S2E8\_final

[00:00:00] **Kelli:** You

[00:00:10] **Ronni:** Welcome to This is Probably a Really Weird Question, the podcast where a medical doctor

[00:00:16] **Rebecca:** and a doctor of history talk about sex, history, and the not at all weird questions we hear from patients, students, and colleagues. About our bodies and our sexualities. I'm Dr. Ronnie Haye. And I'm Professor Rebecca

[00:00:31] **Ronni:** Davis.

[00:00:32] And today's question is, why would I need a

[00:00:36] **Rebecca:** living will,

[00:00:41] **Kelli:** you know, sometimes they'll put me on in a conference where the other things are like, make your own homemade horn, and then I'm opposite that . You know, it's a hard act to follow Kelly. Yeah, yeah. Or the fisting workshop, you know, is happening next door.

[00:01:01] **Rebecca:** So Ronnie, I did want to play something for you.

[00:01:10] **Kelli:** A little LASIK reference for Ronnie.

[00:01:14] **Ronni:** Exactly. I can almost see clearly

[00:01:19] **Kelli:** now.

[00:01:20] **Rebecca:** So. So I got into that and then I, playing on YouTube, and then I switched over to do something else with my computer and it automatically switched to Jazz Cafe YouTube channel. It's like, so when do you want to have that coffee shop feeling?

[00:01:34] And I have to say, I recommend 10 out of 10. It's a delightful YouTube station. Yeah. So your LASIK surgery led me to a wonderful discovery. on the internets.

[00:01:45] **Ronni:** It is weird, you know, like I was telling you, I got my first pair of glasses in kindergarten and since then I have. never been without glasses. So I, since yesterday I've been doing a lot of this, like trying to push my glasses up on my face and it isn't there.

[00:01:59] But yeah, I'm excited to be able to like see in the shower, for

[00:02:02] **Kelli:** example. Or first thing in the morning.

[00:02:05] **Ronni:** Yeah, exactly.

[00:02:07] **Kelli:** Yeah. Um, I'm

[00:02:08] **Ronni:** so happy to see you, Rebecca. Literally, see you. I can see you. I'm so happy to see you too. And I'm so excited about our guest

[00:02:17] **Rebecca:** today. Me too. So we have with us someone who has done some really extraordinary work, and I'm excited to get to know a little bit better.

[00:02:28] So Kelly Dunham, would you tell our listeners a little bit about who you are and what you do?

[00:02:33] **Kelli:** Sure. My name is Kelly Dunham, and I'm a nurse, a bachelors prepared registered nurse, uh, for the last 25 years, and I'm a comedian and a writer. I'm a non binary person. And I guess I try and combine all those different things and they come out as comedy and performing and workshops and uh, right now I'm working on a coloring book for queers to take to their health care provider, um, not to show to their health care provider that they can color when they're going to the, you know, getting their bits checked out or whatever.

[00:03:03] Uh, yeah. So wherever those intersections like that, those particular Venn diagram, that is kind of where I'm living these days. Excellent. So

[00:03:13] **Rebecca:** the question we have is not one that I've ever heard from my students, but that Ronnie had heard in her practice, which was the whole question of living wills. And it's a serious topic, but I'm really glad that we're talking about it in the context of this podcast because it's important to so many of us and to the people who listen, but also You know, there are things that we're able to do today because of LGBTQ activism in the past that has really expanded what the definitions of family are.

[00:03:42] So can I just ask, I'm curious how you got into being an advocate on this issue. I don't know if you

[00:03:48] **Ronni:** want to talk a little bit about your experiences around like caregiving and things like that. And like we're caring for one another.

[00:03:54] **Kelli:** Yeah, absolutely. Well, this is like one of those pieces where like I kind of get called in to do.

[00:04:00] I mean, I used to call it please don't hit the gay kids with sticks. Um, you know, like really, really 101 often when health systems are, you know, I have this round Midwestern face. I'm a nurse. So, you know, nurses trying to trust of the nurses. And so I got to get called into it. I'm like, come on, really queer people are people, I promise you, you know, like really basic stuff.

[00:04:21] And sometimes when people are struggling, um, because I worked for an organization for many years that formerly called itself Maternal Child Health, right, where there is really a lot of resistance to using more inclusive stuff, you know, so I'm really familiar with, with that genre of organization and even work directly with that particular organization to try and make them more inclusive.

[00:04:41] So it's like the, just really the basics. And so. One of the things that I say to people is, A, you can do this, like, you absolutely can be inclusive. You can be inclusive even if you don't want to be inclusive, you know, even if it like hurts your soul to be inclusive. And the other thing is that good care for LGBT people is good care for everyone.

[00:05:01] This is the thing, right? Forget the name of the book about family law and how family law is led by definitely a straight lawyer. It's like from a decade ago that like our family law doesn't make any sense. Our family law is written as if people are going to stay married their entire lives and that is not going to happen.

[00:05:18] Like, you know, my sister, she had a 12 year marriage and then they got divorced and she was like, Oh, it's a failure. I'm like, how is a 12 year marriage a failure? If you lived in 1904, you would have both been dead of tuberculosis. I don't know if you know you need to make public health advances make you feel bad about your capacity to be in a relationship, right?

[00:05:38] So in that way, all our approach to families and caregiving is completely outdated. We know that caregiving by the spouse, by just the spouse, is extremely dangerous. You know, that it increases the chance of you dying the next year. We are meant to care for each other in groups, you know, and so this is the thing.

[00:05:58] We're not the problem. Queers are not the problem. We'd love to do group caregiving, right? We are actually the solution. You know, this is the thing. We have so much information for you. Just like, you know, come to one of our like caregiving group organization sessions. It's literally life saving information.

[00:06:15] So I'm from, you know, a stoic Germanic rural Midwestern farm family. Um, and so like everyone else was. You know, 85 percent of all Americans when asked, and this is across demographics, like all kinds of demographics, asked to agree or disagree with the question, I try to only rely on myself. 85 percent of people agreed with that across economic lines.

[00:06:41] And uh, I, that doesn't, it doesn't look like that's working so well for us, you know? And so let me back up. So, uh, my partner, Heather, was not that way. I mean, not that she wasn't self reliant, but she was like, she had been very ill with ovarian cancer for a number of years. When I met her, she was in remission, but she got sick pretty soon into our relationship.

[00:07:03] And she had a group of folks she called the love troopers, which she was a little embarrassed about that name, but it kind of stuck. Uh, I think she had debulking surgery and, and, uh, came out of it and, um, was still maybe a little, had a lot of pain medicine on board and came up with the name for her caregiving group.

[00:07:18] So it was love troopers anyway. And she really. let people take care of her, right? And this is the thing, like, I watched my mom taking care of her husband and how exhausted she was. And for me, it was not, even though it was very sad and hard, it was not overwhelming because so many people were involved. So all that to say, we do chosen family, right?

[00:07:42] And, uh, teaching people how to make caregiving groups, which does have something to do with what you asked, which is that. that the best person to be the health care proxy isn't always even the immediate family, isn't always the partner, you know? Yeah. So teaching people to expand really their definition of family, right?

[00:08:03] And families have expanded, we just haven't expanded the definition.

[00:08:06] **Ronni:** Yeah. And also I think some of it has to do with like, thinking beyond the right now, right? Nobody really wants to think about, like, what's going to happen if I get really ill or what's going to happen when we get much older and maybe aren't able to make decisions for ourselves.

[00:08:23] But also, you know, I think it's also very important to be realistic. I see not a small number of, like, queer and trans people who are completely estranged from their family of origin, right? And I try really hard, not the best at this yet, but I try really hard at least once a year to ask everybody, like, do you have a healthcare power of attorney?

[00:08:45] Do you have all of your like emergency contacts updated? You know, and I usually don't start, maybe I should change this practice now that I'm reflecting on it, but I usually don't say things like, If you were unable to make decisions for yourself or if you were reliant on, like, life support, what would you want?

[00:09:02] Sometimes that's a little bit of a step too far. Sometimes it's just like, who do you really trust to make decisions about your health care if you can't tell us what you want? And sometimes I get a little pushback, especially from young people, like, why do I even need to think about that? I'm like, well, do you want your parents who kicked you out of the house when you were 14 and continue to deadname you on a regular basis?

[00:09:22] Like, do you want those people making decisions about your health care if you can't?

[00:09:26] **Kelli:** Yeah. And that's really, you know, that's not something anyone wants to hear, but it's also something that's just super important. And we know, we know that it's important, you know, my experience with, you know, Heather, I was not her proxy.

[00:09:41] Her best friend was, uh, which made a lot of sense. And her best friend did have when she became septic. And was really not able to communicate. Her best friend did have to make decisions for her, you know, and that was really important. And I feel so lucky with my second partner who passed away, uh, Cheryl.

[00:09:59] So as soon as she got sick, even though we had only really been dating, maybe two years when she got sick, we did the healthcare proxy. immediately. It was the first thing we did, um, because her mom had a very, you know, like, Cheryl was like, oh, my mom would put me on a machine just to look at me. She would like bring me home on, you know, life support, even though that was not, you know, I would say with Cheryl, she was not, um, you know, some people are like, I don't care what my life, I just want to see the sunrise and the sunset every day.

[00:10:30] And that's enough for me. I mean, Cheryl wasn't really happy on a good day, you know, so anyway, so I. Ended up making a decision for her. She had Hodgkin's lymphoma, which 85 percent of all people who develop Hodgkin's are cured. Uh, but 2 percent of all people who get gliomycin, the main ingredient in the chemo regimen that hasn't changed for 20 years, uh, develop pulmonary fibrosis from it.

[00:10:55] And so Cheryl did. And so she was in the hospital for three months and got better and then got worse and then got worse to get better and worse again. And so after she went back to the ICU, the pulmonologist said, we really need to think about you're going to die and we need to figure out how that's going to work is how he said it, which was a little blunt.

[00:11:14] And. She was like, Oh, well, let's talk about it later. And, uh, I was like, you know, is there gonna, do we have a later? And he said, no. And she said, okay, just ask Kelly then. So even though she was awake and conscious, she did not want to make that decision. Right. So, um, you know, I signed the DNR and she died actually pretty quickly, like within six or seven hours.

[00:11:36] And. Absolutely, her mother would have made a different decision. Absolutely. Um, I have no question in my head that that was not because when we went back and I said, all right, so this is what we talked about and she was like, oh, thank God, you know, and also because she didn't do any other paperwork. We weren't married.

[00:11:53] Gay marriage wasn't even legal then, uh, in New York state, like her mother got her apartment. Her mother also has her body and her ashes. I didn't have a claim to any of that, but. the most important thing happened, which is that, you know, instead of having to die in a complete code or be ventilated, you know, they put her on a morphine drip and I held her and they took off for an ICU death.

[00:12:20] It was unbelievable. Like actually there was a agency nurse there and they were like still leaving the alarms on. And I was like, what is this telling you? You don't need the alarms, but you know, it's. It's not usually that people are not in the code and they ask you. And so an agency nurse was like, well, I don't work here or whatever, even though he did work there and he took off the alarms and so she just died.

[00:12:36] And like that, you know, that's not a happy ending, but that was the best I could do for her. And that made such a big difference. Like, I feel like I, I would like for her not to be sitting on a shelf in a New Jersey townhouse somewhere. And I suspect that's what Cheryl would have wanted as well. Barring, I don't have the capacity to do that, but I did have the capacity to make a choice that meant that she was not tortured to death, you know?

[00:13:00] Yeah.

[00:13:01] **Ronni:** Yeah. Ugh, what a powerful story, Kelly. And, you know, the other things that that makes me think about is like, in some ways, The person making that decision has a huge responsibility, but I also think it protects you in some way from outside forces that would try to force you to do otherwise, right?

[00:13:18] Like if you've got a legal document that says, like, I'm sorry, mom, you know, your daughter clearly stated who she wanted to make her decisions. This isn't about. her partner trying to wrest control of her life away from you. It's like, this is what your, your child wanted. So in some ways, I feel like it's protective, not just of the person who's dealing with the medical condition, but also those who are caring

[00:13:41] **Kelli:** for them.

[00:13:42] Yeah, absolutely. And Beth is real, bless their hearts. They were so good to us. They brought in palliative care. The palliative care psychologist would come when Cheryl's mom was there and take care of Cheryl's mom because Cheryl would have, her breathing would get so much worse when her mom was there because she made everything about her.

[00:14:01] So they essentially assigned a psychologist to Cheryl's mom, you know, so there wouldn't be such a bad physical outcome every time she came. And also that same person text me through the whole night when Cheryl was dying. It was a Friday night, I think. Text me through that whole night. Okay, you know, she can still hear like, I mean, that was amazing.

[00:14:21] And the part that's more relevant that is actually me answering the question is, or the reference is, they also photocopied The healthcare proxy multiple times and they put it in the back and chart in the front of the chart. And then one of the nurses made another copy and she said, put this in your pocket.

[00:14:40] And I was like, really, I just appreciate it so much. And she said, yeah, I mean, of course this is for you, but it's for us too. Right. So that they would not be put in a position. And I mean, this is something I see a lot, like kind of in widow, in general widow stuff is. It happens to straight people, too, that, uh, the parents want to make a different decision.

[00:15:00] Of course. Yeah, so having that protection is just so, so, so important because even if you think you have a good relationship, my friend, Cheryl, a different Cheryl, obviously, who is also the only other, like, queer AFAB person I know who lost two partners in a row, when her first partner was hit by a truck while she was on her motorcycle.

[00:15:24] And she thought she had a great relationship. This was also way before gay marriage was legal in New York. She thought she had a good relationship with the in laws, but they tried to exclude her from the bedside. Like, you know. the paperwork is important, you know. Yeah, absolutely.

[00:15:44] **Ronni:** And you're referencing, Kelly, kind of like before gay marriage and after gay marriage, and I'm sure there's other really interesting historical stuff.

[00:15:51] Rebecca, is there anything that you've dug up in your research?

[00:15:54] **Kelli:** So it is

[00:15:56] **Rebecca:** a universal question because it turns out that it was a human rights lawyer who, first started in the late 1960s saying, we need to have advanced directives. And it was this guy, Louie or Louis Kuttner, who was a co founder of Amnesty International.

[00:16:14] And he was the first one to make this formal proposal. And then it was taken up by the Euthanasia Society of America, which created the first template for a living will. And then it, you know, very slowly states started to pass laws. Basically, allowing people to do this because the fear was, is the hospital going to be liable for homicide if they don't do all measures to try to revive someone?

[00:16:39] What year was this? Like around what time? So 1976, California passes the first living will statute. Um, it's called the California Natural Death Act. And just the year before that, there'd been a case in New Jersey, a young woman who collapsed at a party. a woman, young woman named Karen Quinlan, and she ended up having some sort of brain damage and being in a persistent vegetative state.

[00:17:04] And the parents wanted her to be taken off the ventilator and the hospital refused. And so she lived 10 more years that way, but it was sort of. It became this sort of case in the media of these poor, grieving parents basically saying, when Kelly, like you were saying, like, stop torturing our daughter, like, please just let us let her go.

[00:17:25] And so states start to pass these laws, and then the other sort of watermark case for thinking about this in a queer context is the Sharon Kowalski case. Sharon Kowalski was partnered with Karen Thompson. They met in Minnesota and then Sharon was in a terrible car accident in 1983 and in fact her niece who was in the car died and her nephew was also in the car, survived it.

[00:17:47] But Sharon Kowalski was very badly injured and she was in a coma with a brainstem injury and the family shut Karen Thompson out of trying to help make decisions about Sharon's care and they moved. Sharon to, uh, care facility that was several hours from where Karen lived, so it was really hard for her to go visit Sharon.

[00:18:08] So there was a whole, like, save Sharon Kowalski, like, national mutual aid fundraising to try to help, you know, fundraise for Karen, because she couldn't really afford to... hire all these lawyers to try to keep getting access to her partner. But a judge ruled in 1985 that the father was family and Karen was not.

[00:18:28] And so she lost the ability to make those decisions. And it went through several levels of court until finally, in 1991, it was in the Minnesota I think it was their court of appeals, but I'm not totally sure. In December 1991, a judge Jack Davies said, quote, Thompson and Sharon are a family of affinity, which ought to be accorded respect.

[00:18:51] So there was finally through, but it took her hundreds of thousands of dollars. You know, I was doing a little research and the articles come up in LGBTQ community newspapers all over the country. You know, where publishing updates about this case and appeals to send in more money to help Karen Thompson keep affording the lawyers to keep fighting the case so she could be with Sharon, so that she could help care for Sharon and so on.

[00:19:17] And this whole question of who family is, I mean, today there was just a recent case in New York over an apartment. Uh, you're talking about, you know, your, your late partner, that her parents got the apartment. There's just a case in New York City where a judge said two men could inherit the apartment of a man who had died.

[00:19:35] Basically saying, look, if this guy has two life partners, sure, like, who am I to say that that's not a real thing? Like, sure, they are both... There, fine. And I just find, like, our whole way of thinking about family, I mean, as a historian, it's really sort of overwhelming how much this monogamous, you know, male female, lifelong model, it's a very Christian model, it's a very European model, has been imposed on all kinds of different situations, often very forcefully imposed, and it has never reflected the reality.

[00:20:11] of the way people care for each other. It's never, there's never been a point where that actually made sense for everybody. And you know, the LGBTQ movement has been instrumental in pushing the legal system to change how we address that because there are all kinds of other families that lose out when we have these very cookie cutter models of what makes a family and therefore in law, who

[00:20:36] **Ronni:** gets which rights.

[00:20:37] Yeah. And you know, the other things that I'm thinking about, and maybe Kelly, you can also speak to this as like, We're talking a lot about advocacy and self autonomy at the end of life, but a lot of that also clearly happens before the end of life. And one of your other areas of expertise is kind of helping queer folks figure out how to advocate for themselves in the healthcare setting.

[00:21:00] So I'm wondering if there's anything, anything that you want to share about that?

[00:21:03] **Kelli:** Yeah, I mean, I always think I'm so intentional about my life, but then, you know, if I look at my five year plan, all the things that I've gotten involved in were not in my five year plan. So, um, back in the day, and I mean, really, like, when I graduated from nursing school, people started asking me to speak about LGBT health, even though I was just, like, a nurse who was also queer, you know?

[00:21:24] And there really wasn't any. I remember, like, going to the research and there was, like, nothing, you know? Now there's, like, a whole peer reviewed journal that's just LGBT health, you know? So I started speaking about that, and then I started realizing You know, just being a nurse in the community, I just get a lot of late night texts from people in ERs, you know, and having spent a fair amount of time.

[00:21:50] in ERs with people and, you know, and then with my own partner and seeing the difference it made having an advocate, people being an advocate for themselves. So two things started happening. I both personally experienced it. I experienced it with other people that I was going with into medical care situations, to healthcare situations.

[00:22:06] And then As I started speaking more about this, I mean, originally, literally, just because of identity, you know, I had to look everything up before I spoke and also just being a comedian and being, kind of, having a round Midwestern face, you know, my PowerPoint's being more interesting, I guess. I would start speaking about LGBT health, people would come up and tell me stories, right?

[00:22:25] So I was getting, like, three ways of, input about how much we need to learn about medical self advocacy. And, you know, I will say this with a caveat, um, which is, you know, bad care is never the person's fault. It is always the fault of usually the system and possibly the provider. But there are things you can do, and this is really hard, like when I do a workshop on how to go to the emergency room.

[00:22:49] Well, talk about a workshop nobody wants to come to. Right. You know, sometimes they'll put me on in a conference where the other things are like, make your own homemade porn, and then I'm opposite that.

[00:23:01] It's a hard act to follow, Kelly. Yeah, yeah, or the fisting workshop, you know, it's happening at the store. I'm like, no, let's talk about what happens if you have to go to the emergency room, but. You know, especially as I get older, I, there's more emergency room trips than fisting, you know, may not be true of everyone, sure of me, uh, sure lots of people are still fisting more than, but anyway, so that's not something people want to come to unless they've had a bad experience, you know, and so we end up doing a lot of troubleshooting, just live troubleshooting about like, oh, what could have that prevented that, which is really difficult to talk about, right?

[00:23:37] Because it's like, yes. There's things you can do to prevent that particular situation, but it's not your fault that it's happened like that, you know, like even talking about how you frame things to providers, how much information you give providers, you know. One of the things that I think of just that's coming to mind about that framing it is so important is if you have injuries from like consensual leather play, you need to say it's consensual.

[00:24:02] You need to say like, okay, so I have this injury. The injured part was unintentional, but it was consensual. Like I'm not in a relationship that has intimate partner violence. You know, framing things are important. It's important to say that. Even just telling people, don't say, if people ask what your pain is between 1 to 10, don't say it's 11 because providers like, it's like they turn off their ears, you know, um, and all that is not the fault of the patient, but like those little tips and takes.

[00:24:28] And then the other thing is, is that by the time most queers are like 30, I don't say most, many, especially trans folks. They've already had so many traumatic experiences, I mean, in the world, maybe, but also in the health care system. So people are very, very triggered when they go into that. So teaching people like the grounding and the soothing and you know, I think it's something as simple as, okay, if you go into the ER, it's a security thing that they make you change into a gown, right?

[00:24:59] You know, and I dated somebody who, uh, who didn't make a patient change into a gown and got knifed in the ER, you know, so, you know, there's an argument for it for sure, but you can always ask for a blanket, right? You don't have to make a big deal saying, Oh, I can't be naked, you know, I can't be not covered.

[00:25:14] I mean, not like you have to be naked, but the gown ask for a blanket because ERs are always cold. You know, and you can cover up with a blanket, like that kind of thing. The fact that you do not have to be in a gown to have a pelvic exam. In fact, there's like literally no reason. You can keep on your shoes while you have a pelvic exam.

[00:25:29] My partner, who's a nurse midwife, just tells... People, you can keep on your cowboy boots. If you have cowboy boots and cowboy boots make you feel strong, you keep on your cowboy boots. Oh, I love that so much. So those really, in some ways, little things, you know, taking, uh, smells, right? Smells are extremely triggering.

[00:25:47] So if you can take a citrus, uh, essential oil with you. Most people don't have a lot of trauma around orange smell, right? At least not as much as you do around hospital disinfectant smell, right? So, you know and you're never gonna catch all your triggers, you know. I was with my mom the year after Cheryl died in Florida and she wanted to go to like this Turtle sanctuary, turtle rescue thing, which I don't even want to look at a turtle really, but anyway, so we went there and there was a turtle who I don't know what the problem was, but they were bagging him like with a ventilator.

[00:26:22] You mean, yeah, like, you know, but mechanically bagging them. Yeah. And I had not heard that sound since then. And that really triggered me. My mom was like, what is going on with you? And I was like, Oh, I, you know, I just hadn't heard that sound. And so like, if you asked me what triggers me, I would not have said a turtle being resuscitated for sure.

[00:26:41] An ambu bag. Yeah. Yeah. Thank you. An ambu bag on a turtle. But you know, so you can't know all your triggers, but you know, kind of covering the five senses in some way, like, you know, even the simple as white noise, people are making a lot of. really desperate sounds in the ER and you hearing all of them doesn't really help you.

[00:27:00] You know, it's not like you can do anything for the other folks. So making sure you take headphones, like there's all sorts of little trips and tips that can be really helpful, you know. Something I've,

[00:27:11] **Rebecca:** I've wondered about my own experiences is, you know, I, I've never had difficulty talking back to authority figures, even when I was a very small child, which almost got me thwacked by my granddaddy when I was four and told him he was putting the playhouse together wrong.

[00:27:25] And my mom like whooshed in to sort of be like, I'm raising her differently than you raised me like moment. And yet when I am in healthcare settings. I kind of freeze. What is that? Like, why, what is it about even just being in a clinician's office or, you know, over the years it's gotten a little bit better?

[00:27:48] For me, is that a bigger phenomenon, or is it just,

[00:27:51] **Kelli:** what is it? It's not just you for sure, it's designed to be that way, right? Providers have a great deal of unearned power. Often, they are clothed, then you are naked. Often, they are using your first name, but you're referring to them by their last name, right?

[00:28:04] There's all sorts of things. Their time is more important than yours, right? So all those things contribute. And then I think that there is a historical thing, like, you know, I really want AARP to give me a grant, the AARP foundation to give me a grant, to just go around to like mid sized towns in Florida and teach people of my mom's age, how to talk back to providers.

[00:28:27] I mean, it's much worse, right? Like we have at least some idea, but my mom, you know, so many situations. I mean, I'm, I think of even like my best friend's dad. It's telling me a story. This is like kind of a rich guy, you know, a rich white cisgendered heterosexual man got an unnecessarily colonoscopy, you know, like he didn't advocate for himself.

[00:28:47] You know, like if a rich white cisgendered heterosexual man is getting an unnecessary colonoscopy, you know, the prep alone, it just tells you that people are not able to stand up for themselves. And really it's a problem of design and it's a problem of culture, right? And there's all sorts of ways, right?

[00:29:03] I teach something called strategy words for dealing with providers, you know, that there's certain things you can say that will trigger a response if somebody is not listening, right? And providers don't have enough time. I mean, that's part of the reason why they aren't listening, even though we know that the lack of listening is part of what contributes to medical error, and certainly nursing errors, but it's lack of time.

[00:29:23] And so sometimes you just need language, the language to slow folks down, you know. That makes a lot of sense and

[00:29:31] **Ronni:** we're, you know, we get taught some of those words as like residents and medical students and, you know, because even though it's an incredibly hierarchical system, people who seem to have a lot of power sometimes feel like they just don't have any power at all.

[00:29:45] And one of those words is uncomfortable or concerned, right? Like, I'm feeling really uncomfortable about how X is happening, right? And that, interestingly, that is a word that will get people's attention. So sometimes we use it, they have, there's something called cuss words. Have you learned about this, Kelly, about like the cuss word approach?

[00:30:04] You know, I'm not going to remember what the S's are, but like the first word is concerned. I'm feeling really concerned about how that fetal heart tracing is looking. And then the next one is uncomfortable, right? So that you start kind of like escalating these words. And you're right that there are certain little, I'm going to call them trigger words, right?

[00:30:23] That like hook clinician's attention that you wouldn't necessarily think. And it's not things that we would think, right? It's not like no or stop, right? Those words oftentimes are not hooks for clinicians. But if you say things that are a little bit more coded, you can really get a

[00:30:40] **Kelli:** response. Yeah, I mean, I would say, like, refuse, right?

[00:30:44] I refuse, right? It revokes consent and, you know, I would say, like, that is, like, the safe word of healthcare. Don't say it! unless you really want everything to stop. But if you need everything to stop, you know, and it's not going to work a hundred percent of the time, right? If people think you are actually not of the mind that you could refuse, but it's like the nuclear option, but it's an important word for people to know, you know?

[00:31:07] **Ronni:** Yeah. I think that actually your partner has a really good idea about the cowboy boots. I think we should now start giving people gowns and cowboy boots to change into.

[00:31:17] **Rebecca:** Be a much more empowered situation. For

[00:31:20] **Ronni:** sure.

[00:31:20] **Kelli:** Yeah. Yeah. You know, I guess it's been like a decade now. I did this show, we did a show at the Stonewall Inn called Fuck Your Health. Uh, well, not a great name, but it was very attention getting. And so it was me, Lee Thompson, um, who's a trans guy and Jessica Halem, who's an AFAB femme identified person.

[00:31:40] All three of us got a pap exam live on the stage at Stonewall. Wow. Wow. Uh, which the manager, we hadn't told them that there was going to be, and I said, anyway, it was a Monday night. It was sold out. We couldn't have gotten any more people in there. But one of the things we noticed, we had a, a nurse midwife doing the exams.

[00:32:04] I mean, she didn't actually send away the sample, but she was doing the exams, right? And one of the things I noticed is it was way easier when I had a microphone in my hand. Interesting. You know, and the idea was to demystify it. And I mean, I always say, like, I wish we could have. Pelvic exam parties, you know, but, and I was like, why was it so much easier when I had a microphone in my hand?

[00:32:24] And then Jessica was like, yeah, because it's the thing you're most, it's your tool. It's like that you're a comedian. Of course. It's just like a whole stuffed animal for you. So, you know, like whatever it takes. I mean, I don't know if anyone's, everyone's gonna want a microphone and, well, and also how

[00:32:37] **Ronni:** empowering, right?

[00:32:38] Like, it's not just your tool, but it's like literally your voice is being amplified so that it's heard. Right.

[00:32:45] **Kelli:** Right. Yeah,

[00:32:46] **Ronni:** exactly. I think I might be in the minority, but I am, I will let people do whatever the hell they need to get through a sensitive exam. So like I've had people listening to stuff on their phones.

[00:32:56] I've had people like gossiping on the phone with a friend the entire time. Like I got no skin in the game, right? Like this is not about me receiving the attention that I need. This is about you getting through what you need to get through. I'm also a big fan of. telling people that they get to decide if it stops, right?

[00:33:12] Like if at any point this is more than you bargain for, you just tell me and we immediately abort mission like no questions asked. I don't care if we're like almost at the end and I've got the swab in my hand. If you're done, we're done and we stop. And I think that also is a huge piece of just people's comfort knowing that they have some control over what's happening to their body.

[00:33:33] **Kelli:** Right. And also sometimes knowing that it can stop if folks need it to, then that also gives people the capacity to maybe endure it a little bit longer, you know, because they're like, okay, well, if I really need it, you know. It's kind of like if you go running and you say like, well, if I really need to stop after a mile, I will, you know?

[00:33:50] Yeah,

[00:33:51] **Ronni:** right. Totally. This

[00:33:52] **Rebecca:** is a fascinating conversation. I've had my own struggles with self advocacy in medical situations, mostly related to OBGYN care. You know, so I'm just sort of sitting here like scrolling back through various experiences that I've had and thinking about what I wish I had been able to say.

[00:34:09] Or what I wish someone had said for me in those moments that I just couldn't, I was too overwhelmed by the situation to say what I, what I wanted to say. What I'm thinking about is how those experiences when I felt medically disempowered really affected me. Like, they were some of the most haunting experiences of my life, were those feelings of being in a situation where I didn't have control over what was happening to my body in a medical setting, and that I had to do the most to work through.

[00:34:37] Like, I'm going to self diagnose. I think I had a sort of PTSD after my first kid was born, and I couldn't be around OBGYNs. I couldn't. Set foot in a department. I couldn't go anywhere near that sort of care. And I ended up finding midwifery practice. And at a certain point, my second kid was born with a nurse midwife in the hospital.

[00:35:01] It was an amazing experience. And then I kept going back to the midwives for my annuals. And I was like,

[00:35:07] **Kelli:** not scared

[00:35:08] **Rebecca:** of gynecologists anymore. And I, and I don't have to like take a train 30 minutes into Philadelphia to go to, you know, see the folks at that practice anymore. I can actually go back and just see the person who's 10 minutes away and she's totally fine.

[00:35:19] And I talk with her and she gets me and she's great. And somehow I had an empowered experience and the whole framing of it was different. It's like, You tell us what you want. We're going to write it on this dry erase board over here. So you just have to point to that board when you want us to do the different things on the list, and we're going to follow what you tell us to do when you tell us to do it.

[00:35:41] What a good idea. And it was amazing because you're in pain, right? Like crazy things are happening to your body. You're in pain. And it's really hard to

[00:35:48] **Kelli:** be like, I changed my mind. I'm not, I actually do want all

[00:35:51] **Rebecca:** that other stuff. I wasn't sure I wanted, please do that for me. And then I was fine. And I don't have this sort of like phobia of being in an OBGYN office.

[00:36:01] But the anxiety I felt after the first experience though, was profound. The depression and anxiety was profound. And I'm thinking about Now, trying to scale up, what about somebody who's had experience after experience after experience of that kind of medical related trauma? And so I'm trying to sort of, you know, take my own experience, which has not been that, but which was very much sort of childbirth related.

[00:36:29] And, you know, the advocacy that you're doing and that we need more of just becomes all the more obvious and apparent.

[00:36:36] **Kelli:** Yeah. Thanks for sharing all that. I'm so sorry. It's called iatrogenic PTSD, right? There's a name for it. And it's not studied very much because the same people who would be studying it are causing it, you know?

[00:36:48] Yeah.

[00:36:49] **Ronni:** And iatrogenic, just for our listeners who don't know that word, iatrogenic means it's like caused by the healthcare provider. So, you can have like an iatrogenic. injury either from a procedure or from a medication. So like, that's what happened to Cheryl, right? She had an iatrogenic injury from the bleomycin.

[00:37:07] And so, yeah, it is, it's caused by

[00:37:09] **Kelli:** the system. So, you know, and I've even looked into like, okay, well, what would be some interventions for that, you know, I actually had EMDR, which I don't know how great the research is behind EMDR, but, uh, worked for me. It worked for me too, man. I had a situation where I had emergency surgery for an infected knee and they reversed my anesthesia, which I'm like in 2014, really?

[00:37:34] Why did you do that? But you know, fat people, they just think we're going to hold onto the anesthesia for the rest of our lives. Um, anyway, they reversed me and it was emergency surgery, so they couldn't get a PCA. They couldn't get like a pump. And so I was. You know, immediately after surgery, didn't have any pain control for like 30 minutes.

[00:37:51] Yeah, I was so triggered. My friends actually, I would say had an intervention was like, you have to have an EMDR because we cannot be around you in healthcare systems because you are so triggered, which I appreciate, you know, uh, instead of just stopping being my friends or not coming to appointments with me, they're just like, you need something else, you know, but we're really are not addressing it.

[00:38:11] Yeah, I sometimes I

[00:38:12] **Ronni:** see like colleagues or. Students or other health care providers kind of not believing or put off by somebody's really large, like obvious external reaction to something right? Like somebody is clearly being triggered by something that's happening in the health care setting. And the response of the healthcares around them is like, Oh, they're being so dramatic.

[00:38:37] So one of the examples that I use for healthcare provider, again, sometimes it's like being bilingual a little bit, right? You have to know, yeah, you have to know how to speak to healthcare providers and also speak to non healthcare providers. But I describe it kind of as like a hypersensitivity reaction.

[00:38:52] So when you're learning about allergies and the immune system. There's something called a hypersensitivity reaction, right? And so if you get exposed to something that's an allergen for the first time, you might have like a little rash. And then the next time you get exposed, your body's already primed so that all of those like inflammatory and allergy cells are ready to react even more.

[00:39:15] So the second time it happens, you get hives and then you get better. And then the third time it happens, your face swells, right? Because every single time you're exposed to this, Allergen in air quotes. You have a bigger reaction. So I feel like it's like that, you know, when if you're a queer or trans or like a person of color who gets mistreated in a healthcare setting, of course, you're going to have this humongous reaction that to the person on the outside is like, well, that's Totally an exaggeration.

[00:39:46] That is an overreaction to what's happening. But if you have been dealing with exposure to just trauma and bigotry and violence, of course, you're going to have this reaction. And so sometimes we just have to take a step back and be like, First of all, it's not personal and maybe it is personal. Maybe we fucked up, right?

[00:40:04] But also understanding the context of this reaction, you know, I just had a patient who just went through this, went to the ER and got like misgendered by everybody and then didn't get the pain control that they needed and had already had multiple traumatizing experiences in that ER. And I could tell from the documentation, right, again, code switching, I could tell from the documentation.

[00:40:28] That the physicians that saw them were like, this person is being hysterical, basically, and, you know, I don't think it's hysteria. I think it's probably a trauma response, but we, we don't really think about

[00:40:39] **Kelli:** that, you know, right? Well, and it's super inconvenient, you know, those folks had 12 other people to see.

[00:40:45] And if you have a You know, a traumatized person in front of you who, who is having a hard time cooperating and a hard time answering questions and, you know, they need more time and what you don't have is time. So, I mean, you know, the problem is the system, but, you know, it's just going to keep happening that we're re traumatizing folks.

[00:41:03] When uh, I was doing a. a presentation for the AFT, the New York State, I guess it's like the health care division of the AFT. So a nurses union and a nurses union conference. And I did a presentation like engaging your care averse LGBT clients and who showed up. It was right after Medicaid started paying for affirming trans care, especially surgeries.

[00:41:28] And so immediately all the hospitals in New York immediately had a program. It was just really amazing when insurance started coming in just immediately, you know, fascinating. Yeah. All of a sudden they're so interested in the equity, but they hadn't really done a lot of training with folks. And so what happened is 75 nurses who wanted to understand, but it had a really bad experience taking care of a trans person after surgery.

[00:41:53] Came and they all had the same question, which is like, are you all so sensitive?

[00:42:01] Like one person would raise their hand and then like, ask me a question and then like, I would answer it. And the next person I was like, Y'all know this is the exact same question, right? You know, and sometimes it's hard, you know, I understand. I mean, you know, obviously my compassion is for the trans person here, but it also is, you know, there's terminology to catch up on.

[00:42:21] And also I feel like these nurses especially were set up where they really didn't have training, you know, where it was just like the hospital was like, Oh no, okay, you got to float to this floor. Oh, okay. And so folks were just like, I don't understand why people, why would you, you know, or even things like, People still wanting to be stealth right like or not sharing, you know, like a trans guy, not sharing in the ER having abdominal pain, but not sharing that he had ovaries.

[00:42:47] Right? Well, there's a reason why people don't want to get bad medical care, you know, and that this is the thing, like I had to say, like, nobody wants bad medical care, you know, the system wants to make money. But, you know, most providers, that's not often what they're thinking about in that moment, you know?

[00:43:05] So. Everyone has the same goal, but it's just, you know, if somebody doesn't tell you something, there's a reason. like cis

[00:43:13] **Ronni:** fragility. We need to write a book instead of white fragility. Cis fragility. I don't understand why you're so upset. Why are you yelling at me?

[00:43:20] **Kelli:** Just trying to help you. I'm just trying to help you.

[00:43:25] Yeah, that could be the subtitle.

[00:43:27] **Ronni:** Exactly. Kelly, do you have anything coming up in terms of, like, shows or books or events that you want to plug?

[00:43:35] **Kelli:** Yeah, so I have a show that I'm super excited about. It is called Second Helping, colon. The subtitle is either Two Dead Lovers Dead Funny or a practical queer tragicomedy, uh, depending on who I'm talking to about it, I guess.

[00:43:51] It's available both as a presentation and as a show. If it has a presentation, it actually, uh, has learning objectives and it's, you know, eligible for CEU credit and all. And it is the story of losing two partners in a row. And basically it's a story of learning to accept help and, you know, and not learning to accept help.

[00:44:08] And I just, uh, did a month of shows in Edinburgh at the Fringe Festival. Yeah, it was amazing. Yeah, it was amazing. And, um, so, you know, it's a show, but also it comes with a workshop and that kind of thing. So I'm both trying to kind of make that a real theater. It is a real theater piece, but trying to get, you know, this is, this is not a queer problem.

[00:44:28] This is an everybody problem. And so trying to do some like mainstream theaters and, um, yeah, trying to make that happen. I'm going to film it as a special probably next summer. I haven't decided where yet. I really want to do it in a library. I don't know that that's really related, a library, but I just really like libraries.

[00:44:48] So that's the biggest thing that I'm touring right now. I'm also, you know, I've talked about what I do in terms of trainings and that kind of thing, but I also really enjoying doing, I do a presentation called laughter at the end of life, which is about how people use humor to communicate. Yeah. And as part of end of life care, I just did that for the Minnesota Hospice and Palliative Nurses Association.

[00:45:11] Just did a virtual one on that. And that was really, really fun because hospice nurses already know it. You know, doing a presentation about it's just them shaking their head and saying, Oh yeah, that's really true. Yeah, that's true. But also talking about ways that that can be expanded and ways you can build.

[00:45:26] Intentionally building humor into your life and into your days and into your practice, both with patients. I feel like there has been some really bad publicity for comedy, which is often comedians are kind of their own worst publicist as far as the way we act sometimes. But you know, there's really important conversations to have about our gallows humor as providers.

[00:45:47] And, and there's actually really good research about when it's constructive and when it's not. Yeah, so it's potentially really helpful, you know, both learning how to ask for help and using humor. Those are kind of the things that I want to talk to folks about in a humorous way. Yeah. And second helping is, is.

[00:46:07] Like, as it was fascinating, all the conversations, right? So you do a month of shows in a row at four o'clock at a gay bar in the basement of a gay bar, um, while everyone else is doing shows is like, hi, I'm a drag queen on roller skates, you know, juggling chainsaws, you know, and I'm like, Hey, come see this very funny show about death

[00:46:25] But a couple things happened. A teenagers started showing up for it, which was so touching because it's also a story about community, right? And is there a community out there for you? Right. And families started coming, like a teenager came and then brought their parent the next day. And on the very last day of the show, there was a mom and a, an adult mom and an adult kid there.

[00:46:51] And the mom was talking as they left and the adult child said, Oh my god, mom, we've been trying to talk about this forever. You never talk about what you want around, like, end of life and death stuff. You never tell us. This is the first time you've ever talked about it, you know? Uh, and I was like, all right, well, even if I just went home and second helping never went anywhere else, this was, that was enough, you know.

[00:47:13] Yeah. You

[00:47:14] **Ronni:** changed a life for sure.

[00:47:16] **Rebecca:** Thank you so much for talking with us. I'm really glad to have met you. Thank you so

[00:47:20] **Ronni:** much,

[00:47:20] **Kelli:** Kelly. Oh yeah. Thank you. This was great.

[00:47:26] **Ronni:** You've been listening to, This is Probably a Really Weird Question, which is created, hosted, and produced by Rebecca Davis and Ronnie Hyon.

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[00:48:28] Thank you for listening,

[00:48:29] **Ronni:** and keep on asking those questions.