital that you don't understand. The fact that the interns are there for 40 hours in a row, day or night they're there and then all of a sudden they're gone.

Why are they there so long and then why are they disappearing? Because you kind of build a relationship with them in that 40 hours they keep coming in and checking on you and then all of a sudden they're gone.

So that made no sense to me at all as a kid. Just none of it made sense to you. as a kid. But the other thing that I hadn't thought about for years was like wondering, where is my doctor?

And then hearing the dinging over the speaker and going, bing, bing, doctor, whatever my doctor's was. So I knew he was in the building, but he wasn't coming to see me.

Children, families, and chronic illness

You know, that's a special kind of emotion. I know if you're here you're just remember this one time I was in real

pain and I wanted to see the doctor and I just kept hearing they were calling them and there obviously was some big emergency because they kept calling them but I'm like I'm waiting I'm here I'm waiting he didn't show up what a great story what a great story because that feels like a special kind of like is he ignoring me Here oh my gosh.

Yeah, I mean I wouldn't say I felt like he was ignoring me because that was one thing about If you grow up in hospitals, you see so many, you know, there's lots of other sick kids So you you you know, you learn to temper your demands that like oh the doctor should just be seeing me But I remembered that one day where I just felt terrible and I was like, where is he?

He's here Why isn't he coming in? the relationship. And that's, I think, what's kind of where we're seeing that now that doesn't quite exist in that way, where, you know, as a kid, you could see that same doctor for 40 hours because they just happened to be there.

And I remember that from my own training, which we still were doing long calls at that time. and you know after rounds are done or you're taking a break or a new piece of information's come or you just have a little bit of time and you just pull out a board game or some cards and you play you know a game with your patient and that just allows a different kind of conversation to happen.

So that's one of the things that I always bring up is just like if you've got five or ten minutes and you can just do something that's not related to the medicine but just related to the experience of being together.

And they get to see a different part of yourself. You get to see a different part of them. And I think that was my favorite part of pediatrics is because you can kind of do that.

That's kind of what requirement in pediatrics is to do something other than talk medicine with your patients. So yeah, this, you know. Well, let me ask you since you did pediatrics.

I mean, I found As a kid, I didn't really know what to expect. So whereas you've dealt with kids and adults, so do you find kids easier to deal with because they don't have the fear of what's going to happen to them or the expectation?

Whereas the adults are always thinking worst case scenario. So interesting. With kids, we're more in the experience, right? We're more in the here and now.

They're really not thinking about the past. They may be anxious about the future. And a lot of times the kid's anxiety is made of only the pieces of information that they do know.

So the younger the child, the smaller their kind of window of concern. And so you can address it at the level that that child is at. Oh, I'm missing my teddy bear.

We can get you one or we can make sure somebody brings it in for you and that can help. And I don't think that's different with adults. I think with adults, they hide it better when they're anxious.

And so for me, I find that children are more honest. and more forthright, and they'll just tell you what they're thinking. They're not trying to be extra super nice to you unless they want ice cream, you know, and that's okay.

But with adults, it's hard. I think there are, you know, I think most adults learn in this healthcare system that you've got to say a certain number of things.

You've got to say it a certain way if you want to get something done or You know, there's elements that people have developed over time and experience and contact.

with the, with the healthcare system, which really does color sometimes, you know, these conversations that we can have. And so, yeah, does that kind of answer your question?

I just, like, to me, I, being around sick kids, when I was growing up, the hardest part I would think for you is dealing with the parents because they're totally convinced that, and rightfully their kids should not be going through what they're going through.

Oh yeah. And they want their kid to have a better life and they want their kid to not suffer. And it's, it's kind of like being a veterinarian where you're like very close.

She just said the worst part was saying to the people like your dog is not going to make it. You know, the reaction of the parents or the reaction to is probably much harder than dealing with the actual sick kid.

I would think. It's definitely, I think we're stepping into a little bit of almost the set pieces of illness, right? Is when it's a child, there's always a parent or a caregiver and the dynamic between the child and the caregiver is always in the room.

Their relationship to each other, you know, the child and their developmental age and if they're already rebelling or what's happening here, you know, there's all that overlay.

And we teach that in pediatrics. We're like, your patient is not just your, you know, it's not just the child, the entire family is your patient. And I think that lens is, especially with chronic illness, you know, we've talked about how, you know, having children with chronic illness did have impacts on both your parents and how that also kind of impacted your experience of, of going through what you did as a child and later in life, kind of coming around to understanding like, wow, that was a difficult experience and how that was kind of a full circle reconciliation for you.

And so- Yeah, that was one thing about writing the book. because writing multiple stories about, that especially involved my mom, who I always had a very rough relationship with.

The book, there's several about sort of how overly protective she was and sort of a pain in the ass, but then they, writing the stories, they all came from, all that behavior came from being that overly protective mom that didn't want her kid suffering.

And even as I got healthier and older, she was a full-time caregiver, and that's what she had learned. And she could never let go of that, even as things got better for me.

But it sort of took writing the book to sort of see that chart of her life come through. Yeah. Yeah. And that's what we find a lot of times, you know, is sometimes I would say this, like, you know, we'd have, especially practicing the hospital with children, you just kind of get to know some families.

They're just there frequently, right? And so there's a familiarity, a relationship, a kind of understanding that sometimes the parents are just at their wits end.

And this is a very complex, medically complex child that they have that You know, no matter what, they may not have the capability of understanding all the things that are happening because it is so complex, you know?

And just supporting parents through that, I think, letting them know. I remember this one clear story. In the middle of the night, there was a young boy, actually 20 years old, but with CP, severe cerebral palsy, who was having a respiratory illness.

And the dad was outside the room. And he was just feeling so bad because his son was getting worse, needing a lot of support, had repeatedly needed doctors at the bedside that night to kind of help him out.

And the poor dad was crying and said, I'm so sorry to be so that my son is creating such a burden for you. You know, like he had that moment with me. And I was just taken aback because I didn't feel like his son was a burden to us.

I felt that what I needed to transmit in that moment was, he's reminding us what it's like to be human. to respond to

somebody in need just because they're in need.

And that's it. And I love that about the kind of purity of medicine, which is it doesn't at the end of the day matter who's asking for help. It's just they're there, you have the skills, you help.

And I told him, I was like, all these doctors at this bedside are doctors in training. They're going to learn so much from your child that they're going to take to the rest of their medical training.

So in that way, we should be thanking you. I really felt that kind of depth of gratitude because I didn't feel like he'd ever All he was feeling was, we're such trouble.

I'm sorry about this. I don't know why this is happening. And I really just felt this kind of need to let him know, no, he's not a burden, number one.

And number two, he is giving us the gift of not just learning, but also I felt this kind of expansion in our humanity. Because kids with cerebral palsy get a bad rap.

They do. Everybody thinks they're very medically complex, is very scared of them. They can seem like they get sick a lot, and they may seem frail, but they are human.

You talk to them, you connect with them, and they're there, and they're having an experience. You know, I think a lot of it is just, it could have been me, could have been my kid, you know, if the pregnancy hadn't gone, the delivery hadn't gone right.

And I think it scares a lot of people to see what, I mean, I'm always amazed, and have been since I was a little kid, how many illnesses there are, how many things can go wrong, you know?

And the fact that any of us are healthy into our 60s and 70s is kind of a miracle. I have one friend, a long time ago, he went to Panama for vacation, and he came back and all of a sudden, he just started getting this incredibly bad arthritis from something he drank or ate over there, and it just immediately activated, I don't know any of the medical details of it, but he was so stiff, and I'm like, how random is that, that that happened?

Research, hope, and the future of rare disease care

If you can make it through life without getting hit by a bus or in a car accident and then some, you know, one-celled something in Panama takes you down, you know.

It's really humbling. I love that what you said is that it is kind of a miracle to have health and that I think brings us to this moment right now. I think your story highlights too that, and we haven't touched on it, but maybe we end on this a little bit, is that miracle cure that came through.

for you and other patients with gauches was through years and years of research, research which you participated in as a child and others participated in a massive endeavor, right, over…

Yeah, at NIH. So when I was sick, I gave bone marrow. My parents brought me down to DC. And I finally got the treatment when I was 42 years old. Luckily, I made it to 42. And especially with what's going on now, I mean, all, not all, but tremendous amount of funding for medical research at NIH is being cut.

I was just reading an article yesterday about Europe is trying to get all the researchers over there because they know, not just for humanistic reasons, because they know that economically, The idea of developing new drugs and treatments is a big moneymaker.

But the fact that NIH funding is being cut, there's so many treatments, so many things have been… When I go there, so I go every couple years for follow-up work since I was a little kid, they followed me, they followed my brother and I to see why he developed Parkinson's and I didn't.

And, you know, so I've been going there for years. I have met people with craziest, weirdest, rarest things, like things where only two or three people in the world have it and NIH is working on it.

They're trying to help these people. All that stuff is going to disappear now. or it's going to go to China. So the Chinese are going to be the good humanitarians or Norwegians or the French.

And that's something that should be being done here. I want us to be the innovators. Well, I mean, you know, what you're getting at is also here's the thing, like, you know, when we talk about funding cuts and, you know, we put those under this great big umbrella of, well, we're not going to cut the programs that help a lot of people.

And, you know, here these we're talking about rare diseases. where somebody could just say, well, why do we need to spend money on researching these diseases?

They're rare anyway. Let these kids die. Right. Like that's becoming a possibility. I think that's already become a possibility. Somebody somewhere. It is a country.

It is. And that's where my training was, you know, where I didn't train in a place, you know, where there were treatments and we had to let a lot of kids die.

and coming to the states and, you know, to Western medicine where, you know, if you are unfortunately through genetics or whatever, you've just got a bad hand of cards dealt to you.

I just think in the States there was always the NIH where you could go and say, does anybody know? And there's going to be some smart person who gives you the best answer that they've been able to find.

And they're even wiping out the websites with the research, all that research that's been done is disappearing. So that is, I mean, just on a frightening level and just highlights that, you know, when we share our stories like you have done, right?

When you, instead of, you know, hiding or, you know, feeling, because I think in our culture right now, there's this kind of like longevity. Everybody's biohacking and talking about living longer lives.

But we also need to talk about, well, how do you live with illness? when health is impossible. How do you live with a condition in a way that makes meaning of it?

And I think that's what we've demonstrated, I think, and talked about is that not only is that beneficial for everybody, patients and everybody who takes care of them, because guess what?

The rest of us are going to be patients at some point. Nobody gets out of this thing alive. You know, and Ted's only getting shorter and is only getting younger and younger.

The binging and button effect is in play here. For those of us who are not Ted Meyer, you know, we all are born with this passport, the two passports, one to the realm of illness and one to the realm of wellness.

And at some point we all have to use the other passport that we don't want to, you know. This is true. Yeah, this is Susan Sontag. I just butchered that.

But if you look that up, she had a beautiful quote about it. But I think just for exemplifying and making meaning of and bearing witness and showing that bearing witness and having these stories come out really is an act of resistance.

you know, is an act of saying we two matter and that, you know, if we don't tell these stories, if we don't even highlight what it is that we're about to lose in a way that, you know, kind of transmits to people the urgency and the scale of what we're losing, I feel like this moment, you know, I wonder that day when I picked up the phone and just dialed your number and was like, hey, I need an art gallery where we can come in and some medical students can

do some observation and your response was, I've been trying to get through to you guys forever and when, and I came and we talked and it was just like a moment, you know?

And I didn't realize at that time how looking back now, right? So we're talking 10 years hence, like that moment has such an innocence about it because nobody was…

Got the NIH nobody was trying to rip away patient stories and I hadn't had when I so when I was six or seven They kept saying to me there will be a cure Eventually, there will be a cure The question was always, would I live long enough to take, I shouldn't say cure, a treatment that stabilizes me.

But they all said, there will be a treatment. Hang on, there will be a treatment. And it was because of NIH, there was always this thing in the future, even though I planned my life like I might not.

live long enough to get it. I was always told it's going to happen eventually. We understand. We have to do the research. We'll be able to figure it out.

It never occurred to me it would take 35 years, but now kids won't have that. They won't. I keep hearing the standard answer of like, well, AI is going to make research really fast and it's not going to matter.

Maybe that's true, but it was nice to know that NIH was there working on things. Yeah, the hope that that brings, and we need that hope, because you went through, I would say, dozens of hospitalizations, if not more.

Many, many surgeries, lots of painful procedures, and we need to have that hope to be able to make it through those kind of episodes, and now they don't get better.

Well, Ted, another evening completely strewn, thrown to the winds with stories and just a wonderful evening. So thank you so much for being on the show.

Thanks for having me. Yeah. And I'll see you around. So this was Ted Meyer. If you want to look him up, you can find him at artandmed.com, the Scarred for Life series, book publications, Ted Talks, lots of crap.

What do you have? The medical institution and give a talk about why they should have an artist in residence. Absolutely. And I think since we've known each other, that movement has only grown and spread and you've been a really great standard bearer for this movement.

So thank you so much. Thank you for tuning into Dr. Talks. We hope today's episode has enlightened and inspired you on your path to optimal health. Each day is a new opportunity to make choices that empower your well-being.

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