

# Pigeonhole Podcast 48

## Introduction

[bright ambient music]

CHORUS OF VOICES: Pigeonholed, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole.

[ambient music fades into a relaxed groove with vibraphone and drums]

CHERYL NARRATING: Did you know April 12th was National Grilled Cheese Sandwich Day? Thomas Reid and I, through POD Access, put out a call to d/Deaf and disabled podcasters to generally find creative inspiration anywhere, and to specifically try to find it in grilled cheese. So I'm thinking to myself, I must know someone with a story to tell about disability and a hot, yummy meal of bread and cheese.

What comes to mind when I think of disability and food so often is lack of accessibility. For me, I would very much love to make a piping hot grilled cheese sandwich and then cut that thing in half, on the diagonal, of course. I'm not a monster. On the diagonal. But it's become too hard for me to grip a knife like that, so if I made one, I'd have to serve it whole, still delicious, but without the diagonal-cut nostalgia of childhood.

My friend, Sara, like many autistic people, has some foods she simply cannot eat, for instance wheat bread and cheese. A grilled cheese sandwich to her would need some accommodating and modifying, to say nothing of the fact that growing up in Colombia in South America, the grilled cheese she ate would be very different from the grilled cheese I ate. We set up a time and date, get on a Zoom call, and she's in the kitchen when she picks up!

## Do you like cooking?

SARA: I'm making a strawberry matcha latte with oat milk.

CHERYL: Ooh.

SARA: Yeah, it's one of those things that you put in a smoothie, but I'm gonna try it with papaya. [a long pause, relaxed groove slowly fades] One tablespoon?! That seems like a lot. Yes, one.

CHERYL: And fresh papaya?

SARA: And fresh papaya! I cut it, and I freeze it so it's still fresh.

CHERYL: Mm. Do you like cooking?

SARA: Um...um.... Friend, I'm not sure. I mean. Yes? And...it takes spoons. I like cooking for more than myself. It's kinda difficult when I just cook for myself, but I do like what I cook.

CHERYL: What is the thing you most like to cook?

SARA: Like, in what sense?

CHERYL: Something that enjoy yourself while you're cooking it, and you enjoy eating it. You enjoy both.

SARA: Oof.

CHERYL: [chuckles]

SARA: Oh, God.

CHERYL: Is that possible?

SARA: Ugh! I don't know. No, I don't think so. Ah. You take a long time cooking something, and it takes so little to eat it.

CHERYL: [happy giggle]

SARA: And you're like, did I do all of this just to eat it so fast?

CHERYL: [laughs] Right!

SARA: I'm gonna make noise right now.

CHERYL: Okay, here we go!

SARA: Is that okay if I make noise right now?

CHERYL: Make all the noise you want.

SARA: Okay.

CHERYL: [happy gasp] I don't hear it at all! Thank you, Zoom.

SARA: Wow, this is really thick. Hmm. Hmm! That is so good!

CHERYL: [chuckles]

SARA: Oh, wow!

## Dairy

CHERYL: This smoothie has oat milk, not dairy milk? Do you drink milk?

SARA: I cannot drink dairy, so I've been drinking dairy substitutes for a long, long time now.

CHERYL: So, do you eat cheese, or is that off the table, too?

SARA: I had to quit cheese this year.

CHERYL: This year?

SARA: And no, last year. Last year, last year. And it's been really hard on me. And that's been like at least 15 years that I quit milk. And I said, I'm not gonna quit cheese 'cause that would ruin my life. No, I'm not quitting cheese. I'm not quitting cheese. It really did make me sick to eat cheese, but I just wouldn't give it up. I was depriving myself of so many things at the same time that I just, I feel like I couldn't cope. But finally, I just couldn't do it anymore. I was way too sick. And I had to, and it was really hard. [pause] Look, Cheryl!

CHERYL: A purple glass?

SARA: Mmhmm!

CHERYL: It's so pretty with the green straw that matches your pillow! Look at you accessorizing with your smoothie and your pillow. I wish I could be there! Buffalo's a little bit far away.

SARA: But I would rather me be there 'cause I love Portland, I love you, and I love RouRou. And we could eat arepas.

## Colombian food and family

CHERYL: [gasps] Okay. Tell me about arepas.

SARA: Speaking of things I can no longer eat, but I still will from time to time, just 'cause it's just so hard to not eat something that you grew up eating for every breakfast at least. So, I grew up in Colombia. I grew up eating arepas. If I could've eaten arepas for every meal, I would've. So, arepas are... I don't know that they have a fair, just description in English. They're just a piece of heavenly deliciousness. [laughs] Yes, they are made out of corn, and they're flat. People would think about them as tortillas, but they're really not tortillas. They're thicker, and they have a different consistency. And their process for making them is quite different.

My grandma, for instance, would make them from scratch, which is quite the process. And then she would put those on the grill and cook them until they're crispy on the outside. And you would eat that for breakfast, which is like heaven. You would put butter on them and quesito on top of them, which is like fresh cheese, which is something I cannot for the life of me eat. It would make me so sick.

But that's stuff that I grew up eating, and it's just sad that I can't eat it. You know, I tried many times eating it as an adult, and it just makes me so sick that it's... [sighs] I don't wanna say not worth it. But it's just like, mm, it will just make me sick for days. I have to sort of like weigh the pros and the cons of eating something that I love eating.

CHERYL: Does it feel hard to connect to your roots in Colombia?

SARA: It makes me feel far away, which I've always just felt since I left. But not in the sense that I can't connect with them, just in the sense that I feel removed, and that I long for it. Like, I feel really connected to my roots in terms of like my family and my things that I would do with, like, in my community, but not necessarily with people outside my family, if that makes sense. That is not something that I long for. I didn't have a great experience in school or in high school with people, mm. So that's not something that I long for, but I do long for, like, holidays and cultural practices and things like that. And all those I relate to my family, and all of those have a lot to do or everything to do with food.

CHERYL: Are there foods that you would eat with your family that you can still enjoy?

SARA: Yeah, there are some things that I can still eat. Maybe there are some ingredients that need to be modified. My mom would do that for me, no problem, of course. Every time that I go home, that I'm gonna go home—which hasn't been many times since I've been in the United States. And that's almost 15 years. Imagine—she would ask me, like, “Just make me a list of what you would want me to make for you while you're here every day, and I will make that.” I've been gone for many more than 15 years. But I was in Spain before that. I did not live with chronic illness there, so it was different those times. But I guess the last three times that I've been home, I had already developed autoimmune and neuroinflammatory conditions. So then, my mom already knows many and most of the things that I can't eat, but that changes regularly. Like, I suddenly become intolerant to new things. But the same happens to her, so it's like she knows how to adapt. She always makes it a point to visit me every year. And when she's here, I do the cooking. If, you know, I'm not feeling well, obviously, which is a lot of the time, she will take over. But I really enjoy cooking when she's here. Now, going back to your question, I love cooking for my mom.

CHERYL: Yeah. No, wait. Patacones. You eat those, right? Can you eat that?

SARA: I eat patacones, yeah.

CHERYL: Would you tell me what those are and what's on them and how it feels when you eat one?

SARA: Patacones come from platano verde. And platano verde, don't confuse it with a banana. [laughs] We put cheese on them, and then it'll melt with the heat that the plantain when it comes out, it's obviously pretty hot. So the cheese will melt if you put it immediately after taking them out, out of the pan. Another one that I really love is you make a little tomato and onion, little sofrito. I usually do it with green onions just because I cannot eat white onions! But you can do it with whatever onion you like. And

then you sauté that until it's like juicy. And then you put that on top of the patacon, and it's pretty delicious. Of course, guacamole goes great with platanos. Whatever it is, really, that you wanna put on them works.

CHERYL: I love it. And there's a place I used to go that served it as a sandwich. So, you know, the stuffing in between two layers of the patacon. Just [chomping noise] big greasy sandwich. Yeah, so good. [chuckles]

SARA: Yeah! Delicious. Yeah, delicious. But, friend, didn't you make arepas one time?

CHERYL: I made it one time. It wasn't good. No, I made it a second time, and it was better. But it's still not, I mean, it wasn't like someone who's practiced 'cause I didn't practice.

SARA: Okay. I can help you if you wanna make them one time and you wanna call me on FaceTime, and I can guide you.

CHERYL: Oh, that's so sweet. Oh!

SARA: [giggles] Yeah. 'Cause that's the other thing. So, people here, because they don't really do the whole grinding process like my grandma, like cooking the corn and all of that, is they use something called masarepa.

CHERYL: Yeah. That's what I used. Mmhmm.

SARA: Exactly. And so, that really doesn't taste like real arepa. But it's a pretty good substitute to the real thing actually. There's a lot of arepa places in the U.S. that use that thing, and then they stuff them with different like meats and cheese and chorizo and stuff, and they're pretty delicious. But there's nothing like a real arepa coming out of your grandma's grill, right?

## The right food for the right body

[relaxed groove with vibes and drums returns]

CHERYL NARRATING: I didn't grow up around a grandma who was into home cooking. I do remember mine introduced me to tofu when I was little by handing me and my sister low-salt Saltine crackers each with a small, wet glob of uncooked tofu on it. [bad imitation of New York Jewish grandma accent] "You have to try this. It takes the flavor of anything you put it with!" [back to regular voice] We were really not okay with that particular snack, but I absolutely adore cooked tofu now. Some things have to be just right. They simply won't work unless you use the right combination of flavors and textures. [relaxed groove fades out]

SARA: Oh! And another thing is I really don't like olives. But! But I must eat a pizza with black olives otherwise I will not enjoy it. Unless! Unless it's Hawaiian pizza, which I love. Some people hate Hawaiian pizza, so they'll say that that's not a pizza, and what's going on with me? But I love it. I love it. And it was obviously an Americanized thing in

Colombia, and I adore it. But if it's not Hawaiian pizza, and it's another pizza, it needs to have black olives. But if you hand me a black olive just to eat it, I'll be like, "No, gross." It's so weird. I don't know.

CHERYL NARRATING: Sara, if you could have been there 40 years ago when I was handed some cold, wet tofu, you'd know preferring your olives on pizza and only pizza is not weird, I totally get you, I've been there, it's fine.

Sara and I talked a good bit about autistic tummy. This is something that she and I have both noticed in our day-to-day lives that it seems like so many autistic and neurodivergent people have some particular foods that they can't tolerate, whether that's the taste or texture or that it causes too much digestive distress. It seems amazingly common.

SARA: All neurodivergent people I know are chronically ill. All of them. And most of them have autoimmune diseases or conditions. All of them. It's a thing.

CHERYL NARRATING: Yes, including me. My autoimmune disease doesn't affect my tummy, so I don't relate to Sara's tension of wanting the cheese so badly but knowing that she should not have the cheese. But I do have things I want to do that cause me too much pain, like trying to cut my grilled cheese sandwich. I know that it will be painful and won't even result in a good cut, but I still sometimes want to do it. I asked her why the brain wants something so badly that the body is just not having.

SARA: I don't know, but it doesn't want it. It doesn't like it. It's really sad because the brain really does want it. And the bodymind is one. So, what's up with that?

CHERYL: Yeah. What the fuck?

SARA: What the fuck, indeed.

CHERYL: Can we, like, just all agree we're all on one team and play like teammates? [laughs]

SARA: Mm, I don't know. It feels like it wants to be Cartesian. I don't understand why that is a thing.

CHERYL: [laughs]

SARA: I mean it. The Cartesian theory of like the body/mind split where we're trying here so hard to speak of the bodymind, and my own term, embodyminds, and here's the autistic tummy trying to be Cartesian and split it again.

CHERYL: [laughs]

SARA: 'Cause the brain wants the cheese, but the tummy is like, "No." And so, here we are trying to fight that.

BOTH: [laugh]

SARA: Yeah, yeah. I would say that autistic bodyminds can be really... [guffaws] I don't even know how to say it, but most of the time, there's either miscommunication between our bodyminds and our, I don't know. [long pause] There's like a part of our bodymind that's going one way and another part of a bodymind that's going another way. So there's no split of the mind and body, but there seems to be like countercurrents [laughs] flowing through our bodymind, right?! And that's, I guess, how I can maybe think about it. I don't know. It's hard to describe. Like, my brain is hard to describe.

And you don't see my struggles. You don't see how I cope with not eating the things that I wish I could eat, 'cause that's just such a big part of life. It is so hard for me every day with food! It's like I am scared every time that I have to be out all day, just 'cause I know that I'm gonna struggle with food because I know I'm gonna be sick. Even when I order out from maybe a place that I know will perhaps help me avoid [chuckles] many of these issues, there still will be this fear of will they look at the instructions where it says, please don't add this, please take this out. And will I eat this and feel sick? It's really freaking difficult to feel sick every single day.

CHERYL: Can you eat pizza anymore?

SARA: Yes. I mean, it needs to be gluten free, of course. But if I do, I need to take something to help me digest the cheese. I won't feel good, but I will really enjoy it.

CHERYL: [laughs] In the moment, it's nice.

CHERYL NARRATING: Sometimes with accommodations, even for the simple question of cheese, the answer is not so simple. Yes, there are good alternatives to dairy, a variety of grains to try, and a million food blogs with advice on how to make things taste wonderful even if they taste nothing like home. Having someone like Sara's mom who gets it, who asks what Sara needs, and who shares in cooking it, that might just be one best accommodation of all.

## Wrap-up

CHERYL: Every episode is transcribed. Links, guest info, and transcripts are all at [WhoAmItoStopIt.com](http://WhoAmItoStopIt.com), my disability arts blog. I'm Cheryl, and...

TWO VOICES: this is Pigeonhole.

CHERYL: Pigeonhole: Don't sit where society puts you.

## Music in the episode

"Vibing Over Venus" Kevin MacLeod (incompetech.com)  
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