Japan and the United States have very different ideas about pain management, health care, and how people ought to feel. Both of us having medical issues means we’ve had a lot of experience with both systems, and we compare the two from our perspectives.

**Transcript**

K: So, lately I’ve been thinking a lot about pain management.

C: Yeah?

K: Yeah because I have a new pain guy. And, so, I have an endocrinologist and a general practitioner that I see. And my GP does my pain management for me. They’re not, like, officially a pain management guy.

C: Because pain specialty is really rare here in Japan.

K: Yeah. So, the last time we talked about pain management in Japan versus the U.S. it was really upsetting for some of our listeners, and so I wanted to dive a little bit deeper in that. It’s not a subject I’m really comfortable talking about, though.

C: So, first I want to ask you: why do you have a new pain doctor?

K: Well, because my old doctor has cancer and had cancer for six months before telling me. And he said, “I’m just going to go in the hospital for a month for some treatment, so here’s a prescription to get you through”, and then he retired. And continued to see me for six months after he retired. And, while he researched another doctor for me because he was also my hereditary coproporphyria doctor. I thought that was kind of sweet but also kind of strange. Like, okay, why didn’t you tell me you have cancer? He’s like “if they won’t see you, I’ll still continue to see you.”

C: Which is nice, but…

K: Yeah, so I had a really great relationship with my previous doctor, so

C: I think that was the fourth or fifth GP you’ve had since we moved to Japan, and all of them have retired, and that’s why you’ve switched.

K: Yes. This one’s younger than – usually, I like my doctors in their eighties. (laughs)

C: Yeah, I think the first time that we went to saw – he came to Japan to do medicine after World War 2, so

K: Yes. Right after World War 2.

C: Right, so I think he’d be over a hundred now.

K: Yeah. I hope he’s still around. I absolutely loved him. He was awesome. And then my second doctor, I didn’t like him as much because he would spank me. Like literally spank me on the bottom if my weight went up.

C: Yeah, which is just no. Don’t do that.

K: Yeah, I don’t like that. But, so, I don’t know why I tolerated that. And then I got sick of that, but he retired, and so I switched to another doctor, and then he retired. So, now, I’m with a doctor who I think is in his 40s, so

C: Oh, that’s good.

K: Yeah, so I think I can get like – I think he’s the one.

C: I think we might have mentioned this before. So, we’ll talk about pain management, but one of the reasons that doctors in Japan tend to be older is because you don’t become rich as a doctor by default.

K: Correct.

C: Because it’s not prohibitively expensive to become a doctor, and medicine itself is not prohibitively expensive to receive because there’s no insurance middleman.

K: Right.

C: So, that’s a whole effect of socialized medicine.

K: And we tweet a lot about the fact it costs like five bucks for me to go see my doctor.

C: Yeah. So, a lot of doctors in the U.S. are horrified of a system like the Japanese one because you don’t get rich being a doctor in Japan. But it’s increasingly the case now that you don’t get rich being a doctor in the U.S. either if you work for Kaiser Permanente or something like that. So, total digression out of the bat, but pain management.

K: (laughs) Yeah. So, I want to explain something about my pain management in the United States that I didn’t explain before. And that is the last time I saw a medical professional in the United States was ten years ago. And the last time – and we’ve lived in Japan for 14 years, so when I’m talking about my surgeries and my pain management and all of that, I’m talking about 14 years ago. I’m not talking about the current state of United States medicine. I’m not current, and this isn’t current events, but it is my lived experience.

C: Right.

K: And I’m sorry if my lived experience hurts you or pisses you off, but it is my lived experience I’m not going to lie about it.

C: Mhm.

K: And, for me, 14 years ago, it was incredibly easy for me to get pain medication. It was incredibly easy for me to have pain medication overly prescribed at a dosage and rate that was killing me. It was easy for me. But, here’s the thing: I had amazing healthcare coverage because, when I first got my healthcare coverage, I was healthy with no pre-existing conditions. I was the optimal weight. And no – they had no idea how bad and off-the-rails my health was going to go. And, at that point, I think I had a six million dollar cap.

C: Yeah.

K: And we were like “no sweat, there’s no way in my lifetime I’m going to need six million dollars’ worth of medical treatment”, and then I had a bunch of surgeries and ate through that very quickly. So, after that, I also had a pain specialist doctor who was helping me cope with the amount of pain medication that they had me on in-hospital to transition to find my working dosage of pain medication. So, for me, I come from a very privileged place when I was in the United States. And I want to acknowledge that.

C: And I think, too, that biologically for whatever reason, your body is very tolerant of pain medication. And I know that this is a theory – I don’t know how well it’s been documented – that people become more tolerant over time if they get more. But your first surgery, when you were not on any pain medication, you woke up an hour into it.

K: Yes.

C: And they told me after – they were like “there was no way, absolutely, that she should have woken up at all. We had to put her back under.”

K: Yeah. It is horrific. It is horrific waking up in the middle – horrific and painful waking up in the middle of a surgery. So… I have a unique biology and unique physiology that requires massive amounts of pain medication to be effective. And I also had a doctor that I had been working with – like, I had teams that I worked with, and, again, privileged. I was financially privileged in that I could build a team but also as a woman of color, I think that we don’t talk enough about how often I borrow your white male privilege – your cis het white male privilege. Cis-gendered, heterosexual, white male privilege.

C: Yeah.

K: And I borrow it quite often.

C: Well, when you were about thirty, I would go with you, and they would be like – they wouldn’t say it directly, but the tone would indicate – “is this little girl telling the truth?”

K: Sometimes they would ask you directly.

C: Oh, they would often ask me directly if

K: “Do you believe her”

C: Do I believe her? Is she telling the truth? But sometimes they would treat me like I was the adult in the room. I’m 23, she’s 30.

K: (laughs) Yes. I was sucking your youth from the beginning.

C: Yeah.

K: Young, hot, and tender. That’s what you were when we met. Young, hot, and tender.

C: She doesn’t have a picture of herself in an attic. She has a picture of me.

K: (laughs) Explain that reference. Nobody’s getting it.

C: There are lots of people who will get it. It’s a reference to A Portrait of Dorian Gray.

K: Yes. (laughs) So… yeah, and that picture is, is having the opposite effect because you look old. You look way older than me. Everybody assumes that you’re older than me.

C: Yes, they do.

K: Because you have a gray beard.

C: Yes.

K: And it’s quite striking. And, now, I’m finally like I have one gray solid streak, and I’m styling my hair to make my (laughs)

C: To emphasize

K: Yeah, to emphasize it. I’ve changed my entire look to emphasize it because I want to be obasan to the world.

C:” Do you think people would notice I put aluminum foil in my hair to make it sparkly?”

K: (laughs) I love my like – I have a proper gray streak now. I’m so into it. I want all my hair to go gray. I think that’s going to be freaking stunning.

C: It’s already stunning.

K: Thank you. So, I would borrow your privilege quite often, and I just – as a habit – always take a male with me to the doctors.

C: Mhm.

K: And I did that with our son, Rasta, because they often believe our son over me. Here in Japan. And… I prefer doctors to communicate in Japan, and so he communicates with my doctors in Japanese. And it validates everything I’m saying because he can say yes, he witnessed this thing happening to me.

C: Right.

K: Although I don’t know how anybody witnesses my physical pain. Because I don’t like – it’s rare that I roll around moaning and crying. There are some days when it’s bad enough that I do, but most days I don’t.

C: Well, I mean, to be frank, which we try to be on this, there are days where your pain is so bad that you slur your words.

K: Yes. There are days that my pain is so bad that I don’t speak at all.

C: Right. That you can’t read because you can’t see well enough to read. That you… have trouble walking straight. And this is with no pain medicine on board. This is just pain.

K: Yeah.

C: But you’ve been… so conditioned that pain medicine is bad that you’re like “should I take pain medicine? Because maybe all of this is because of the pain medicine.

K: Well, and you were really hard on me about the amount of pain medication I was taking because the amount of pain medication to get me through my day doesn’t allow me to function mentality. Like, I have to choose mental functioning or pain management. I can’t have both.

C: Well, plus, in the U.S. every doctor’s visit, they would try to find an opportunity to speak me privately – “do you know she’s a drug addict? Do you know that she’s going to die of her pain medicine? But I’m going to prescribe it anyway.” Which was just… infuriating.

K: Yeah. I could see why that would be infuriating. I don’t care what the doctors say about me in the way that you do. Because that’s been my whole life.

C: Because you don’ have any trust in them is my thinking.

K: Because I don’t have any what?

C: Any trust in them.

K: No, I don’t. At all. I’ve never trusted my doctors. I’ve never thought my doctors knew better than I did because my whole lived experience. I’ve had great health insurance my entire life because the one thing – even though I was in and out of foster care – my mother always kept me on her health insurance.

C: Mmm.

K: And my mother – I don’t’ know if she had a little bit of Munchausen by proxy going on, but my mother would often come to visit me in foster homes to take me to the doctor for no reason. And just out of the blue show up, and I wouldn’t know she was coming. During the week, or she would show up at my school – it would be like “you need to go to the doctor’s.” And I think that that’s… I think that was her hereditary coproporphyria affecting her.

C: Probably.

K: Because I know when my porphyria is affecting me, I’m hyper-vigilant of Rasta’s health. I’m like “he’s sick.” It just triggers something in my brain. “He’s sick. I’ve got to take care of him.”

C: Yeah.

K: And, so, I feel like maybe – maybe not Munchausen. Maybe it was – the porphyria’s a weird thing. The mental effects of porphyria is such a trip, but that’s a different podcast. (clears throat) Excuse me. Sorry, I’m going to be clearing my throat. Yes, I have a chest thing. Sorry. Don’t get mad. And I have to drink lots of water. (laughs)

C: I’m so mad about that.

K: Oh my gosh. You almost got sprayed with water.

C: (laughs)

K: Seriously. Entertain the people while I drink water.

C: Kisstopher is sucking so hard right now.

(laughter)

K: I drink my water out of a straw. Why do you want me to laugh while I’m drinking? You would not enjoy

C: I would not enjoy

K: Me spitting.

C: But you’re so good at not doing so.

K: Yeah. I really am. I don’t know why you enjoy it, though, like you’re temping fate. One day, you’re going to get sprayed. You’re going to get a shower.

C: It wouldn’t be the first time.

K: No, it wouldn’t. But it’s going to happen to you again.

C: Yes. But I like – I like seeing you laugh.

K: So, I think that part of the… the healthcare issue now, there wasn’t the war on opiates that there is now.

C: Right.

K: But I’ve never taken – I think it’s called oxycodon?

C: OxyContin.

K: Oxycontin. I’ve never taken oxycontin, so I’ve never taken oxy. It was a brand-new drug right before we left the United States.

C: Yeah, so the oxy part confused me because you were taking oxycodone.

K: Yeah, oxycodone.

C: Which is Vicodin, or it’s under different brand names depending on its formulation.

K: Yeah.

C: Before we left the U.S. and that’s not legal at all here in Japan.

K: No.

C: So, here in Japan, the strongest outpatient medicine you can get for pain is tramadol.

K: And I was only ever prescribed fentanyl once.

C: Right.

K: So, fentanyl wasn’t highly used. And I was prescribed Demarol on the regular.

C: Right. Injections.

K: Yeah, Demarol injections. So, Demarol injections with promethazine injections. And that’s not done anymore. Like, Demarol’s not used anymore. They’re using morphine now. And fentanyl patches were regularly prescribed until about ten years ago, I want to say. I think they had a five-year window where they were regularly prescribed, but, for me, I didn’t feel any effect from fentanyl. So, fentanyl was completely ineffective on me. Like, you could put two or three patches on me, and I’d still be in pain and lucid. So, I don’t

C: Right.

K: When the news started coming out that people were getting high on fentanyl, I was like “how many patches are they wearing? What are they doing to get high on fentanyl?”

C: Mhm.

K: I feel absolutely nothing. From it.

C: Yeah. And you’ve always been very resistant

K: And I also had pill-form morphine that I was like “this shit is not working.” So, for me, the most effective pain medication that I’ve ever had was Demarol.

C: Yeah. I think the last time that you were in

K: They also did dilaudid, but dilaudid was – also wasn’t as effective for me as Demarol.

C: Yeah.

K: And, like, morphine – it takes big doses of morphine.

C: Yeah. I think when you were in the hospital the last time in the U.S. they had you on a drip, and I forget which medication it was because now I think they state everything in terms of morphine – like they just convert – but you were on the equivalent of 40 milligrams of morphine per hour.

K: Yes.

C: and you were still awake and lucid.

K: yes.

C: and they were like “what’s going on with this? We can’t give you more if we give you more, it will kill you.”

KL: Yeah.

C: But “how are you possibly still in pain?” And it took me a while to understand it, but… you don’t cry while you’re sleeping over pain that you’re making up.

K: Right. And, so, I think for you – how often, because you often fall asleep before I do, but how often I cry in my sleep, you’re like “okay.” It took you a lot of years to understand how bad my pain is.

C: Yeah, it did. And I think part of that is because I don’t know if me having pain makes me more or less understanding.

K: It makes you less understanding.

C: And I think that’s the trick that happens with a lot of people. I have chronic pain too from ankylosing spondylitis mostly. But I can get… effective pain management at much lower doses, and so it took me a while to

K: And for years you would just take my pain medication.

C: Yeah because it wasn’t worth going to the doctor.

K: So, please don’t hate on me. Yes, I gave my husband some of my pain medication in the United States. Yes, I gave my husband some of my pain medication in Japan. The biggest thing that I used to give you that I’m not on is I used to get Valium and give it to you to help you manage your seizures.

C: Yeah.

K: For years. And years.

C: Now I just have my own prescription.

K: And now I bum valium off of you when it’s too much.

C: (\*laughs)

K: The list of medications that I’m on – I take fourteen pills a day, and that’s a lot of medication. And… it’s really frustrating. So, when I tweet about being thankful that I have proper pain management, I actually do not have enough pain management prescribed to me to get me through a pain-free day. So, I’m not saying that I’m having pain-free days. I’m thankful that I have any pain medication at all in Japan because there’s only one opioid that’s prescribed in Japan. And that’s tramadol. And I’m really grateful and thankful that tramadol works for me. So, I get – I’m prescribed 75 tramadol per day but can take

C: No. 75 milligrams.

K: Yeah, 75 milligrams, not 75 tablets. That’s a lot. 75 milligrams a day, but I can take up to 100 if there are days that I don’t take tramadol.

C: Right.

K: So, I have to manage my tramadol very closely and very carefully. I have to manage my pain very closely and very carefully. And most days it results in me being in excruciating pain the entire day. To the point where my stomach always hurts. My abdomen, my diaphragm, the whole front of me is always in agony. And so, I wear really loose jeans and really baggy clothes. And the reason I do that is because it hurts to have clothing. It hurts to get dressed in the morning.

C: right.

K: And it hurts to get through my day wearing clothes. And I know that I don’t talk enough about it, but I don’t feel like my schedule in Japan does anything to change how the senate is voting on pain medication in the United States. So, when Americans get really pissed off at me, I’m like “my… my thing, and this podcast, is not changing legislation.”

C: Yeah. It is not. Sadly.

K: Yeah. I wish everybody would just – I don’t ‘know. I feel like, for me, being addicted – it’s really hard to tell. Are you addicted or are you getting an effective dose? It’s a fine line.

C: Yeah. And I think it’s a line that is socially determined.

K: And it should be medically determined. Tolerance over time. That’s addiction. That’s medical addiction.

C: You may have noticed a slight glitch there. We had technical problems that resulted in a lot of noise, so I had to clip out that part. But we are back.

K: (laughs) I’ll be so amazed if you actually clip it out.

C: Yeah. I’ve done it before. It’s not often.

K: So, part of the reason why I don’t like talking about my pain medication is I don’t like actually talking about my health.

C: Mhm.

K: But I don’t mind tweeting about it.

C: Why do you think that is? What’s the difference for you?

K: On twitter, I’m much more open than I am in person.

C: Mhm.

K: Like, I don’t talk – I feel like people think it’s boring. And, on twitter, I know our audience. I know our tweeps, and I just feel like – I don’t know, it feels safe.

C: On twitter?

K: Yeah. On twitter, I feel really safe, and I feel like everybody knows that I’m disabled, and everybody accepts that I’m disabled, and we have a really, just beautiful group of friends, and I think of them as family, friends and family. And I’m coming to trust the Musick Notes to hang tough with us through difficult conversations, but I’m a little bit worried because there has been backlash sometimes for some of the episodes. And we don’t really have backlash from any of our tweets. So, I don’t want this to upset – because I never want to upset or hurt anyone.

C: Right.

K: And I felt like the upset of us talking about how easy it was for me to get pain medication in the United States – that upset, I felt like it was real, and I felt like it was valid for people’s lived experience now who are fighting, and it’s a completely different climate.

C: Yeah it is.

K: There was no war on opioids when I was in the United States. So, that happened completely after I left.

C: Well, and anybody who’s been following it from the side of being a patient, I think, is aware that the mass numbers of deaths and all of that. Those are heroine and illicit fentanyl.

K: Yes.

C: People are not dying of these other drugs in the numbers that are being said.

K: And oxy. People are smoking and snorting oxy.

C: But, these days, that’s not even available anymore. So, it’s just… diverted fentanyl and heroine. And, so, if you look at how many people are dying of prescribed drugs, whether they were the person given the prescription or not, it’s very low. It’s not zero, but people die of taking aspirin. People die of penicillin. You can’t – if you ban every drug that people die of, there are no drugs.

K: Yeah.

C: So, it’s a matter of what’s the risk versus the benefit.

K: Yeah. So, I have to go see my doctor every three months, and I can not go to see my doctor early. So, there are times when I’m completely out of pain medication, and it’s just suck it up buttercup. And that’s the way it is. But that doesn’t make me any less grateful for the fact that I have access to pain management.

C: Yeah.

K: And I feel like I have the right to say that I have access to effective pain management and medication. But, for me, when I’m saying effective; how I’m defining effective is I finally found a medication that works and that works at a reasonable dose. I didn’t like getting 125 milligrams of Demarol to deal with my pain.

C: Right.

K: That is a whopping dose. Doctors would be like “whoa” when they heard that, and people would assume that I was a drug addict rather than understanding my metabolism and how the different things I have going on with me medically affect pain management. So… in Japan, there are no opioids except tramadol, you can’t get Demarol, they only give morphine to people who are in hospital, and sometimes post-surgery, but most often not.

C: I think not post-surgery. I think you have to be terminally ill to get morphine.

K: Yeah. I think when they’re just trying to make your comfortable, then you can get morphine, since it’s most often said if you have cancer you can get morphine.

C: Right.

K: And then, for childbirth, they do not routinely do epidurals. So, you have to request a pain-free childbirth. But that’s rare. There are a few clinics that do epidurals. I am so happy that I’m past childbearing years. (laughs)

C: On the other hand, at least in Nagoya, they pay you to have children.

K: Yes, they do. So, that is

C: You don’t come away with a hospital bill. Instead, you come away with some extra money. It’s not a lot of money, but some extra money to help with diapers and all of that kind of thing.

K: So, extra money to help with diapers and that kind of thing.

C: That’s the way it’s explained in the literature.

K: Okay. I don’t know how much it is, but I do know several people that are getting a check for kids.

C: Yeah. It’s like a few thousand dollars over the first year. It’s non-trivial, but it’s not enough to just make having kids feel like your job.

K: I know someone with a thirteen-year-old that’s still getting a check.

C: Okay, that’s interesting. I haven’t heard of that. They send us – the city sends us notices that you can get a mammogram for five dollars. And that if you have a baby, this is how much they’ll give us. My reaction is always “if Kisstopher has a baby” we’ve talked about this before; we’re going to be much wealthier because

K: Yeah. I’m suing fools. I’m taking every house and car you own because there were two doctors in the room that said I had a hysterectomy.

C: Yes. Plus, my vasectomy, so somebody somewhere’s paying up.

K: (laughs) Well, no, your vasectomy doctor said it’s one in a million. So, he covered himself. He made you sign a paper saying that you understood that there’s a one in a million chance you might actually still be fertile. Because we did the follow-up and they didn’t find any swimmers, but

C: Yeah.

K: I think it’s irresponsible when somebody has a vasectomy if they don’t do a follow-up.

C: Yeah. Like, it must have gone well.

K: Yeah. And they – he took a chunk out of yours. Sometimes, they just snip them and sew it. And they grow back together. So… but you had one that they were like “this is not going to be reversible” because of the torsioned testicle.

C: Which we’ve talked about before.

K: (laughs)

C: And the pain medicine I got for that; I think was Motrin.

K: Yeah. (laughs) And after you had your vasectomy, you were so rowdy. I lent you some of my pain medication because I was trying to put you down, and you were just roaming the halls, talking and doing stuff, and then we had these clothes racks in our dressing room

C: Yeah, I remember.

K: And the clothes rack fell, and you were like “no, babe, I’m going to do it.” And I was like “babe, go lay down. Get out of here, go lay down.” And then you just collapsed. I was like

C: I fainted. I remember this. I sometimes fall down when I have seizures. Usually, I know that there’s a seizure coming on, so I’m not standing. But I fainted, and it was a weird thing because I knew that I was going to fall. I was like “whoa I am going to fall.”

K: You fainted in slow motion.

C: Yeah.

K: And I didn’t try to catch you or anything because I thought I’d just jack you up worse.

C: Probably you would have.

K: I made sure your head didn’t hit anything, but we had talked previously about it, and you said, “if I faint, please do not try and catch me.”

C: Correct.

K: So, I was like “okay.”

C: But it was a weird experience to say, “wow, I’m falling. My body is falling down. I can’t do anything about this. What’s going to happen? Ow, I hit the floor.”

K: Yeah. I don’t think you got – I think that was Vicodin. I don’t think that was Motrin. I think you got Vicodin. I don’t think I had given you my Vicodin.

C: Okay. Well, whatever it was, it wasn’t the medicine that made me faint. It was just the pain that made me faint.

K: Yes. Because that was the same day an hour after getting home. And you just randomly were wandering around the house, and I kept trying to get you to go back to bed and put peas on. Put your frozen peas on.

C: I get rowdy when I’m on different medicines. They make me rowdy.

K: Yes. Yes, they do. So, how was your pain medicine and your pain management in Japan versus the U.S. because I feel like in the U.S. you were in denial about your pain, you were in denial about how sick you were, and you were just bumming meds off of me.

C: So, first of all, in the U.S. I didn’t have health insurance because I had had health insurance through work, and then after I quit working, when I applied for insurance, I was honest about how much I weighed. And the insurance company said, “you are too fat to insure. There is no amount of money you can give us for which we will insure you.”

K: Yes.

C: So, then, I had health insurance for a little while while I was at Berkeley which had a 250,000 dollar cap on it. So, I think that I used a few thousand dollars in services because you had to go to the health center there. And I was trying to get some help with my joint pain because I had not been diagnosed.

K: Correct.

C: And they just did x-rays and things and told me “oh, look, all these little spurs here, you just have very sharp bones.” So… now that I’ve been diagnosed, I know “okay, those are calcification from ankylosing spondylitis” and whatever, but they didn’t give me any pain medication for it. They were just like take some aspirin or Tylenol or whatever and deal with it. Now, my pain management is I have 50 milligrams of tramadol a day, but I usually only take zero or 50.

K: Yes. (laughs)

C: So, it tends to last me twice as long as it’s prescribed for because if I’m at a 5, let’s say, I don’t bother. So, unless I need to get to sleep at a particular time, and the pain is keeping me awake, I tend not to bother. And if I get to like a 7 or an 8 if I’m having a particularly hard day, like if I had a seizure or something that can make the pain worse after, then I’ll take the medicine. But I’d say my pain management is pretty good overall.

K: Mhm.

C: So, I think most days, I’m probably about a three or four. Which has been my entire life. So, I know for sure that I started complaining about pain when I was six because I can geographically locate to where I was living at the time.

K: Where were you living?

C: I was living in Texas. And they told me I had Osgood-Schlatter’s disease, which is a tendon malformation in children that you outgrow. So, when I was six and they were like “well, either we can do nothing for you, or we can put you in a full-body cast for six months, and you will forever be a little weakling” which is basically what they told me, I was like “well, then do nothing for me.”

K: (laughs) We can ruin your life, or you can suffer.

C: right.

K: Which is the story of so many people.

C: So, from the time that I was child, from my earliest memories, I had joint pain and that kind of thing. I was just told there’s nothing you can do about it, just live with it. The reason that you started giving me medication was because you were trying to convince me that actually there is something you can do about it. You can get relief. Try this out. I was like “no, pusher man, no.”

K: (laughs)

C: But, in the U.S. I didn’t have health insurance, so to get a prescription for medication was like a thousand dollars.

K: Yeah.

C: And

K: But we did get you properly diagnosed for everything in the U.S., I pushed for that. And we paid out of pocket for you to go and get all your Dxs done.

C: For the epilepsy and stuff. The ankylosing spondylitis they didn’t confirm until here in Japan. So, because here an MRI is less than a hundred dollars, in the U.S. they were like “you don’t have any insurance, so we need 4000 dollars up front for an MRI.”

K: Yeah.

C: So, that was an issue. But I feel like my pain management is pretty good now. I’m not in more pain than I was when I was a child, so I’ve never known the pain-free day. If I’m not so heavily medicated that I’m not lucid. But it doesn’t bother me. Like, it’s not even something I would mention as a complaint unless somebody was asking me specifically “do you have any pain?” Yeah, of course.

K: Kind of like how my knees always hurt.

C: Right. Kind of like how I hear and read a lot of women say that they were told that periods just hurt. Like… so, then of course it hurts, not realizing that for some people that’s not the case.

K: Yeah.

C: I think I was in my twenties before I realized that some people just didn’t actually have pain.

K: Yeah.

C: So, you know, my management is I have medication I take as needed and don’t take it everyday because I don’t feel like I need it every day.

K: So, do you feel like your pain management is more effective (clears throat) sorry. More effective because of the system in Japan or because of the cost of seeing a doctor in Japan, like, why – what made the difference for you?

C: I think the predictability of it. I think that I go to my doctor, and I just tell him what’s going on with me, and if I want him to, he’ll run tests. But after they went through the tests, they don’t feel the need to retest. So, I had x-rays and MRIs and everything, and my most recent set was to finalize the AS diagnosis, but before that I had an MRI when I had a bicycle accident and stuff. But once they’ve got them, they don’t feel the need to keep doing them again.

K: Yeah.

C: Because it doesn’t benefit them financially for one, they’re not trying to cover themselves in case of malpractice for two, and they don’t have an incentive to disbelieve. So, and I think in the U.S. in particular, and I don’t know about other countries, the U.S. system and the Japan system are the ones I know. In the U.S. in particular, they do a lot of excessive testing to cover themselves against malpractice, but also, I feel like a lot of the doctors just really want to believe that you are faking. They have an incentive to believe that you’re faking for whatever reason. In Japan, they’re like “why would we do this x-ray again? We’ve already done the x-rays and the blood tests and the genetic testing and all of that that show you have this incurable condition. Why would we test to see whether you’ve been cured of an incurable condition?”

K: See, and I have a different situation because I have different issues than you.

C: Right.

K: I get tested every month, sometimes – sometimes I get tested every month. I try to push it to every two months. But every time I go to the doctor, every doctor I see, I get a blood draw.

C: Because you have a blood disorder.

K: Yeah. So, saying they don’t retest stuff like “oh, we’ve got your diagnosis now, pip pip off you go.”

C: Right, but I think the difference there is that, for effective management of your disorders, they have to know what your blood levels are to know that you aren’t

K: Some of them I have to fight to get. So, I find that I don’t know if it’s because I’m foreign or if this is the experience of Japanese nationals as well. I haven’t talked with any Japanese nationals with their health care experience, but I find I have to be very directive with my doctors and say, “these are the tests that you need to run and make sure you run these every time you see me.” And the one that I fight most about is having my amylase levels checked to see my pancreatic functioning. And they don’t really like to do that one at all, and I don’t know why. You’re already drawing my blood. It’s one – I don’t know if it’s more difficult to do than the other ones, but I’m like in my mind, they’re already putting it into the subterfuge

C: Centrifuge.

K: Centrifuge, thank you. Subterfuge, different thing.

C: It’s hiding.

K: (laughs) They’re already hiding my blood. Ugh, today, I’m sorry if you hear me itching. I’m covered in hives today, and I don’t know why. That’s another gift of my lupus and hereditary coproporphyria. Random hives, so I just itch, and itch, and itch. It’s awesome. Awesome. Not at all. So, I’m debating on whether or not to take Benadryl today to stop the itching.

C: Mmm.

K: So, that’s something I never leave home without is Benadryl. (laughs)

C: And the dosage

K: I had someone tell me the other day that it’s irresponsible for me to do therapy on Benadryl, and I was like “what the hell you say?”

C: I think it’s like a lot of medicines. If it’s actually doing something, then there’s not really much effect from it. Like, a lot of people take it for sleep, so what are they saying? It’s irresponsible for you to do therapy when you’re sleepy?

K: Because they feel like I’m high. If I take one Benadryl, they think I’m high. And I’m like “I would love to be you because that must be a fun existence” like one Benadryl, you’re high as a kite? You’re slurring your words? Like, what?

C: Mmm.

K: They’re like “you can’t pop pills,” and I’m like “okay. So, you’d rather have a therapist covered in hives, distracted – just itching themselves like a mad person because – rather than paying attention to you. Or I could take one Benadryl… and stop itching… and focus and be present.”

C: Well, your therapy is so powerful, it might as well be surgery with words.

K: (laughs) I wouldn’t do surgery.

C: So, you’re going into surgery.

K: I don’t know. Would I drive a car if I took a Benadryl? I don’t have that quandary.

C: You would not because we’ve been in that situation.

K: Well, I don’t drive at all, so the answer would be no. I can’t – I’m trying to think in the U.S. did I ever drive after taking a Benadryl, and I don’t think that I did.

C: No, you didn’t

K: I was really don’t drink and drive, don’t do drugs and drive in the U.S. I was really super strict about that.

C: Yes. And when you’d go to the doctor, they were really super strict about you have to have somebody driving you. So, okay, I will drive. I’m the epileptic one.

(laughter)

K: People are going to be so mad at us for that one. I feel like, I don’t know, I feel like this epi- maybe I’m just being paranoid because I feel like the last episode, we recorded was super controversial as well.

C: Yeah. You want controversy.

K: I’m feeling controversial. I feel like there’s lots of controversy. I don’t know why because I don’t enjoy controversy.

C: Right.

K: And I don’t want to be controversial.

C: You’re just trying to express yourself.

K: Yeah, so I don’t know.

C: I think you get a little bit shy anytime somebody says that what you said hurt them. Like, even if you couldn’t have predicted it.

K: Yeah, I do. I don’t like to hurt – I do not like to hurt people. And I really, it’s hard for me when my truth or my existence hurts people. Just the way I live. Just me being me. So… that’s it for today for me.

C: Yeah? You’re all done?

K: Yeah. I’m all done. All talked out. We’ll do the take two after this. So, we always do a take two or behind the scenes or our thoughts how we felt about the episode, and if you become a Patreon member at the ten-dollar level, you have access to over 40 take twos at this point.

C: I believe so. There might be a few missing. We had a transition where we went from written to spoke

K: Spoken.

C: Yeah.

K: Mmm. I think it’s about 40. I don’t know. Join Patreon and let us know. (laughs)

C: Depends on when you listen. If you’re listening super late, it might be hundreds.

K: Who knows? It’s a mystery.

C: Yeah.

K: (laughs) I hope you tune in next week. Bye.

C: Bye-bye.