

Pigeonhole Episode 54

[bright ambient music]

Introduction

CHORUS OF VOICES: Pigeonholed, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole. [bright music slowly fades out]

CHERYL NARRATING: I dress up for video calls. I like themes.

[chime from a Google Meet call connecting]

SARA: Hi.

CHERYL: Well, hello there! Here is my shirt. It says “Exhausted.” [long, tired chuckle, then a sigh]

SARA: I like your shirt.

CHERYL: Thank you. It’s kind of ‘80s beach vibe, little sunset colors.

SARA: I have a shirt that I think you would really enjoy that I’m not wearing today, but it says, “Introvert but always happy to talk about accessibility.”

CHERYL: I saw it on your Instagram. [laughing] Where did you get that shirt?

SARA: I’ll send you the information. I’ll see if she still makes them. It’s a great shirt.

Photo description

CHERYL NARRATING: Now that we’ve dealt with wardrobe, I want Sara to set up her photo exhibition, *Our body is a clock*. I’ve seen it in person. I ask her to pick any photo that’s on the walls at Blue Sky in Portland and describe it.

SARA: A horizontal rectangular image. In the center of the rectangle is a white woman from the bottom of the rib cage up. Only the top half of her body can be seen. She’s facing away from the camera that is capturing her likeness, but her head looks back toward the lens so that she is gazing right at me. Both arms are stretched outward, away from her trunk, one in the foreground holding an electronic medical device that tempers how quickly an IV drip will enter the body. And we can see on that hand that holds the IV pole that the IV line is inserted into her forearm. The other arm outstretched behind her body further away holds another IV line similar to the one that’s powered on and allowing the medical drip to flow

into her body. But this one on the far right of the frame is not powered on. It is just a decorative element in the horizontal picture.

The room is cast with this warm yellow glow that only a beautiful fluorescent overhead light can imbue within a space. Everything else holds this yellow glow because nothing can be balanced correctly once that overhead light touches it. You can imagine that this is an infusion suite because there is a fabric curtain visible in the very background of this horizontal rectangle. I understand this fabric to be ubiquitous for these environments. It's like some sort of milkweed decorative motif on a yellow piece of fabric that's meant to feel calming or soothing, but for this viewer, it feels maddening and crazy and not relaxing at all. The last detail perhaps worth sharing about this image is that there's drop ceiling, also not very comforting, that you can see just at the top of the frame.

CHERYL: I don't know if you see I was trying to act out the description you were trying to get in the position.

SARA: I saw.

CHERYL: Yeah.

SARA: I really liked it, but each time I'd glance at you, I'd start to feel like, wait, which part of speech am I speaking from? Like, am I the maker as I'm narrating? I don't know.

CHERYL: When you were describing, you were describing somebody, and you, Sara, were the viewer even though it is you, Sara, in the picture.

SARA: There are about 13,000 pictures or so in this project as a whole. And in order to start working with them in any productive capacity, I can't look at the figure in the picture as myself at all. Each time I try and work on the book, which is the thing that I hope to make, I have to try and create this separation of me talking and looking and the person depicted in the photographs.

CHERYL: Which is so extra surreal because one of the reasons we're talking is because of my experience of looking at your photographs of you, [laughing] and then I went into your photographs of you.

SARA: It's a really interesting sort of unpeeling of the work.

Making photos during the pandemic

CHERYL: Earlier on in the pandemic, everybody in the infusion suite had to wear a mask of some sort, and many people still do. I still do, and some of the nurses still do. Did you have to wear a mask earlier on?

SARA: I did. I have felt like the pictures with the mask on are too indicative of a specific point in time. And I think as the project goes on, they'll come back. So far, I've just kind of put them into a pile. I call it my B pile. But it could be also that I just don't like thinking about that time. There's just something where I am able to place the timeline. Like, the clock isn't just the aging of the body. The clock is also the mask, and that's a very discernable time.

CHERYL: Now, your hair changes. Your hair grows or shortens. I'm not sure! There is a sense of time passing, and I don't know in what direction. But when I looked at all the photos together, I saw there was a bob, there was the long hair like you have now. So I felt a timelessness to the collection that was up at Blue Sky for that reason.

SARA: The longest I went without getting a haircut in my adult life was during the pandemic, which is probably true of a lot of people, where my hair was longer than it had ever been, like down to my ribcage, and then I cut it all off.

[mellow tune on acoustic guitar plays]

CHERYL NARRATING: Seriously. My hair also got the longest it's ever been, and the roundest, thickest, and bird's-nestiest in the first couple of years of the pandemic. Then I cut it, and then my hair wouldn't grow. Which my rheumatologist assured me was not the infusion medication but was hormones. And at my age, we know what "hormones" is code for. When we were talking, Sara mentioned how young kids change drastically in a year compared to adults, so changes in her hair length can be how the photos note time passing. I check to see if that's true for me too. When I tap through photos on my phone, I recognize how the length and breadth of my hair is more of a timekeeper than any other part of me in the past 15 or 20 years. [mellow music finishes and fades out]

And even though sometimes there's a nurse or someone else in Sara's infusion pictures, she's most often solo, long hair, short, or medium. And I wanted to know how she narrowed down her 13,000 to the incredible collection I saw at Blue Sky Gallery in early May.

How the photo series started and people's responses to it

SARA: I have been making edits and selections periodically over the last 11 years. I started the infusions in 2014, and I made only a handful of photographs like the ones that are seen in the exhibition. And when I say that, I mean they're really formal. The ones at Blue Sky Gallery are printed pretty large. The camera that I used to make the prints of the photographs that are at Blue Sky Gallery, I used that camera when I made a handful of pictures in 2014. But I became very...bashful. I became very frightened in a lot of ways. 2014 until 2019, I made pictures with my phone for that duration. After my daughter was born, I had been off my medication for about a year, and I was living in this fantasy where I

had become this more powerful being after having a vaginal birth, and like, I would never have symptoms of MS again, and I would never need another IV drip. [laughs] And then that all came crashing down. It started as some stiffness and pain to just the most extreme version of stiffness and pain.

CHERYL NARRATING: Sara needed a homecare nurse for her medication for a time.

SARA: Once I'm plugged in, and I'm getting the medication, I'm holding my infant, and I'm just like, I know that it feels really wild, but I can't tell what this looks like. And so, I just put my camera on my tripod. And I used my phone 'cause some cameras have an app you can download where you can use it like a remote. And I made over 300 pictures. Every time after that that I've gone to the infusion suite or have had someone come to my home to administer medication, I've used a more formal camera to try and make pictures and documents of this experience.

CHERYL NARRATING: But then, how to choose from 13,000 for one small exhibition?

SARA: There's been these two phases, these distinct phases where I have a few thousand pictures made on my cell phone, and then I have probably 6 to 8,000 that I've made since 2019. And some of them are just bad, like they're too dark or they're too bright. Some of them are very easy to say, "not these" because I don't like the way I look or something more superficial like that. But then there's also this third way of editing where I feel this kind of intuitive, visceral sense that it just is saying the thing I imagine needs to be said. So, for this show in Portland, which was the first time I've ever shown the work, I just thought, I'm gonna leave that off, those cell phone years, and I'm just gonna try to create this feeling.

CHERYL: They are stunningly all very different even though they still center around you and facing the camera. 'Cause sometimes you're looking over your shoulder, sometimes your whole body's facing the camera. Sometimes you look relaxed. I don't think you're smiling in any of them.

SARA: None of them that were in the show include me smiling. There are some in my 60-picture edit that include smiling. But you know, even a resting face isn't necessarily an unhappy face. I know that's not what you were implying. When I switched infusion sites, I asked someone with authority if I could still make these pictures. And I was later told by someone else that this was meant to be a joke, but the person I asked said, "You can make pictures if you smile in them." [chuckles, then a long pause]

[upbeat, funky jazz plays through this section]

CHERYL NARRATING: Just a note that Sara's not so much chuckling at this story so much as she saw the way my face contorted into a different kind of exhaustion. The exhaustion

came from remembering when a doctor told me to retake my photo for my medical ID because I'm not smiling in it. And it would look better with a smile! I told him, from where I was slumped against the wall that I don't smile when I'm here because I never feel good when I'm here. So, like, yeah, I smile at other times. I smile here at Sara. [music ends abruptly with a note on guitar that rings out]

CHERYL: You're right that I wasn't making a comment about whether you were happy or not, but it was very much so, I feel the imperative to smile when someone points a camera at me. [laughing] And you were told you should smile!

SARA: The person who said this to me about smiling, I was really grumbly about it. And then finally Topher, my husband, was like, "I think it was a joke." And I'm like, I'm not sure. I'm really not. I mean, Cheryl, I'm not sure if it was a joke!

CHERYL: [pained whisper] Yeah.

SARA: I think I'm trying to achieve a few different things. I believe that I am my first audience, and I never know, at least I hadn't known until recently, if anyone was ever gonna see these pictures or care about them. And so, I want to use these pictures in at least a primary capacity to try and catch a glimpse of myself almost in a mirror. So in that way, it's important to look at the eye of the camera or the lens to feel like I can make eye contact in that way, where if you wanted to look at your face in the mirror, you would do that.

The moments that include any sort of upturned corner of the mouth, usually, it's when I'm not alone. So the nurses are there, or maybe I have another visitor in the room, and we're talking about something, and that's why I would smile. So it would be a moment of distraction from the actual activity that brings a person into that space.

CHERYL: Oh. So, the lack of smiling in the pictures is not, "I'm so sad that I'm sick and getting an infusion." I didn't think about it, but when I go in the bathroom and look in the mirror, I'm not smiling. [giggles] I'm just looking at my face.

SARA: I've been showing the work to publishers, and I've been pitching it to galleries who might be interested in showing it. I got some feedback from a person who is in their late 70s whose response was that to look at someone in a hospital over and over and over without any sort of moment outside of that scene—no photographs of landscape, no photographs of flowers, or something that would take you out of this steady tempo of being in the hospital in this infusion suite—that it felt to this person like they could see themselves. When they looked at the photograph, they weren't looking at a young woman, but they were instead looking at their own likeness as they would imagine it in the hospital. So, they were seeing something that was indicative of their mortal flesh and their own eventual death.

This was a huge surprise to me. And I don't necessarily like it, but I think of these treatments as lifegiving and those of hope and physical comfort, the things that come after. It was a great surprise to hear this feedback because it's just not something that I would've come to on my own because of my experience. I think since then, I've tried harder to expand my own perception of why people might not wanna show it. Or people who have said, "I'd be interested in making this into a book, but I think we need to show more views of, like, [chuckles] the depth and breadth of a full life that a person with this illness can have." That's not the experience I wanna create because I think that's the story we all think we know, like doing all of this that is expected of a person in society despite adversity and hardship. [chuckles] I don't identify with that story and that fiction, and that's not the story that I wanna tell.

I wanna create this book experience that's just infusion over and over and over because I don't wanna give someone an escape from that. I wanna create this experience that it is inescapable, that it is ongoing, that that is an aspect of my good fortune that I can do this over and over and over again. In my own experience, it has been really hard to get approved for some of these medications and then stay. [chuckles] Even when everything seems to be going right, to then have a \$50 bill go to collections that should've been covered by the pharmaceutical company. These things can just bat around and get the whole system off its rails. So, it seems like I don't wanna create another sort of leisurely experience of looking at art and have a person be able to wander off on their own escape hatch 'cause that's not...that's not true to me.

CHERYL: I really resonate with that a lot. Yes, it's inescapable. And like you were saying, the experience of receiving the infusion is the experience of receiving relief. I can't be more tickled or more thankful for that day and sitting in that chair. The diseases that we each have are inescapable. The need for medication is there. But the medication is great. Yeah.

SARA: I mean, it's truly an oxymoronic thing.

CHERYL: It is. It is.

[breezy melody on acoustic guitar]

SARA: During my artist talk at Blue Sky Gallery, you asked this question from your perspective of feeling how quiet the scenes seemed to you, in contrast to your own experience of being in an infusion suite and it being very loud and not peaceful. [breezy music fades out] I loved that response because in a lot of the photographs that I'd made before really turning to self-portraits, people would look at still lifes and I suppose landscape pictures that I'd made, and they would say like, "Oh, the volume of this photograph is so quiet." But that wouldn't feel like a compliment. It would feel like an

appraisal of something more on a personal level rather than just something about a piece of art or an image. Which perhaps says something more about me [laughing] than it does about the person who made those comments. But before the infusion pictures, it was almost like I wanted everything I made to have a louder presence or a bigger presence. But not until I heard you make that comment about the infusion suite photographs feeling quiet did I really understand that it is that sense of a sort of sound erasure, no-more-sound quiet that I like about those pictures, that I can do that. Because those rooms are not quiet at all. There is no soundproofing. In some cases, there's multiple like televisions whose sounds are at war with each other, just sort of sound waves drifting across you. And there's no privacy. You always kind of know somebody's business. It seems like most people don't mind. [laughs] It's not quiet. It's not peaceful. And I feel like it's a small victory to be able to make a picture that feels quiet there.

CHERYL NARRATING: And if you didn't check out part one of this two-part story, check that one out when you finish this one. Part one talks about that moment and the quietness and getting immersed in her work. In her artist talk at Blue Sky Gallery, she talked a lot about the paper these pictures are printed on, a blend of rice and bamboo fibers, really big.

SARA: I think on average they're 25 by 36 inches. I wanted to see what it would be like to have this lightweight 75-gram paper just hang on the wall to sort of create or recreate that experience of walking by the curtain in the hospital 'cause it moves, or you can touch it, have that kind of resonance, having the curtain in all of the pictures and then having the paper sort of echo that fiber.

For the most part, each time I set up the camera, I look through the viewfinder, which is the eyepiece, to set the scenes. I go in front of the camera, and I photograph until I'm literally too tired. Sometimes when I'm making pictures, I'm like, okay, I don't wanna keep doing the same thing. So, what am I gonna try this time? I'm gonna tip upside down. I'm gonna move my arms. I'm gonna try and interact with the other IV stuff that's around here. Or I'm gonna see if I can move from this part of the wing to that part, so there's a greater distance. And sometimes I am trying to be playful 'cause I wanna keep it interesting for me.

I think I'm now in this place where I'm like, do I want to overtly be more funny? What is funny? Well, sometimes it's like not what other people expect to be funny! I'm also kind of playing with my own sense of what I think is funny.

CHERYL: Yeah! Yeah. There's gotta be some infusion-specific humor.

SARA: I don't know what it is yet. [chuckles]

CHERYL: I don't either, but I feel like there must, [whispers] there's gotta be something. I don't know. I'll see if I can pinpoint anything when I go. I go in a couple of weeks.

[breezy melody on acoustic guitar plays through the next section]

CHERYL NARRATING: Well, I went for my infusion, and I still can't think of any infusion-specific humor. But I'll wrap up by describing an interesting painting. There's a picture of the painting in the episode's blog post. It was hanging at a different hospital than I usually go to. And I was there for something unrelated. The left and right borders each have three colorful ribbons twisting loosely around each other as they float down the sides, reminding me a little bit of strands of DNA. In the center is a circle of six dancing stick-figure girls in single-color dresses, four with pinafores. Each girl holds a ribbon the same color as her dress: purple, then green, yellow, blue, red, and orange. The ribbons are attached to the top of a maypole that they're circled around, and they've only just begun twisting as the six girls twirl around the pole. They dance in a lovely green valley with rolling blue hills and a snow-capped mountain in the distance. Six birds that look like ravens fill the sky. Some are soaring, some look like they're divebombing, but it still feels very playful and sweet.

I was captivated, flooded with joyful memories of my own maypole dancing experiences in public elementary school. [breezy music ends] I remember thinking as a kid, "Wow, these non-Jewish people have great dances too!" I snapped back to the present when it was pointed out to me that the ribbons attached to the top of the pole that course down to the girls' hands look a lot like the IV lines that course down from the IV pole and affix to Sara's arm in her photos.

To the right of the maypole painting, and under blaring fluorescent lights, is the door to the infusion center, which really was a chance find. There are caution signs in the window, one warning people to open the door slowly and the other warning people that the door is automatic! I admit I was stumped by that for a little while, but I can't find a joke in it. I'm standing there, looking back and forth between the painting and the heavy door that leads into that loud room with the exceedingly comfortable chairs and the maypole-style IV poles. I don't know if placing it there was intended to comfort infusion patients specifically or not. But I let the painting shift in my mind from a childhood dance party to some kind of weird group infusion session that can be done while running and dancing, and I'll admit I did have to chuckle just a bit.

Sending my appreciation to Sara J. Winston for her exhibition, her book, her artist talk at Blue Sky Gallery, and for chatting with me.... Wait a minute. Hang on. Sara! [goofy chuckling] You really have a wonderful way of infusing your photography with your heart and soul, for which I truly thank you.

[bright ambient music returns]

Wrap-up

CHERYL: Every episode is transcribed. Links, guest info, and transcripts are all at 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

Stock Music provided by Scary_Bodega_Productions and SweetMusicProduction, from Pond5.