K: So, lately I’ve been thinking about how this is not the Christmas episode. I don’t care if you’re listening to this on December 25th. I am an atheist. I do not believe in Jesus Christ. And, if you are a Christian, like super-duper Christian, then you know that – if you believe in Jesus Christ – that he was not born on December 25th. That all of the Christian theologians say that he was born in the summer, and that this is a stolen pagan holiday because it used to be the solstice, and it’s a couple of other religious things. So, this is not the Christmas episode.

C: Nor is it the Mithrandir episode.

K: What’s the Mithrandir?

C: Mithrandir was the – one of the primary ones that the December 25th thing was taken from. The sun god was Mithrandir.

K: If anything, this is celebrating the former emperor’s birthday. I was always down with that. I loved emperor Akihito.

C: Yeah, and his birthday was the 23rd. So, it was nice because it gave us, like, a holiday two days before… the 25th. And then – I was working at one Japanese company, and another guy there asked me, he said “do you think I could get the 25th off or has everyone already requested it?” He asked me in August.

K: Mm.

C: “Has everyone already requested December 25th off?”

K: Mm.

C: I was like, “no. None of us care. We’re all working that day.”

K: Yeah.

C: “You are the only person in the company who cares about that day.” “So, I can get it off?”

K: (laughs)

C: “Yes, you can get it off.” Nobody cares.

K: So, to everyone’s shock and horror, I’m taking this week off. It’s rare that I take two weeks off. I usually take one week off.

C: Right.

K: And I usually take the week off – whichever week – has the first in it. And sometimes I take no time off. And so… I have people disappointed about me not working the week of the 1st, and I have people disappointed about me not working the week of Christmas, so I’m just all-around disappointing all of my clients. I have – like – so, I divided my clients into three groups. The group that’s bitter that I’m practicing good self-care

C: Okay.

K: And I let them know that that challenges me because we spend all of our time talking about good self-care, and wouldn’t they want a therapist that was focused on good self-care, or do they want a burnt-out therapist?

C: It’s like if your – if your pulmonologist is a smoker. Like… you know it’s bad for you. Quit.

K: No, I think it’s worse than that.

C: Yeah?

K: Yeah. A burnt-out therapist can do harm.

C: Ah, yeah that’s true.

K: A pulmonologist that’s smoking is killing himself unless he’s smoking while you’re in the office.

C: Right.

K: But like… because here’s the thing – and yes, I’m going to tell a secret – letting the cat out of the box for all therapists. We do not tell you what we really think. And all of my clients here – Musick Notes – you can ask me do I give you my real opinion. And then I’ll say, “ask me a different question.”

C: Mhm.

K: Because I am honest with you, but do I give it to you unfiltered? Like, the unfiltered blunt truth. Most couldn’t handle it.

C: So, you’re saying you give them the useful version of an opinion.

K: I give what?

C: The useful version of an opinion.

K: Yes.

C: Rather than the self-expressive version.

K: Yes. I give the opinion they’re ready to hear.

C: Right.

K: Most people don’t come to therapy ready to do the work. I have, currently, of all my clients… there’s two that – no, three – that like it hot. They like it just don’t mess around – and y’all know who you are

C: (laughs)

K: Because if I start to give any kind of warm fuzzies – if there’s like even a hint of patchouli oil – they roll their eyes at me. And they’re like, “come on. Tick tock. Come on, let’s go.”

C: Mhm.

K: And I absolutely love it. Because I’m like

C: Enough with the sandwich method, where you say something nice, then you say the truth, then you say something nice. They’re like, “I don’t need that bread. Just say the truth.”

K: No. It’s where, you know, a gentle truth. They’re like, “don’t be gentle.”

C: (laughs)

K: “Be blunt. Be direct. Be efficient.” I had one client tell me, “I value efficiency. And you’re using too many words. Spit it out.”

C: Mhm.

K: I’m like, “really? Do you really – I’ll do it once, and then you might never talk to me again.” I did it, and they applauded me. And they were like, “thank you. I knew you could do it.”

C: (laughs)

K: “Oh. Okay.”

C: You were being serious.

K: Well, alright now. And they’re one of my favorite clients. I absolutely love them.

C: Well, it’s something you value in friends too because when we met, you asked me, “can you handle the truth, or do you need to pussyfoot around?”

K: Yeah.

C: And I said, “I don’t know. You have to show me both.”

K: Yeah, I didn’t say pussyfoot around.

C: I know that you didn’t say pussyfoot around because I thought, “she wouldn’t use that – she would not use that phrase.”

K: No. I said, “do you keep it real? Are you on the 100?”

C: Okay, thank you.

K: And you were like, “I don’t know.” I’m like, “is it because you don’t know what I just said?”

C: (laughs) I did learn a lot of new vernacular.

K: Yeah, because you didn’t know what the – if I was keeping it real, why was it on the 100?

C: Yeah, what does that even mean? Like, 100 out of what?

K: 100 out of 100 times, I will tell you the truth.

C: So, like 100%

K: Yes. All truth all the time.

C: Okay.

K: Real talk.

C: As opposed to fake talk or as opposed to like… something different?

K: As opposed to the coddling that you usually get from me.

C: Oh, okay. Yeah.

K: Because you need to be coddled.

C: I do. I like that.

K: (laughs) So, real talk, this is our second time recording this episode because anyone who’s a Musick Note who’s following us on Twitter – you know that I’m deathly ill today and in a lot of pain. And I was speaking too sharply for Chad. (laughs) So, we stopped the episode, and we just lost 8 minutes. And we’re having to re-record even though I’m deathly ill and in tons of pain.

C: Because, as the rest of the Musick Notes might be able to take your 100

K: (laughs)

C: Is that the right way to say it?

K: No. I’m saying that – like – three people in my life – and that is not including you or our son – I have three people, and they actually pay me for it. They pay me to keep it real with them. Only three people want the realness.

C: So, they’re like getting the Everclear of therapy.

K: Yes, they are. And it is… awesome.

C: (laughs)

K: It is awesome. Because, like, they come in and I’m like, “I don’t think you’re ready for this.” And they’re like, “then why am I here?”

C: (laughs)

K: I love that. I love that. Because I spend my whole day figuring out how to deliver objective truths in a way that they remain objective but do not cause harm.

C: See, that’s interesting because I’m thinking about how it relates to my work. And I don’t do therapy or anything of the sort. Just that… there are people who are highly technical who are like, “just tell me your blunt opinion of what we ought to do for this technical thing.” And there are other people who are like, “well tell me how it’s going to fit in with the whole ecosystem of personalities and people’s egos and what we’ve got going on and how much it’s going to change the things.”

K: To be clear, they both get the same thing.

C: They both get the same thing, but it takes a lot longer to explain to the people who don’t want it straight. So, I could see where somebody saying to you that they just want it straight would save you a lot of time.

K: No, they still do 60-minute sessions just like everyone else.

C: But do they get more information in those 60 minutes?

K: Oh, yeah. They get like 3 or 4 times as much information.

C: That’s what I’m saying. Like, they’re getting more information for their personal growth than the people who are not getting it straight.

K: Yeah, so I tell people honestly that if they want to be on the no homework system – one of them is like “I don’t have time for homework. It’s a chore for me to get – carve out this 60 minutes to come and see you.”

C: Mhm.

K: “It’s difficult for me in every way, so I need to get everything I need to get. Any epiphanies, or any growth, needs to happen within this 60 minutes. Go.” And I’m like, “cracking. I can do that.”

C: See, and it’s amazing to me that you can do that because I can’t do that. I don’t do therapy. I think I said that before. But when I’m teaching people math or whatever, if they want it all in that – confined to that time

K: I am so dizzy, I think I’m going to pass out, so please continue listening, and it’ll be interesting to find out if I throw up or pass out.

C: Yes.

K: Yeah. But you were saying?

C: I was saying that I can’t

K: When you talk about math, it makes my stomach really nauseous.

C: Oh.

K: (laughs) That’s just – I’m sorry, I can’t filter it.

C: No, no. I have – I have tutoring – I had tutoring students who were the same way. Who were like, “when you talk about math, it makes me nauseated.”

K: Babe. I am so sick, and we have to record this episode.

C: And I’m sorry you’re so sick.

K: I am so dizzy. So, I think we should talk about lupus.

C: Okay.

K: I think that’s something… I can manage. So… I have something called hereditary coproporphyria, which is a blood disorder that causes – actually, Chad, you’re better at explaining – explaining HCP.

C: So, porphyria is a blood disorder that causes certain enzymes to not be correctly synthesized, and what type of porphyria you have determines the pathway that doesn’t operate correctly to synthesize necessary blood enzymes. A side-effect of this is the buildup of porphyrins in the system. Kisstopher has hereditary coproporphyria, which is hereditary as the name applies, and causes an excess of coproporphyrins.

K: And I also have lupus. And… of my 14 siblings, I am the only one that inherited lupus from our father.

C: Yes.

K: So, yay. Yay me. Lucky me.

C: One of the first things he told me when I met him was, “I have lupus.” But then he denied it in many other circumstances, which made it tough for you to get diagnosed because he would never commit to that when you were trying to get diagnosis.

K: No – I’ve known – we came into the relationship with me saying I have lupus.

C: Yes. But getting you a formal diagnosis was a tough thing.

K: No, I’ve never wanted it. You wanted that for me. I didn’t.

C: Oh, okay.

K: Because I don’t want to be on any of the medications that they want me to be on.

C: This is true.

K: And I’ve already had that fight, and then you were like, “no. You’re going to get treatment for your lupus.” And I was like, “you think you can make me.” You and others have tried – like my mother couldn’t force me to get treatment for my lupus, and anybody who knows me knows that if my mother couldn’t make me do it, no one can.

C: Yeah.

K: Because the only person I have ever feared in my entire life was my mother. I’ve only ever been afraid of her. I’ve never – I just don’t have the capacity to be afraid of anyone else.

C: Yeah.

K: So, I think that’s kind of a cool thing.

C: that is kind of a cool thing. So, yeah, you’ve – you haven’t been treated in the way that your doctors wanted to for your lupus.

K: Ever.

C: And the same thing for your porphyria because, when you got diagnosed with porphyria, the – the preferred treatment was heme – and I forget the specific brand name – but was blood transfusions. And you

K: Yeah, and I don’t do blood transfusions

C: Yeah.

K: Because I was alive and well during the AIDs pandemic.

C: Right.

K: And the HIV pandemic. And I lost… almost everyone I loved to the pandemic except for one. Only one of my friends survived it.

C: Yeah.

K: Every other friend I had at that time died from HIV.

C: Yes.

K: Except for two. When I think about it, two.

C: Yeah.

K: So… and I had a big circle of friends. And all but two of them died, and it was really, really a sad time. And so… I don’t do blood-borne products because I – if I get – so, there’s another type of porphyria that’s caused by hepatitis, and if I get a blood transfusion with hepatitis in it, then I’ll have two different strains of porphyria, and it will probably kill me.

C: Yeah, that’s a… porphyria variegate-cutanea or something like that. It’s a – it’s purely a skin one. So, HCP is unique in that it’s both hepatic and cutaneous. So, it affects the liver and the skin.

K: Yeah.

C: And… AIP is the most common form, which is only the hepatic part. And it’s very heavily studied in Sweden because Swedish people, for whatever reason – I’m not saying inbreeding – but for whatever reason

K: (laughs)

C: Are more likely to have it than other people.

K: So, if you follow us on Twitter, you know that the world’s leading specialists in hereditary coproporphyria in two countries – I am the only person that they have ever met with it because it is so rare. And I just don’t want to sign up to be anybody’s guinea pig.

C: Right.

K: And the thing that they do is that, in exchange for studying you, they’ll give you all the morphine you can take.

C: Right.

K: Like, all the morphine you can handle, so – they’ll like put a morphine pump inside your body, so that you are constantly getting morphine pumped into your system. And I was like, “no thank you.”

C: Mhm.

K: Cool ride. I think if I didn’t have a child, I would have totally went that route. Like, much to your chagrin – I’m sorry I can’t say if I wasn’t married to you. I would’ve been like, “what? I’ll learn how to function through it.”

C: You and I have had great conversations when you’ve been on morphine or dilaudid or Demerol – or the different things they have given you to try and stave off the pain from porphyria.

K: Yeah. And, so, basically the past three days I have spent curled up in a ball chanting to my body, “please stop.” And that’s because I’m having the cross between a lupus and a hereditary porphyria attack. And that’s from overwork. I’ve been working 15- and 16-hour days for about 3 weeks, and… my body just… something happens in my brain where I just can’t sleep. And I get a brain – what I think of as a brain fever. And that’s usually the porphyria because it causes an actual chemical change to my brain, and I cannot sleep. And, so, I stay hyper-vigilant and hyperactive. And everything starts to break down – like all my cognitive functions start to break down.

And then… with the physical aspect of it, lupus – you need to sleep. It’s really important – a really important part of self-care. And so, my – I’m having… aphasic speech where it’s really hard for me to form words. And… I have muscle spasms that start at the tip of my head and involve all of my skin and all of my muscles. So, doing… recording this episode is an act of love for my husband because he really, really, really loves this podcast an insane amount, and I love him an insane amount. And I really appreciate everyone who tunes in and listens to us every week. And I really dig you guys. So… this is hard to do, but I also think… part of the reason why I’m doing it is because I think that some of y’all have porphyria out there, or some of y’all have lupus out there, and to have someone be like, “hey… I have lupus. And this is hard. And I’m doing it anyways – and I’m doing it because I think you’re awesome” – I don’t know, means the world to me when someone does that for me.

C: No, I appreciate podcasts and writings and all of that kind of thing from other disabled and chronically ill people. One of the things that seems toughest to me as an onlooker is that you have the paradoxical reaction to sedatives. So, if we give you something that ordinarily makes people sleepy like Benadryl or something, it will make you wide awake and completely unable to sleep plus anxious.

K: If I took Benadryl right now, it would make me psychotic. So, here’s a list of weird, random things that would make me psychotic right now. I think this will kind of be funny. Cinnamon.

C: Yes. Yes.

K: (laughs) If I had – if I would eat – like the cinnamon challenge. But, no, I’m not even talking like a teaspoon of cinnamon. I’m talking about something with cinnamon in it. So, I can eat Hot Tamales. They don’t have cinnamon that’s too high, but if I do kabocha – which is Japanese pumpkin – with cinnamon sprinkled over it, or even like French toast with cinnamon on it

C: Yeah.

K: I will have a psychotic break, and I will completely become detached from reality. So, cinnamon will do that. Garlic will do that. Benadryl would do that. What else would do that?

C: Well, there’s a whole list of several hundred porphyrinogenic drugs that will do that. So, most antibiotics

K: Oh, eggs. Eggs would

C: Eggs, yes.

K: Freak me out right now. Oh my gosh. If I were to eat an egg right now, I would be in so much pain. So much pain. So, like eggs don’t make my brain weird. They make my body hurt.

C: Right.

K: Lettuce. Oh my gosh.

C: Oh, yes.

K: If I ate any – if I eat any leafy greens right now, it would just be like eating razors.

C: Well, and it’s specifically the lettuce spines.

K: Yes. (laughs)

C: And like with egg, it’s something specific because you can eat mayonnaise without that reaction

K: Yeah.

C: But you can’t eat eggs without that reaction.

K: And so – I think it’s the sulfur level.

C: Probably because you have – you have severe reactions to the sulfates in the other antibiotics that are based in sulfur.

K: Yeah. Pineapple.

C: Pineapple.

K: Bell peppers.

C: Yes.

K: So, yeah, those things will all make me crazy.

C: So, and all of the things that you just listed are the recipe for… a really good salsa that goes on top of scrambled eggs.

K: Yes. That I love.

C: Which is how we discovered that like, nope, it’s every single ingredient in this.

K: Yeah. (laughs)

C: It’s not one of them. (laughs)

K: Because I make this really great, sweet and spicy salsa that is… pineapples with the pineapple juice – so, it’s pineapple, apple juice, red, yellow, and green bell peppers with red, hot chili peppers and their seeds all chopped up and thrown into a box. Then you let it sit overnight – it’s just a splash of apple juice. It’s really good.

C: Yeah.

K: And everyone who eats it is like – the best thing anyone ever said is, “I am seeing this, but I am not believing.”

C: (laughs)

K: “I am seeing this, but I am not believing. This is so good.” And, so, I would eat it on chips I would eat it on salad. I was like green eggs and ham’ing it. I was eating it everywhere, and I was like, “god… why is my stomach just so bad?”

C: Yeah. You’d be like, “I have made a bleu cheese quiche.”

K: Yes.

C: “Let’s put some salsa on top of it.”

K: Yes. And so… that’s another thing I can’t eat right now is bleu cheese.

C: Yeah.

K: So, like, certain cheeses I can eat right now, and certain cheeses I can’t.

C: I think that goes with the antibiotics. The mold – the ones that are like strong in mold like the bleu cheese – you just can’t eat them.

K: Yeah. So, another weird thing about me is that I have MRSA – which is a form of staph – and it lives in my dermis. So… before anyone who’s my client freaks out, it’s noncontagious. Chad has never had staph. They do not understand why it lives in my dermis, which is why I said in my dermis and not on my skin. So, if you cut into three or four layers of my skin, you can get deep enough that the infection will be activated, and then I will be covered in MRSA sores. So, right now, I have to be slathered in antibiotic ointment, which is triggering my HCP and making it worse and triggering my lupus and making it work.

So, I’m on antispasmodics. I take them every 45 minutes. Like religion and clockwork, or I suffer greatly. And… yeah. It’s pretty awful being this sick. It’s pretty humbling. And… the feeling of helplessness is… surreal. Like, the helpless loneliness. Because nothing is more isolating, I think, than pain.

C: Yeah. I think – I think pain is one of those things you can’t ever know what it’s in somebody else’s head. Like, even if they tell you what pain they’re in, you don’t feel it, and you don’t see it except how they react to it. And I saw doctors just treat you like, “oh, you’re just being silly.” We went to the emergency room once because you had an infection. You said, “I have MRSA.” And the doctor said, “you don’t have MRSA. You’re not qualified to diagnose it.” And then they took a sample and came back ten minutes later and said, “hey would you like to participate in my study of drugs to treat MRSA?”

K: Yeah. And they also wanted to book an emergency room.

C: Right.

K: And I said, “no thank you.” I left the emergency room. I went literally around the corner to my regular doctor. He cut it out. And… and pulled it out. And so… the person, ironically, who said it wasn’t MRSA was also a partner

C: In the same practice.

K: In the same practice. And so, I left and left them humiliated, and then they got to see me walk into their practice. And then I told on them.

C: Yes.

K: (laughs)

C: “At 3 am, I went to the emergency because I was having psychosis and pain, and told them”

K: I wasn’t having psychosis and pain.

C: Okay.

K: I had seven different MRSA lesions.

C: You did, yes. Okay.

K: And I wanted them to remove them.

C: Yes.

K: And so… I went to the emergency room, and they did not remove them because we live in Japan, and we were there on vacation because I wouldn’t take part in the trial, she was refusing me medical care.

C: Right.

K: So, then I refused to have any of – I refused to have her paid by my insurance. I refused all payments.

C: Yeah.

K: I had her document that she was refusing me care

C: Because you wouldn’t participate in her trial, which is completely unethical.

K: Yes. And then I went to her – the head of her practice who had also done surgery on me years before. I had him diagnose me with MRSA. I had him take out all of the infections and pack it with antibiotics and treat me, and then I told him that I notified my insurance, and my insurance company would not be paying her. They would not be paying the hospital, and I would be writing a formal complaint.

C: Mhm.

K: And he was like, “thank you for letting me know.” And so, she got sanctioned. And, so, that’s what happens when you mess with me because I’ve been in the system

C: (laughs)

K: The medical system

C: Your whole life.

K: My whole life. And I’ve been sick my entire life. And I don’t take any crap from doctors.

C: Yeah.

K: I just don’t take their crap. And this is complete privilege because I’ve been a foster kid, but I’ve always had health insurance. And that’s the one thing my mother did for me up until the time she died. Is she made sure I always had health insurance. She said, “that’s the only thing I can ever do for you.”

C: Mhm.

K: “Is make sure you have health insurance.” And then when I aged out of her health insurance – freakishly, she died the same year I aged out.

C: Yeah.

K: And so, I had to cover my own health insurance. But I’ve always had health insurance. I’ve never been without it.

C: Yeah, you had – you had continuous coverage, which is something that was important to you when we got together. You were like, “I have had continuous coverage of health insurance”

K: Yeah. And I have to. And I have to have it with blue cross blue shield.

C: Yeah.

K: Or else everything I have is a preexisting condition, and I can’t get treated.

C: Yeah, because this was before the ACA and such. And now, in Japan, they don’t have the idea of preexisting condition because they’re like, “it’s just your health.” Like, it’s just your medical history. Everybody’s got something. Because it’s universal. That’s the joy of universal.

K: So, I think everybody’s going to forgive us that this is 25 minutes because I really can’t do more.

C: I think they will.

K: And… so, can you kind of talk to the people about why you wanted to record an episode? Because I don’t want people to jump on you or paint you as a bad guy or anything like that.

C: So, I wanted to record an episode because we record episodes every week, and I know that might sound silly, but for me it’s really upsetting to break routine. And it’s one of those things where people will talk to me, and they’ll say, “there’s no way you’re autistic.” And then they’ll run up against something like that where it’s just… profoundly upsetting to me to change things. And then they’ll say, “there’s something wrong with you.” Yes, I told you when met you I’m autistic. That’s one of the first things I tell almost everybody I meet because… it affects things.

K: Yeah.

C: And I – it’s really, really painful for me to… have my expectations not met in ways that I felt like I could control. I tend to go into the self-blaming state of… if I had just done things differently, then things could have been met. So, I wanted to record today because I didn’t know at the time that I set this idea of recording how sick you were going to be today. So, it wasn’t that I woke up and I saw, “oh, Kisstopher’s super sick, we should record.” It’s that… I had set in my mind from… a week ago that, okay, we’re going to record this day because this is

K: I was sick a week ago.

C: Yeah.

K: I feel like you need to be completely honest in this moment and talk about how painful it is because I think what they’re not seeing is how painful this is for you. That… you’re stuck in this place of “can my wife push it through and make this sacrifice for me, so that the rest of my week isn’t torpedoed, and I don’t know how long it’ll take me to get back to some semblance of good or normal or functioning because we didn’t record today.” That you’re on the verge of an autistic meltdown if we don't record today, and how painful that is for you.

C: Yeah, it’s – it’s really painful, and I… I feel really vulnerable talking about it, but I’m… doing so in support of Kisstopher, who has recorded despite her pain. But it’s really upsetting for me, and it’s one of the things that has made employment really hard. Right now, I have a really good job that understands and values what I bring. But, in the past… I just don’t like having my schedule changed. If you tell me that, tomorrow, I’m going to be shoveling horse manure all day, and I come in and you’re like, “instead, we’re going to be listening to music” it is really upsetting to me.

It’s not that I wanted to be doing… you know shoveling horse shit or whatever. It’s that that was the plan. And, so, for me, changing the plan is just… I feel unmoored. I feel like I don’t know what the world is anymore. I don’t know where things are going. Like, how does this affect all of my plans? Like… you know… my whole world gets shaken by what seems like small scheduling changes that happen at the last minute.

K: So, the decision to record today was 1) to prevent Chad from having an autistic meltdown. 2) is because I do value the connection with the Musick Notes. I think you guys are awesome, and the fact that you tune in every week to listen to our ramblings – I just feel so humbled and honored, and 3) if you’re suffering with chronic illness, you’re not alone. Like, hit us up. You know?

C: Yeah. Definitely.

K: Send us a message, and… I always have room to tweet out, you know, sending spoons and good vibes. And, sometimes, when I receive that kind of tweet, it is everything to me, and I literally break down in tears because someone tweeted at me, “hey. I care.”

C: Yes.

K: And… you know, you don’t have to go through this completely alone. So, as much as strangers on the internet or strangers on a podcast can make you feel more human and make you feel more connected, that’s why I’m doing this. I’m doing this because I wish someone would do it for me, and there are people who do it for me, and I want to pay it back. I also don’t want my husband to become unmoored. And, so, we are going to do the take two. We do have stuff to talk about in the take two. And it won’t be about us being ill. But… (laughs) it’s going to be a quick one.

So, thank you for spending 30 minutes with us and hanging out with us. And I should be okay by next week, but no promises. Can’t promise anything right now. I’m hoping I’m better by next week kind of thing. So, thanks for tuning in, and I hope you head on over to the take two.

C: Thank you.

C & K: Bye.