Pigeonhole Episode 50

[bright ambient music]

Introduction

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

Alpen

CHERYL: It's 2022. I'm on the Superfest jury, which is a group that helps choose which films will show later that year at the festival. There's a very short experimental dance film called *Alpen*. I'm in love immediately. I'm crying. Not that it's a sad film, and none of my other colleagues on Zoom are crying. I'm crying because it's beautiful and because I see myself in it. I hope more than anything that this film will be selected (it is) and that I can audio describe it because describing it would mean watching it at least five more times, sometimes fraction of a second by fraction of a second to get it all right. Someone else ends up describing it, but it's in the festival, so I'm happy.

[small, hard wheels of a rolling chair scraping back and forth across the floor plays through the next two paragraphs]

Alpen: The dancer is at home. She's moving around her kitchen. Like me, she was an athlete in the first part of her life. Probably always on the go. Now in severe chronic pain and stiff, she's discovered that her adapted way of moving is like a dance: pushing off a countertop with a hand, plopping onto a rolling stool and propelling from here to there. I can't take it. I'm in tears.

Because just before we sit down on Zoom for the Superfest jury, I'm at the doctor's office receiving a diagnosis about a weird thing with my hand. [chill lounge music begins to play] And this diagnosis would be very likely to send me down a path where I'm going to start to move just like the woman in *Alpen*. [rolling chair stops rolling, and chill music continues] So I'm crying because she looks like she's in pain, and I'm in pain, and I suspect I will one day be in as much pain as she is. And? I'm crying because watching her, I don't feel alone.

The people leading the jury know I've been at the doctor, but I only tell them as a warning in case I'm late to get back home for the jury because I'm on a public transit marathon. They don't know I've just been diagnosed with something that relates to this dancer until after we view it, and I'm trying to not cry in saying how much I love this five-minute film about someone scooting in her kitchen and touching countertops and the innocent box of Alpen muesli that looks to me a little too high to easily reach for such an easy-to-eat food. I'm crying because my increasing pain now seems inevitable. But I'm reassured that one day, I, too, can turn that pain into a beautiful solo dance.

[chill lounge music stops abruptly with a crashing thud]

OK, the diagnosis is wrong, LOL. [pained chuckle] The diagnosis I get a few months later was, in some ways, more upsetting because it means I have an autoimmune disease, and I will be on medication for life. But it's less upsetting because if I find a medication that works, at least some of my pain could go into remission. The wrong diagnosis is osteoarthritis, based just on an exam in the clinic. When the X-ray of my hand comes back a few days after that appointment on Superfest jury day, it shows joints that look almost just the way they expect a 47-year-old's joints to look. The doctor writes me this, "I hope your hands are feeling better." And I write back to her that I didn't get better in the last week. And I ask if it's not osteoarthritis, then what is it? Some other doctor sees this online exchange and springs into action, getting me into rheumatology, and rheumatology gets me into the correct diagnosis of psoriatic arthritis. Which could just sorta sit there for the rest of my life and hang out or could slowly destroy my joints and continue to increase my horrid fatigue, etc., etc. It seems to be going the second route.

We try a bunch of medications. One doesn't do a damn thing for the disease, but it does relieve the grueling pain in my neck I've had constantly for over a decade. The next one is a chemotherapy drug that works wonders. But in my deal with that devil, I spend the entire weekend on the sofa every single week, moaning with nausea and fatigue. However! The work week is pain free and full of energy and open sores in my mouth. Leave it to a workaholic like me to choose the weekend to be sickened by my medication. This goes on for a while. Then I finally get onto a different medication, an infusion that feels much better. Other than being immunosuppressed, which means yes, I still mask indoors no matter where I am unless it's my own house. And yes, I avoid crowds when I can, even if I'm masked.

[chill lounge music returns]

Abi Palmer Invents the Weather (Light)

It's 2023, and *Abi Palmer Invents the Weather (Light)* is on the schedule for the Superfest jury selection committee that I'm on again, on Zoom. How is this possible? [super-contented cat purring builds and plays on and off through the next two paragraphs] I see myself even more in this film, this ridiculously neat film about someone isolated inside with chronic illness in early COVID days who builds elaborate ASMR-inducing dioramas for her cats [whining cat meow] so they can experience the changing seasons and the outside world, inside. [trill-meow] I guess it's sort of like high-concept, analogue Zoom events for cats. [two high-pitched meows] I want nothing more than to audio describe this one because it would mean watching it at least five more times, sometimes fraction of a second by fraction of a second to get it all right.

And I get to. And I love it. And wow, are those cats cute! And Abi Palmer's film so beautiful to me. The film is weird and luscious, and I feel simultaneously connected to the filmmaker and her cats, Lola and Cha-u-kao, [trill-meow] and I also think about how isolating earlier days of COVID lockdowns were [purr-trill] and how isolating current days of immunosuppression-motivated stay-at-home days are. So, yes, being sick and on this medication, even today, after lockdowns are well over can feel isolating, except thank goodness for Zoom. [music fades, contented purring continues a bit, then fades too]

Existing Patient

And for Superfest jury on Zoom. Because in 2024, a film called *Existing Patient* comes to the jury. And this time, I don't cry so much as have to pick my jaw up off the floor after we preview it. Is that me in **this** film too? No, that's not me, but is that…me?

[chill lounge music returns with soprano vocalizations]

Again, one woman alone at home. She’s not dancing, and I can’t tell by looking whether she’s in pain or not. But she’s definitely got a chronic illness because she’s on the phone with her insurance company trying to get her medication approved. I feel like I have two brains at once. One is watching and listening to the film, admiring the innovative editing techniques, the fantastic and biting script, the exquisitely on-the-mark acting, and the haunting set. My other brain is going down a checklist of all the things that I have in common with the character. Or is it with the actor? Wait, both? What. Is. Happening?

While my insurance situation isn’t nearly as bad as what’s shown in this fiction-but-not-really-fiction film, I have failed to get my promised reimbursement from Pfizer for months. At one point, they reimburse me but refuse to send me the money. They put it in an account. Before I can grab it, they take it back. I ask for it to be returned. They return it. I take out a small portion, and they take the rest away again. And now they won’t reimburse me at all! [chill lounge music number ends and gently fades]

If anyone hears or reads this and feels the urge to give me advice, save yourself the trouble. I’m trying all the things one tries, and all the things Colleen, the quote-unquote “character” in the *Existing Patient* film is trying. Jenn, the actor, is so convincing that when I finally meet her a few months later in person, I call her Colleen, and she doesn’t even seem to even notice. How is this script so damn good? How is this actor so damn good? It’s clear that she is such a good actor for at least three reasons. One is that she’s a good actor. Can’t downplay that. Two is that the script is written by someone who knows this stuff, not some outsider who wants to break into the market segment of disability stories. Three is that while it’s a fictional script, this is Jenn’s life too. It really is. She has a chronic illness. She takes a medication. She calls insurance and asks them why they won’t cover her treatments. She calls again.

And I get to audio describe this one, and I’m in bliss because it means watching it at least five more times, sometimes fraction of a second by fraction of a second to get it all right.

I’m gonna tell you much more about this film in the next episode. I sat down for an online call with the star, Jenn Covington, and the filmmaker, Aaron Abolt, to talk about this film and their experiences making it. [jaunty tune on acoustic guitar and goofy trumpet plays till the end] They already knew my experience of watching and audio describing it because there is a lengthy and effusive email thread where I was trying to deliver the audio description script for review but couldn’t stop saying how much I loved the film. I got to meet them onsite at Superfest 2024 after watching the film in an auditorium filled with masked sick, Deaf, and disabled community. I spotted Jenn from across the auditorium and started sweating. After the screening was the time I called her Colleen. Then we stepped outside The Exploratorium in San Francisco where Superfest was being held. The late-October day was bright and warm. We took off our masks and smiled at each other in 3D and made a plan to record a conversation, which is what you’ll get in the next episode.

[jaunty music fades into ambient music]

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 and sounds in the episode

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