

# Lessons from the Clowns When Going to the Doctor's

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# Lessons from the Clowns When Going to the Doctor's

## Introducing the podcast 00:45

Do you ever feel like you're part of someone else's play? Especially when you go to the doctor's office as a caregiver or caree (also known as patient). You and your caregiver or caree feel like crap, you're exhausted, you're cranky. What are we doing here? The staff is unfamiliar (really, they're strange). What were we going to accomplish? With these strange people? I'm a nurse, a patient expert and a caregiver expert. Yet most of what I know and teach goes right out the window when it's me in the doctor's office. It's 50/50 whether it's a good appointment or a shit show. I need different skills, an attitude adjustment, something when I go to the doctor's office. I used to work at Boston Children's Hospital where I led the Patient Family Experience Initiative. I took a class there from the clowns - they were known as the Big Apple Circus then and the Laughter League now. I wondered if we could learn some of what the clowns can teach us as patients and caregivers about relaxing, reading the room, figuring out what you're there to do, and not ending up more stressed than you went in. Maybe even having a bit of fun. In this podcast we will speak with Jason Stewart, a clown at Boston Children's and listen in on a working session I led at the National Caregiving Conference in Chicago this past November, entitled, *Reading the Room and Yourself. Lessons We can Learn from the Clowns When We Go to the Doctor's Office.* Here's Jason.

## Jason Stewart interview

### Introducing Jason Stewart 02:28

**Health Hats:** Let me introduce to you Jason Stewart who is a clown at Boston Children's Hospital. I met Jay in 2010 when I led the Patient Family Experience Initiative and I took a course that he taught called, *Reading the Room*. I never forgot that day. I had thought, going into the class, that I was a really empathetic, sensitive person and I have to say taking the class really upped my game. I became a better listener. It was my first introduction to mindfulness, even though I don't think the word mindfulness was used in the class. And it expanded my tools to be able to manage stressful situations. So, welcome, Jay. I wonder if you could tell me a little bit about your journey becoming a clown at Boston Children's.

### From Theater to Ringling Brothers Circus 03:29

**Jason Stewart:** Okay. Sure. My story is kind of long. I'll try to give you the condensed version. I was in theater in college and kept getting cast as the comedy relief in all the shows I was in. And the directors, every time I would ask, can I do this? Jay, go with your strengths. Jay, go with your strengths. Well. okay. And then one of the directors that I really respected a lot said, Jay you fall down well. You should look into physical comedy, clowning and physical theatre. And it really struck me, and I thought, well, okay if he says that, then I'm going to check it out. And about that time the Ringling Brothers Barnum & Bailey circus came to town near where I was going to school and there was an audition for the clown college. And I thought what is that? Because I've never really even seen a circus. And clowns, to me, meant the guy that shows up at your kid's birthday party, you know, I didn't know anything more about that., But I got talked into it and went to the audition. It was the best thing that ever happened to me. It was a two-hour

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workshop of all kinds of improvisation and comedy and slapstick techniques. And get up and show us what you got, kid, was the attitude and I loved it. It was elephants in one ring and those people flying on the trapeze the other ring. Right in the middle there we were with the clown alley. And so, I just said, you know, what if they'll take me, I'm doing this because it was too great. So, I auditioned for the clown college and I got accepted. I was one of the lucky ones. It was a ton of people. And they would put it down to just 60 students at the time. It was more like a boot camp than a college. We were there for 10 weeks and it was seven-days-a-week and you know knock yourself out all day long. So great training though. Has always carried me well. And at the end of the term graduation was an audition to get onto the show. And I ended up back out on the road with those guys. Same group that had auditioned me. I joined that group and so in some ways I kind of knew who they were. In some ways they were these unapproachable heroes of mine. And then I began to realize that no, we're like sort of the same tribe here and I spent two years out on the road, and I knocked around 500 shows a year. Was great. About that time, I realized I needed to go back to school because I left grad school to go on the circuit and I was going to lose that degree if I didn't go back to get the thesis written. So, I did that. Left the road and then I was asked to teach at the clown college during the period of time I was traveling all over the place. I was taking every gig that I could get to use my newfound love of clown and then went overseas. I was in Japan with a circus. I came back to Ringling. I was the boss clown on The Greatest Show on Earth and writing gags and casting people and supervising the whole crew and blah blah blah it went on and on.

### From Circus to Boston Children's Hospital 06:41

And so, after my Ringling days were done. I met my wife do the circus. Our kids were born out on the road. We traveled for several years and then when the kids got to be about school age, we decided to get off the road. And by hook or by crook I ended up hearing about this team of performers and variety artists and clowns who were performing in hospitals. And I thought, wow. Okay. Well, it's a gig for a clown, right? So, I'm going to audition for it, and I did. And it was here in Boston Children's Hospital and just by absolute fluke I fell into this wonderful thing. And I said, okay, I'm a clown for 20 years. I've been all over the place, done a ton of things. But this is the hospital and I'm looking wow. What am I going to do in there? You can't throw pies. You can't do a bunch of falling down slapstick, you know blowing things up like we did in the circus. And I was thinking I need to really shut my mouth and learn something about what this is. I can't come in with these guys who have been here for at that time about 15 years, but I can't walk in here and act like I know more than they do because I may know a lot about wowing, but I don't know the venue. I don't know the style. I don't know what's required in that in that environment. So, I was that was another one of the very smart decisions I made was to realize you don't know anything. Come in as a newbie. Come in as the new guy and just learn. And so that's what I had to do. I kind of had this impression. That the kids in the hospital were somehow some kind of different creature. They were some different species. Oh, it's a sick kid. And I was tiptoeing around and worrying that I was going to do something wrong. And then I realized you know, Jay, it's just a kid who happens to be sick. The kid doesn't want you to come

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in and walk on eggshells and pat them on the hand and tell him he'll be okay. He wants you to be a clown for him. There's an expectation that comes with that nose and those big shoes. And the kid wants you. He doesn't want to be there. He doesn't want to be in the hospital. Nobody does, right. And so, I'd learned quickly to not walk on eggshells and to not treat them as if they were some special case beyond what is required for the environment, but just to be a clown for him and to bust the joint up a little bit. Because that's I think what every kid deep down kind of wants. And so, this is now my I'm into my 12th year performing at Boston Children's and also down in Providence at the Hasbro Children's Hospital in Rhode Island. And you know, I work two sometimes three days a week in the hospital. It's an intense experience, but it's wonderful and I do value it very much.

### Embracing failure. It's what clowns do. 09:45

**Health Hats:** So, I came out of that experience with you when I was at Children's a lot less afraid to fail. Actually, embracing failure and I think that was something that you talked about in the course. Can you talk more about that embracing failure in your work?

**Jason Stewart:** Sure. Yes. I always say that I have honed my craft of being a failure. Because it's really what I think for comedy, generally, an audience wants. So, failing is taking a chance to making a big choice. It's going beyond your comfort zone and then not hitting the target. For me the idea of the clown is in many ways a reflection of all of us. It's every man. There's been clowns in every culture and because there's a need the basic human need for that person. That's that entity in their world. The clown is the reflection of us all and the clown can allow us to vicariously fail and to vicariously enjoy or feel good about ourselves. Because here's somebody that we perceive as even a bigger failure than ourselves. It's a way to laugh at ourselves. And by the clown making themselves vulnerable and making themselves the butt of the joke. The clown opens that door to our own insecurities, in our own foibles, and our own fear that we are losers. Any good comedian as a loser. And because the audience, the people that you're encountering, they want that. They want to see it subliminally that they are not alone as a loser. And they can commiserate, and they can at a subconscious level kind of feel a bit superior and empowered by going, "well, at least I'm not this guy." In the hospital, I feel like that's very pointed. It's very true that anybody who's in the hospital can probably use a laugh. And anybody who's in the hospital probably feels a bit like a failure. And when I say that I mean subconsciously the kid of any age, you know, not a little baby but you know kids who's gotten to a certain point probably feels like they've done something wrong down deep because they're in the hospital. They aren't you know, their normal world has altered and it's everyone's paying all this attention to them and trying to do all the stuff and they probably feel like they're not really succeeding in being a kid. The mom and the dad probably feel like failures because they couldn't keep their kid out of the hospital. They probably feel like, "oh my gosh, did I do something wrong? Did I pass a gene on to this kid?" Am I a failure? And so, in this stew of bad emotion and fear and anxiety and feeling like a failure. In comes the clown and I find that there is a level of, I want to say, desperation, but just a very welcoming. Please come in here and do something for my kid.

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So, the way that people perceive what's going on. In the hospital there's tests and there's blood draws and there's all these medical discussions going on is all very high stakes and it's very high, you know anxiety. And everybody gets their shoulders up under their earlobes and they can't breathe, right? And then we come sailing in. We take that on, and we redirect, and we give them a good laugh and hopefully when we're leaving, they take that breath. And they can realize and say hey, they're still good out there. There's still laughs and idiots who are willing to walk face first into a door and do all these ridiculous. For nothing other than just to give you a break so you can breathe again and just kind of go. Okay, what's next? You know, I want to know okay. Now I feel okay good a little more reset, balanced and go and a lot of that comes from the idea of these guys are failures and they empower the kid. The kid is always smarter. The kid is always funnier, stronger, the better example. We need the kids help. We need Mom and Dad's support. We need them. They can feel like they are helping us. Even if it's just to accomplish the silly goals that we have set. And that in us being a failure needing their help subconsciously that lifts them hopefully through a good laugh at the end. You set up something, you build it up and you blow it off with a good laugh. We can leave them in a better place.

What I consider a failure is that if I go into that room and I don't have an effect. If I go in and it's kind of, not a positive reaction or not enough. I can't get through. If I can't bring them up If I can't leave them a little better off. I mean nobody bats a thousand There's going to be room to go in and it's just ice cold and they're not going to engage and their in a hospital. You can't blame them for that, right. In some ways it empowers them to be able to say no to us. Okay, they cannot say no to anything else in that environment because the kids get the kid even the parents if they walk in. We got to do a blood draw. There's no parent wants to hear that. But you got to stick a needle in my kid's arm. It doesn't matter but they can't say no, they cannot you're not in control of their experience right then and they probably feel like a failure because of it when we can come in and let them say no to us they can you know in some ways I feel like even the rejection of, not today, clowns. We're not up for it today. In a way that's an empowerment and it if I see that as my failure, it's their win. And that's why I'm there.

### Embracing failure. Caregivers can do it. 16:29

**Health Hats:** I hear a couple of things here. One of them. Is that in my professional life as a patient-caregiver expert or as a nurse I always thought that if I succeeded at everything, I didn't set my sights high enough. Failing means I tried something, and it didn't work, and I need to adjust. I need to learn from it and I need to try something different. I feel like managing your health is like that. You take a medicine, you get exercise, you change a habit. And sometimes it helps and sometimes it doesn't. It's accepting that it's such a shitshow being sick. And being able to find the humor in the insanity, in the tragedy, in the disappointment, in the pain. Yeah, just helps you know deal with it.

**Jason Stewart:** I agree a hundred percent. I always say that when I talked to the team, I always say, look, we work in the toughest environment there is -the hospital. I mean when I've done shows. I've worked in big circuses. I've done festivals. I've done stage work. I've done a lot of

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different things. But the audience is always kind of at a distance and they're always sort of anonymous and I'm coming out to present my routines and myself. Hospital very different. There's no room for any of that and there's no time for any of that and it's a lot more about who you are and not what you do. And so, what I would say to the guys is, we're working in an environment where there's illness and anxiety and all these negative emotions and things and even death sometimes. You have to say it, that's what happens. And yet there's laughter and that's just a miracle in my mind is like, how can there still be that and my brain boggles at the idea of the courage of these kids and families. In the indomitable human spirit that is there.

### The best human we can be 18:55

That in the middle of all of that they can still be wanting us to come in and break up the room and to laugh and to enjoy and to be what I consider your best human. I feel like laughter is when you're at your best, you know to me it's when you are the most human. Because laughter is like an autonomic response. It's not applause and it's not, "gosh, wow, that was great." It's a real authentic reaction to something that delights you. And so, when we shoot our sights up to hitting that laughter, as opposed to just, "Oh, that was a nice song or wow, cool trick." But when we can actually get to what I consider the autonomic response like breathing or you know swallowing. You don't think about, once you've swallowed something everything else happens by itself. When laughter happens by itself, then you know, you've done something. Yeah, so I always say when do we can be in that environment and face what is a little bit, we faced it with them not like they're facing it. But we know where we're going. We know what floor we're on. We know what diagnosis this is going to be. We know a little bit about what's happening and what we can go shoulder to shoulder and stand-in there with them and say you're not alone. They're still good. We're still laughing. We're still you know, we're human.

### Sometimes shit show at doctor's office 20:27

**Health Hats:** When people go to a doctor's office, sometimes it works well and sometimes it's a shit show. You're really stressed. The doctor is crazy busy. And sometimes when I go. I feel like I'm on stage and I have stage fright. And even though I'm a nurse and I'm an experienced person, all that goes out the window and I think that I wish that I was better at improv. Things are just happening so fast and so I'm wondering how we as lay people can use some of the skills you have as a clown and in improv to help make that doctor visit less stressful and more satisfying. So not so much like the technical: what are my questions, and what's my plan? But helping to change the dynamic of those five minutes that you have with such high expectations.

**Jason Stewart:** I think you're onto something there. And its human nature I think to assume that someone who's an expert in their field is somehow unapproachable and somehow should be treated differently. And so that raises the anxiety level. You're going to go see a doctor. You're going to go see someone who does things that you can't do. And is someone who you have to turn to in this time of need. So, of course, you naturally are going to assume they're some kind of superhuman. And to me that adds a level of stress to the encounter. When you go to the doctor if there's any way to tell yourself and to make it feel real. That this is just a guy, or a

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woman, its just another human being. I do think that we often skew things in our own minds to make, "Oh, I'm not worthy of taking up this doctor's time." And it the improvisation side of that, the clown side of that, would be to, of course, always come back to the equalizing power of laughter.

I don't think that that's everyone's wheel house. Not everyone feels comfortable shooting for comedy. But if they can at least take the mind, this is just another person that's there.

The reverse side of that would be understanding that if you're going to see the doctor when he goes home, he's going to sit on the couch and watch TV just like you do probably. He's not some carved in marble, Greek gods room in the Parthenon or whatever. He is a guy and you need to approach it in that way. I think to just not feel so at Sea but just not to feel so lost because we're all regular people down deep.

### Humanizing the doctor. Check body language 23:31

**Health Hats:** I think that humanizing is good. Sometimes when I work with caregivers and patients, they try to put a smile on their face, even if they're not necessarily feeling that because they find that the other person the professional will mimic them. Right, helps to diffuse some of the tension I think a lot of this about you know, it's so tense.

**Jason Stewart:** We are all human beings. With our subconscious mind we're all reading nonverbal communication. And that's part of what that Workshop was we did back in the day. Was that idea of how can you read that to know how to respond in any given situation? What is the person telling you without saying it? What is their body language say? What are their expressions? What are the emotions that they're giving off? What does all that say? And it's all sort of subconscious and not something that that they're choosing to communicate. But it is probably closer to the truth than whatever words they're choosing to express themselves. And so, it's being to me part of our work as the clowns in the hospital is to read those nonverbal communication opportunities. That's the that's the skill that I think the hospital clown develops because of the focus of our work. We aren't necessarily just trying to cure anything, you know, we're not there to see the charts and understand what this medication has done and what this procedure may have helped with. We don't know any of that. We do know the spirit in the room. We do know the emotional values that are present in this unique setting. Because each room is different. Every room has different people in it and different people responding in different ways. It's an exhausting mental process for the clown and everybody who does this work will tell you. About end of the day you're probably shot. You've been at that heightened level of its of awareness of kind of read every little expression and every little body language type movement and see what you can do that's going to contribute and instead of detracting from. The last thing you want is to make it worse for those folks. Yeah, tell me that is that's the old medical value. First, Do no harm. And that's us.



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### Laughter is the best pain management 26:11

**Health Hats:** So, I want to ask you one more question and then I'll let you go. One of the things that I saw you guys doing that was really impressive to me was that you didn't just go into people's rooms, you sometimes you went with people to procedures and the kids ended up needing either no or less pain medicine to get them through the procedure. So, what's that about?

**Jason Stewart:** We don't go in there thinking that we can cure anything or that we're really going to be able to affect stuff medically. However, there is truth in the fact that the patients and families emotional state will affect how things proceed. And so, there's been a lot of evidence and a lot of attention shown to the idea of the human emotions are important and laughter and the release of the stress release and the comfort level of the patient will dictate some of that. There's a group in Israel that you actually get assigned when it's a pediatric thing. That kid gets assigned a clown that that works with the kid and before anything happens. And actually, goes along through the stages of the procedure that they can be there for and actually is it's a whole different focus than what I think we are about. But there is evidence that that is of benefit. Now we go into areas where it might surprise people because will be asked hey, we're trying to get you know, this kid to hold still a minute to put an IV in. Can you guys help us with the distraction with creating an experience where the kids will be able to focus on something else while we make these things happen. Now, we're not scrubbing in and going into an emergency room, operating room or anything like that.

### Part of the circle of care 28:29

But I do feel like we're part of The Circle of Care in our way and how we can use our strengths. We can contribute and often with stress reduction and with distraction and with raising emotional positivity. that it can contribute to things like needing less sedation or needing less painkillers later on. There's truth in the fact that laughter releases endorphins which lead to healing and to just lower blood pressure and that kind of stuff. And so in that way I'll take you that I'm sort of a medical person. Not really see myself as a doctor other than the fake name that I use when I'm clowning there at the hospital.

**Health Hats:** Hey Jay, thank you so much. I really appreciate you taking the time. This has been really valuable.

## Caregiving conference breakout session

### Intro 29:31

**Health Hats:** Isn't that great. I'd love to have a clown in my circle of care. Maybe my grandkids. Anyway, I spoke to Jay before I went to Chicago for the Caregiving Conference. That was before I was podcasting. I didn't record that conversation. He helped me design the breakout session. Next, we'll hear that session. The audio is fair. We passed a microphone around. It took us a few seconds to get the mic to attendees as they spoke. Nobody was actually mic'd. The volume is uneven. I led three exercises during this 50-minute session. Here's the beginning of the first



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exercise. In this exercise I've asked three people to leave the room while the remaining participants non-verbally emote first a positive emotion and then a negative emotion. We ask the people who left to come back in and guess what emotion is being emoted by the group.

### Reading the doctor's vibe. Now what? 30:31

**Health Hats:** Okay, fine folks. Here's the story. You're walking into a doctor's office. We are the doctor: all of us collectively. I want you guys to figure out what emotion are we emoting? Okay. What's that? Yes, relief. Good. You go to the doctor's office and you come in and you see that there's this doctor who is relieved. What do you do with that? How does that inform how you're going to handle -whatever it is you plan for that visit? When they're feeling relieved? Whenever you enter a room, this particular room is a doctor's office and you're a caregiver and you're going with your caree and you get this emoting of the clinician you have to integrate that into your whatever it is you're going to do in the visit? How do you do that? Yes, ma'am.

**Participant:** I guess because I'm a caregiver. One, I would be like, oh, wow, they seem to be comfortable and there you know, so maybe I can be comfortable, but then my very next thought would probably go to what had them so worried to begin with.

**Health Hats:** We did another round with the doctor emoting a negative emotion, condescension. The audio's pretty bad here. Attendees said that feeling condescension from the doctor put their hackles up, they wanted to give her the finger. They didn't like being talked down to. It puts their guard up. Ok, now let's go back to the session

It's disconnecting. That's what I feel. I got five minutes. I want to connect but you know I'm spending four of it being pissed off doesn't help. So, the point of me doing this is that the there's so much about managing a doctor visit that is not sort of technical. Like my list, my goal, the things that we're trying to accomplish. This is the first one which is the nonverbal of what you have to deal with because they're people and they're coming in with something. Like I know I love my primary care physician because she always comes in with this big smile. She's really glad to see me and she sticks out her hand and says, "Danny I'm glad to see you." I'm just ready for business.

### Mimic. Micro-expressions. Put a spin on. 33:13

**Health Hats:** Another participant talked about micro-expressions and their impact on the vibe of the room. Again, the sound is uneven and there's sounds of the mic being passed

**Geri Lynn Baublatt:** Your micro-expressions imitate them and that's actually feedback to your own body. So, I think, you know that experiment where they make people put a pencil between their teeth? And it actually makes you feel happier. Well, yeah because your mind takes its cues from your body. So, when you mimic other people's self-expressions, you do actually feel what they're feeling. So, I think there is something to forcing yourself, even when you see somebody coming at you like this. My husband's really good at this. I am not. I just get pissed and angry, but he'll go into hi, smile mode and like really lay it on. Because people actually then if they if you smile at them and they're forced to smile back. Basically, it actually changes their emotions

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too. So, it changes your emotions to mimic them but then it changes their emotions to mimic you so you can actually work at changing that if you realize this person's in a pissed-off mood. I'm going to be in a really good mood and like change their day and their emotions. Right? Right, right because when they give people Botox, they actually have a harder time reading your emotions because they can't mimic your facial expressions.

**Health Hats:** A participant asks what you do when people look sour but act pleasant?

**Geri Lynn Baumblatt:** But if you smile at people, they naturally smile back at you and that can change their state. Well, then you probably have a different problem. But even on a subtle level they will. Like it's not conscious.

### Being remarkable, not a factory widget 35:10

**Health Hats:** So, the next thing that I want to talk to you a little bit about is going to the doctor's office is being part of factory work. You are a widget. They have production and they have the productivity goals. The time is short, and I think that one of our goals or one of our tasks when we go to the doctor is to be remarkable. Remarkable. So that you're not just another widget. One way of being remarkable is looking good. Oh my God, does somebody have a camera? Anyway, is to be remarkable now. When a couple of weeks ago, I was at my primary care doctor's office and I said to the office manager, who's very cool and she's been there forever. I told her I was coming to do this. How were people remarkable? I said so are people remarkable because of how they look? They wear a scarf or like me I'm always wearing a hat? Or do they bring cookies or flowers? Or what makes somebody remarkable? And she said well, you know, my staff likes that kind of stuff, but what I like is people who are decent to me. This is hard work for all of us. People are sick. We're trying to help and it's just challenging. and I said, so in your 25 years of being an office manager, who is the most remarkable person you've ever met? And she said, "oh absolutely she still comes here after 10 years and every time she calls, she goes, "this call will be recorded for quality purposes" and she just loves that because she can see that this woman is on the phone because her staff sits up straight. And they're immediately engaged and they're worried and they want to do the best job possible. And I said do you think she's recording the call? She says, I don't care, if she does, she does. If she doesn't, she doesn't. Makes no difference to me. But she likes that the customer service that this patient gets. In my career both as a nurse and as a patient and a caregiver, I've made it my business to have relationships with the office staff. Because I personally think the quality of the care I get is directly related to my relationship with the office staff. If things happen. If the portal isn't working. I'm not getting what I need. I need an appointment. I need a piece of paper. I need a form, whatever. And I know that they know who I am cuz as you can see, I'm a character. They're very responsive. So, my question to you guys is how either as a patient or a caregiver. How is it that you are remarkable?

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### Genuine connection. For real? Relationships 38:33

**Participant:** You know something that I try to do, even if it's just like it the coffee shop or whatever is that connection in that you really appreciate something about the person that you're interacting with and I mean genuinely. You are beautiful, blue eyes. I can see the kindness in that. And I mean it has if you're not genuine is like it shows but it gives you a chance to connect and next time you go into that coffee shop. It's like oh yeah, you want your latte or whatever you start to build relationships.

**Participant:** I agree with what she said if I would have the patience to do that. But I'm thinking of a time specifically where I go to this bank, a local bank, just for whatever, it's not a big deal and I'm probably in a hurry and the person always says, "so what do you what are your plans for the weekend?" I mean, I don't know this person. I'm to tell you the truth. I'm really irked and it's like. Now and I'm kind of a smartass. I say I really don't know. What about you? You know, I mean, I just I don't want to talk about my plans for the weekend with you. And what's that's bad. Maybe that's bad. So, when you said it's got to be genuine. It's got to be genuine and it's and it's true. And I know that this person was trained in their last in-service to ask everybody what they're doing for the weekend or what are your plans for tonight or you know, and they don't care. You know anyway,

**Health Hats:** So, it's genuine this piece what you said and what the office manager said.

**Participant:** Got the job and they're doing what they're supposed to do, but it's not it's just clearly a rote. Yeah, you're right. Great. Anyway,

**Participant:** I work with Walgreens and we do some investigations with these kinds of things, too. And we want to develop relationships with folks and some of the things that people say that I come to your place because I trust this pharmacist. I might switch doctors, but I can ask them, and they'll tell me anything and they're great. But the front of the store. So to speak. That might vary depending on who's managing the crowd and what their incentivizing folks. So, they're trying some things and I'm just giving this an example for how you can be genuine or not. Of tips that come up on the register screen for the someone checking you out and happy birthday generally seems to be okay. It's like oh, yeah. I've been here for 15, 20 years. They know it's my birthday. Thanks for acknowledging that. But it's like well thanks for coming in. It's been a month since we've seen you. Wait a minute. They know I'm in the store then they they're tracking me. There's this creepiness to it. So, how do you strike that balance? Say? Yes, and those with more data with people and how we understand them. We have to be really cognizant of just because we can technically do it doesn't mean we should fit.

### It's not looks. It's humanity 41:28

**Health Hats:** Your example is from the point of view of the medical system to the patient. I'm really interested in what we do in terms of that. I know except for my mother who would never leave the house without her face on, caregivers and patients are not really thinking about how they look and whether they're wearing a nose or a funny hat. It's really not that often It's about

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looks. I mean, sometimes it's about looks, and you know as the office manager said, cookies donuts flowers, some people like that. But let's think about what we do. Because I think it's important. It is hard to be proactive when you're a caregiver. But you're going to need them when the shit hits the fan. You need them and so having a relationship is important and when you're like feeling like crap and it didn't go that well having a relationship there's more forgiveness. Yes,

**Participant:** So I am not a caregiver, but I have been on the receiving end of the care and one thing that I found with my oncologist was that she really connected with my spouse and even though I didn't need to take him to my appointments like he brought a bit of levity to the situation and he has a good sense of humor. And she also really got his sense of humor. So, I started just encouraging him to come because I think she enjoys you. I think we get more attention if you if you come.

**Health Hats:** I think that's a great strategy. I mean, I'm sort of a whatever it takes. That it's unique. Office is a different thing. So, yeah, thank you. That's great. Anybody else? What do you do? What does anybody else do yes?

**Participant:** So, I was a long-distance caregiver and I had to do a lot by phone. And when I would call the office, I'd always be like hi I'm Mary's daughter. My name is Anne. What's your name? Because I wanted to know who I was talking to in terms of following up or something and be like, "oh mom always liked you best." You know, I would just try to do something. Yeah to kind of soften it, you know when I needed them to fax something or get a renewal or something like that. So, I always try to personalize it and you know trying to be genuine. She didn't always liked all of them best. So, I try to find something to say to them, but mostly just, as much as possible avoiding getting into a crisis situation. So, if you could be proactive so that you're not putting them more burden on them. It's being organized and communicating well needed but as much as possible also trying to personalize it.

**Participant:** Yes. My mother had and I shared the same doctor. She'd been going to him for I don't know how many years. But they were all very pleasant in the office and I was always pleasant with them. So, it got to a point when then Mom was bed bound and I couldn't really get her out and things like that. I could call up and say okay Mom has another UTI. Because I could tell by the symptoms and okay, we'll call in a prescription. So, it was that relationship that we had and the fact have how well the doctor knew her and knew me from how much I when I would bring her in and things like that. I had that relationship. When she passed in August and I went in to tell them that she had passed. They took time out in between their patients to come out and speak with me and every person in the office came out and said something to me about how wonderful she was. And you know, what a great job you did she wouldn't been here that long if you hadn't taken such great care. But it meant a lot then from the office staff because I had this relationship with them. Yeah. that you know, the doctors came out, the nurse practitioner came out, the medical assistance the billing department everybody, you know, it was just nice, you know that kind of and it wasn't anything that I didn't have to bring them

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cookies. I didn't have to do anything like that. It was just. Not yelling at them. Yeah, you know understanding where they were what they were doing.

**Health Hats:** Like really, if I feel like there is no building a relationship, I fire them and I'm fortunate because I live in Boston and there's lots of specialists. I see six specialists and when my mom was in San Diego and saw a lot of specialists. Sort of the same thing. This isn't going to work. I could fire him. Find somebody else. But when I know it's really working is when I can call up and go, "I just got to tell you I am so cranky today. It's not you." And then I do my cranky unhappiness and like, "okay, that's okay, honey. What can we do for you?" It would have it would have. It would have been a whole different situation. Yeah, I think so. I mean people can get into... They understand crankiness and the word, cranky, people like. I don't like call and say look I'm going to be an asshole, you know, it's like, you know, I'm feeling cranky. It's a good everybody can relate to cranky.

### What if I can't fire my doctor? 47:19

**Participant:** I wanted to contrast your situation in Boston. I am a remote caregiver for my dad in Iowa. Okay, and there's not as much choice in Iowa as there is Boston. Yes. All right at my dad and up remarrying in his late 70s and so he has a new wife who's a character. And so, as we talk about these roles in these hats we need to put on with these folks. It was a challenge just to start working with her. My-my dad's wife and him when his dementia started kicking in and kind of going up and down. And we talked about know how to broach these topics and get permissions. And there was reaction like, "all you just trying to put us in a home. What you going to do here?" And really defensive. So the dynamics that we're talking about can get kind of complex. When it when it gets into the caregiving area not just with physician or nurse, but family members and stakeholders and other people in the mix here. So yes, we've worked it out, but it took a while and putting on for several rhetorical hats here was pretty critical.

### Where's the humor in failure? 48:32

**Health Hats:** So let me that's a perfect lead-in to the third and last thing we're going to do. So, I got the idea to do this session from the clowns at Boston Children's Hospital. So, I used to lead the Patient Family Experience Initiative at Boston Children's. They have clowns that are full-time people that go room to room and procedure to procedure with the kids. I took a class from them. That was a two-day course called Reading the Room. And so Denise said, "do you want to do anything?" I didn't want to get up there and do some traditional thing. And so, I sort of wrote this up and I was sort of shocked that she accepted this. Then I had to go back to the clowns and say, "do you guys remember me?" "Oh, yeah, we remember you." And I need help. Okay. Well, you know, what do you need? And so, we talked for about an hour about different things we could do like they gave me some ideas. Like the first one we did. But then I said as we were leaving, I said, so if you were doing this session, what would be the one thing you'd want to get across? And they were like the two of them were right away both of them. "You gotta find the humor and the story behind failure. Because we are professional entertainers and we have done this work for 20 years and we fail at it more than we're successful at it. The kid is scared of

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clowns. They're just like tired. The parents wish you weren't there. Or, we read it wrong and it wasn't appropriate. And we just have to leave the room. And go "man, we messed that one up" and then we have a little funny story to tell ourselves and we share it with our colleagues. There's six of them that are clowns. What they would want to get across is that going to the doctor is a shitshow. There's just no doubt. I mean, sometimes it's wonderful, but the whole experience in so many ways obviously caregiving is a shitshow. There's just no doubt. It's heartbreaking. I think there's two things one is being able to find the humor, tell a funny story on yourself and then share it with your cronies. Like that is big. So for example, my son had melanoma, metastasizing melanoma. He got his first. Well his I was going to say his first, but it wasn't it wasn't even a second, but a round of treatment at a place in Rochester, New York. The clinician, the doctor kept talking to me or my wife, whoever happened to be there. We just kept saying "he's I mean he was 20, 24. He's the patient, and it was just so stressful, and we ended up going somewhere else. But you know, we just made a story out of it and in a way that was good. Because it was three months before he died and he was writing a lot of poetry and his handwriting was awful and we decided to go to Circuit City and get a computer for him. And the young brand-new young salesman was trying to sell them a lifetime warranty. My son just kept saying "I don't really want a lifetime warranty." The poor guy. It was on his list of things to do and he probably went to the in-service and finally he had to say. "I have brain cancer and I'm going to die within three months and I just don't need a lifetime warranty." And the poor guy was mortified. Well, we were hysterical. We were absolutely hysterical, and we just shared that with everybody. So yes.

**Participant:** My mom lives in a smaller town like Keith's dad and there's no gerontologist or geriatrician. There're very few primary care doctors. Hers isn't that great, but we're not going to get like a better one and it is really hard though to recover those relationships. And so, I feel like yeah, we have some interesting stories about my mom's doctors, but we don't have any place else to go. And so, I feel like we can tell ourselves stories, but we still have to go back and deal with him and I'm not quite sure in some cases how to start over or change the dynamic because people remember you and you know, there's been harrowing situations. Sometimes he's been great another time. Really horrible and they like I don't even know where to where to go from there. Sometimes well, I'm going to funny story for us or whatever. It's for you for us, but we still have to go back and there's nobody else to go to. So, it is I got still a question in my mind about. How do you like level set and start over or somehow shift that dynamic because it's very hard.

**Health Hats:** I don't have an answer for you.

**Participant:** Like I know there's notes in my mom's medical record that like I'm a huge pain in the ass.

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### Stress you can manage, stress you can't 53:57

**Health Hats:** The best thing I ever learned from my grief counselor was that there's stress you can manage and there's stress you can't. My son was dying and died. The doctor was a jerk. Well that he's dying is stress you can't manage. That he's a jerk is stress that you maybe can manage and the how you deal with it is something you definitely can manage. That was such an ah ha to me. Is this something I could manage myself? or with somebody, with my family, with a friend with a drink. I don't know. But I could manage and so it really helped me in the long run to deal with all these totally can't manage to sort of can't manage things. Because I wasn't spending so much time on the things that I could. So one of the things that I appreciate about this suggestion from the Clown's is that things go wrong. And actually, I think probably the most important part of that is having cronies to share it. And I know that caregiving is a really lonely business. For one thing, here you've got a bunch of cronies and if you don't have cronies to share shitshow stories with, exchanged phone numbers and email addresses so you've got people. But I think that's really important. So, I'm not solving your I think your dilemma is so real and your rural dilemma is so real that there's no choice. Anyway. Yes, ma'am,

### Karma. My bad doctor's mom 55:43

**Participant:** I can't solve it either. My husband has Alzheimer's and 15 years ago, maybe 12 years ago his primary care physician was bad. And we got out of that situation, but it was bad for a long time and now 20 or 15 years later, my husband is in a memory care facility and lo and behold that physician's mother is there. There's Karma. I mean there is karma. When they walked in the physician and his wife and I looked on the hall and you know, what is he going to do here? I am sitting here with my husband, who he was horrible to. Who now has Alzheimer's? I'm kind of saying, "I told you so" but not really. But I handled it so well when we broke it off before it was just a break off and I never talked to him again. But now that his mother is there, it's a whole different situation with he and I were people we're all just people. He's not the shit doctor that he was before. He's somebody's son who's in the same situation as my husband is and what goes around comes around. And it kind of gave me a little fun feeling but then again, His mother is one of my favorite other clients. She and I get along so well, and he comes she comes to my husband's room all the time. I find her sleeping in his bed. It's really it's kind of funny. If you can't laugh you cry.

### Cranky is, cranky does 57:13

**Participant:** I don't know if it would work, but I wondered about your advice about the cranky. You know just heading it right right head on. You said well, I'm really feeling cranky today and then they got that and then you know, if there's something in that file that happened, to confront that I know that I haven't always maybe been the easiest but I hope I hope we can move past that I mean somehow so you'd feel better. I don't know that would take a certain amount of courage but at this point.

**Participant:** I have a difficult and not an older person that I'm caring for, but my son has obsessive-compulsive disorder. And so, I've had to deal with the school a lot about that and it's



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not exactly the kind of thing that school see a lot, so they don't really get it. I don't feel like I am that person. Because I'm not like an angry person or a frustrated person. But it's the situation that is making me frustrated and I'm sure it's the same for you. I see their principals and I interact with them and I try and do things at the school to volunteer and be active so that they know that I'm not just this one-dimensional person, but I acknowledge that they may see me as that Mom, you know, because I never give up and I'm always in their face. We need to do this differently. This is what the evidence-based practice says blah, blah blah. Sending them research articles or like I'm not going to read that. Yeah. Yeah, right. Oh, yeah. Don't like that. I know but they should. But you can't get you can't give up right. So, I guess I just part of how I cope with it is just by acknowledging that I am not that person, but I am in this situation and if they were in this situation, they would understand why I have to be this person, so I'm not feeling guilty. But I'm just acknowledging that. I have to be an advocate for my child because no one else will be. Sometimes it's okay just to know that you know that you're not that person.

### Which Thursday? 59:20

Back to the humor and coping. One of my friends, sadly, his mother was dying of cancer and they the doctor told them while she probably only has till Thursday. So, there's five kids, all the grandchildren came in. They were all there and it's Tuesday and it's Wednesday and Thursday. It's Friday. Now the kids are certain to go crazy and they're taking them bowling and they're trying to do all the stuff and you know, then they'd all come back to the hospital and they're waiting they're waiting. So, it's Saturday and he said we're coming back from bowling again. And we see the doctor walking down the hall and John says to the doctor, "so when you said Thursday, did you mean next Thursday or the Thursday after that. Which Thursday?" So, they just all got such a great laugh and you know, that was kind of what they think about that this time here. They were all kind of stuck there together. But so, humor really help them through.

### Managing the accoutrements 1:00:20

**Health Hats:** So what do you think? I've been trying to focus on the sort of a nonverbal, non-medical, you know managing the accoutrements. I don't know of the challenges of going to the doctor. So, whether you're chronically ill yourself or you're going with you know, somebody you're supporting. What other. What other things do you are you aware of do you try to deal with?

**Participant:** Just as a simple principle, I try to be aware of reciprocity that's built into everybody. And I think someone over here mentioned it like if you smile to them, they'll probably smile back. Even if you don't feel like smiling, it can level the situation a little bit and just watch for cues as they're talking with you. If I'm talking with this gentleman with a hat and I match what he's doing he knows that I'm interested because I'm mimicking his behavior and I don't even think about it often times. But if I do people will see that and automatically go, "they're taking me seriously." Even though there might be thinking that. So just little things that that give this back and forth and just having those in your mind. If you need to diffuse a situation those bodily cues might help.

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**Health Hats:** Using your body and finding the humor and sharing it with somebody. If I have a lesson here. That's them. Keep the hats.

### Having a bad today? 1:01:59

**Participant:** One of the things I think is also important with provider family or provider patient encounters is also as the person who is interacting with the provider kind of reading them to figure out. Oh, they if they're really angry. They might not be angry at you, but maybe they also had a bad day. And so sometimes like when I'm in the doctor's office trying to get an appointment scheduled like around my time, and they're really busy but they look like they're super stressed. I'll say things like, "oh, it seems like you're having a bad day. Like how's it going?" So, I'll I will also acknowledge their feelings and sometimes that helps the situation because they realize like you're not just focused on yourself. And I realized that's really difficult, especially if you are also having a bad day. But it can make the situation a little bit better and then be a little bit friendlier to you as well.

### The 30<sup>th</sup> person before lunch 1:02:42

**Ben Carter:** That was great. I think and it made me think of a situation when I was caring for my mom and my mom was a diabetic. When I talk about diabetes, I talk about the personality of diabetes because everyone's experience with it is so different and I think when you go in to see a clinician. It's not like they're jaded or cynical. They're busy and they've seen cases over and over and over and over again and sometimes we talk but we don't listen. And what I found was when my mom would explain what her experience was there wasn't a lot of listening. And so, I think from the opposite side what we can start doing is acknowledging what's happening for the clinician. So, I might be the 30th person they've seen before lunch. So, if I can listen to how they even say hello to me. How the phone shuffles as they're picking it up and if I hear paperwork in the background or if I'm with them I can tell that they're physically with me. But they're also paying attention to these seven other patients in each room that they stick us in, right? So, they stick you in this room you wait for 20 minutes. They come in two minutes to check in on you. Okay, the nurse will have something for you at the desk and I think sometimes that's what a lot of clients walk away feeling. No one heard me. And then we get into the right or wrong. I'm right about how I feel today. And you're making me feel wrong because you're not either hearing it or you're saying something that doesn't make sense to what my condition is. And I hear that now as a coach in Telehealth for my clients with diabetes and cancer. My oncologist sees so many people. That he doesn't hear what my experience is. And now when I go see him before we even communicate there's tension. So, when you call over on the phone, you're on your there's already tension based on the conversations you've had in the past. And so, I think sometimes if we just stopped and intuitively listen and then respond right without I'm right he's wrong. Because that's what's happening. You're in the position that you're in and you know what, you know, right and it might even be right and he's the doctor. I'm right. And so, where do we meet where we take that off the table and we hear each other?

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**Participant:** So, I think part of the reason why sometimes conflicts happen is it's not about the patient anymore. It's about who's right and who's wrong and sometimes when we sent her it back towards I just want the best care for whoever it is you're caring for and how can we work together to achieve that? And like even though you're still accomplishing the same thing as what you were doing earlier or what you're trying to do earlier, whatever it was. It can be a more pleasant experience. Not that it always works. But sometimes like reframing the logic or the thinking and reasoning behind why it is that you are acting the way you are can help the other person also understand you a little bit better too. Because no one can read your mind. I make that mistake all the time with my husband. I'm like, what do you mean you don't understand this and then we realize we just really have to. It's a lesson in communication I suppose and figuring out how do we reach a new understanding of each other.

**Health Hats:** And I would just to end I would add on to that what the clown said, they're professionals and they fail more than half the time at it. They just and they just say we just got to tell a funny story and move onto ourselves and move on to the next thing because it's too heavy. I personally like that. Well, thank you all very much. This was a different kind of... Keep the hats. Please keep the hats, keep the noses. Keep the beat

Closing 1:07:24

Lessons from the clowns? Humor, humanity, failure. Reading the room. You are not alone. Thanks for your time.