

epilogue

Sun, Jun 25, 2023 2:55PM 18:36

SUMMARY KEYWORDS

insomnia, podcast, elle, sleep, episode, work, disability, life, writes, state, wrong, season, learn, create, diagnoses, spelling bee, envy, beautiful, watched, ableism

SPEAKERS

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E Elle Billing 00:00

Hi, my name is Elle Billing. I am a chronically ill queer femme, and I'm tired. I'm here this episode and every episode to dig at the roots of our collective fatigue, explore ways to direct our care and compassionate and sustainable ways, and harness creative expression to heal ourselves and our world. And welcome to Hoarf Radical care in a late capitalist heckscape. My name is Elle. I'm a chronically ill queer femme, and I'm tired. Welcome to Episode 16. I am still sick, I am still tired. In fact, I think I am more tired than I was when we launched Hoarf in October. But I am several months and over a dozen episodes wiser. Honestly, that's not very much. But I want to cap off season one with a kind of epilogue. In a style similar to how we started, a bit of an audio essay, the State of Hoarf, but less formal, perhaps more rambley. But definitely more gratifying for at least some of us, at least those of us who enjoy discussing disability pain, politics, love and revolution. To recap: Elle. Ill. Tired. I had a birthday. So now I'm 38. I still live with my parents. My insomnia is definitely worse. I'm wondering if that's just an annual spring event now. I feel fortunate to be in a situation we have created here wherein my insomnia is not threatening my health or safety. I know it comes up a lot. And if you've listened to the previous 15 episodes, in part or in whole, you probably already know parts of the story up to this point. Two years ago, in the spring of 2021, I went on medical leave from my teaching position because something was really wrong. And I was really scared. Among the diagnoses I collected in that medical leave - transition to not working time, my years-long struggle with sleep was finally documented as severe clinical insomnia. The reasons for this insomnia are among still more diagnoses: Restless Leg Syndrome, which had been diagnosed at the National Institutes of Health in 2011, ADHD, fibromyalgia, frequent nightmares. Insomnia in this case, would be more of a symptom or an effect of other things in my body and brain not collaborating as a team. Now, let me tell you about insomnia's effects ON the brain and body. Have you seen the Al Pacino / Robin Williams film Insomnia? I have. It takes place in Alaska in the summer and Al Pacino is a police detective investigating a homicide. And he's not used to the long hours of daylight, and he gradually kind of loses his shit because he can't sleep. I remember when I watched it? I thought wow, that's messed up. You know what's messed up, being sorely physically, mentally and spiritually exhausted and not falling asleep. Kate C Bowler is an author and Duke professor, and I have followed her on Instagram for quite a while. I'll put her links in the show notes. Her podcast is called Everything Happens. Not everything happens for a reason. No, just everything happens. With Duke's Everything Happens project, she works

to cultivate empathy. There's a mural in Durham, North Carolina where she lives and works that has her quotation on it in big black letters. Life is so beautiful. Life is so hard. If I've learned anything in the last three years, it's to hold multiple truths at once. Life is so beautiful, and life is so hard. So what's hard? I miss my friends and chosen family every day. I miss teaching. I miss the students. My abilities in sign language and Spanish have certainly suffered. My Spanish is an ongoing project in the first place and learning a new language while living with a neurological condition is challenging. My friend and friend of the podcast Andrew Gurza has one of my favorite approaches to posting about disability on social media, and it's because of his unfiltered thoughts about his day and his life. He writes about the hard stuff, the grief, the rejection, the hospitalizations, the ableism, the internalized garbage he is working through. Andrew writes about the funny and awesome stuff too, but they resist pressure to fit within the parameters of toxic positivity or inspirational disability content. Because sometimes life is hard, and it's just hard. It's not hard in order to be inspiring for someone else, it's just hard. On the episode I did with Andrew, they shared a story about eating a small handful of nuts and ending up in the hospital needing emergency surgery. Like what?! I was at a birthday party last weekend, and my cousin's first grade age son was chowing down on mix nuts. And I was envious. I love cashews. But the last time I ate them, I almost went into anaphylaxis. So I went from envy to laughing because it's really silly for a 38 year old me to be sitting there envying a seven year old's snack food, right? Except nuts make up just one of the things I can't eat. If I rattled off a list of 100 things I can't do since getting sick, 50 of them would be foods I can't have. But still, we're here, back here, sitting with me a 38 year old grown ass adult, feeling envy for a first grader snack at an eighty-year-old's birthday party. And then the level of silliness keeps growing. And that's my life. It's full of these observations about food that will kill me or might kill my friends and then laughing about how silly that is. But if you ask me how I'm doing, I will tell you: I'm not sleeping well. It's allergy season. Antihistamines make my legs ache and make it hard to sleep. But they also make it so I can eat fruits and vegetables during allergy season without overloading my system. But then I'll say, hey, at least I can nap. Because I love naps. And I'm fortunate to have a structure to my life that facilitates napping. Life is hard. But it would be even harder if I was getting even less sleep. And that, friends, makes me think of the times I was getting less sleep. And not just 2021 When I thought my world was ending. the spring of 2007, when I was in my last semester of education courses at college, and I had a six week bout of insomnia when I was supposed to be doing my elementary methods practicum. I mean, I was supposed to be doing, it and I did do it. I just don't remember doing it. Or the three vehicle collision I caused in 2019 when I had only slept four hours the night before. I watch a lot of TV with my parents. My dad has watched most of the 19 seasons of Grey's Anatomy. And I have watched the most recent two since I lived there. I can't really speak for that show. But I did watch ER back in the 90s. Something I've noticed in these two seasons of Grey's that I've watched is there's a push back on the glorification of double shifts and overburdening of the interns and residents to the point of exhaustion. The show regularly challenges the wisdom of "it's how we learned so it's how they should learn." Which for a show that actually has the 19 season backlog of episodes to say "actually, yeah, these interns were abused by their supervisors" is something at least? will we ever actually stop glorifying the grind, sleeping on the on call room, glorifying comparing who got more or less sleep? I don't know. being intentional about my sleep hygiene is a privilege. It is a luxury. And it shouldn't be. walking away from a job was possible because I had a house to sell. And because I had a place to go where I didn't need to pay rent and utilities. I'll spare you like the long drawn out history version of this. But it's generational wealth and land ownership that allows me at this point in my timeline to be producing a podcast and creating art and sleeping 12 to 14 hours a day. Even once my savings runs out, it will be generational wealth and land ownership that allows me to keep doing this. I keep reminding myself even when my savings runs out, and I don't have money, or I have very little money, I still have a lot more privilege than a lot of people.

Even then. A lot of this shit is hard because we're exhausted. It's structural, systemic, intentional. Why the push to return to the office, to declare the pandemic officially over, even though folks are still dying and becoming disabled by COVID in droves. a recent statistics at that 1 million people have become permanently disabled from COVID. In the last three years, 1 million people who have long COVID or chronic fatigue syndrome, just those two conditions from COVID and who can no longer work. the push to return to the office is because when we work from home and have control over our schedules, and have the ability to rest we have the ability to imagine and create something better. Exhausted people don't have time to protest, create art, demand change, or testify in front of thier legislators. When I am at my most sleep deprived, and my most vulnerable, I don't have the imagination to see myself past the age of 40. Let alone envision a better future for my nieflings. Life is hard. Life is so hard. I see you out there doing your best. Life is beautiful. Life is so beautiful. The beautiful doesn't cancel out, or negate or bypass the hard. They coexist. Multiple truths exist simultaneously. I miss my friends and students and and and, and yet. I wouldn't be anywhere except where I am right at this moment. I am healing my relationship with my mother. I'm seeing my brother's younger children grow through their childhoods. And I'm involved, which I missed with his eldest. I'm getting to know my parents as people and not just as parents. My dad is really cool. Like, I really genuinely enjoy his company. My sister is getting married soon. I'm seeing the things I loved about my hometown through my adult eyes. And a lot of it holds up. Thank heavens. Some of it doesn't, of course, but we can do something about it. And that's what's beautiful too. the art, the podcast, the community are how we create the beautiful life we want. And we have to build it together. That's how we build it, is together. What have I learned from doing this first season of Hoorf? I am enthusiastic about talking to guests! so enthusiastic that sometimes I talk over my guests, and I need to work on that. The guests I seek are so interesting and deep and they have so much to share, I need to let them share without talking over them. So if that annoys you, I know I do it and it annoys me too. I also usually have a hard time cutting us off at the 40 minute mark. I'm working on it. I have also recognized that I have a deep, deep fear of being wrong and public. And I have to be okay with being wrong in public. I think anyone who has known me long enough, especially from my K-12 days, would recognize this trait about me. let me tell you a little side story about the spelling bee to illustrate this. And as of yet, this is only known by a few people. So this is a big reveal. In eighth grade, I won the County Spelling Bee and I got to go to state with one other student from my county. And then I didn't study. I procrastinated. I didn't study, I don't have a solid understanding of time and elapsed time and how much time it takes to do things. And then suddenly, it was the state spelling bee. And I'm a really good like written speller. Like I can write things out to spell them, but I'm not a good oral speller. And that's a huge part of the spelling bee. So I was so scared that I would get to the oral spell down and then embarrass myself and, worse, embarrass my parents, in front of the entire state of North Dakota, that I intentionally spelled words wrong on the written qualifying test to make sure I would not get to the second stage because I was so scared of being wrong in public because I knew I would be wrong in public, I wasn't good enough to win. And so if I couldn't win, I didn't even want to make the top 20. so that, you know, my fear of being wrong in public is very deep, and has been my whole life. I recorded an episode last fall that we haven't released yet. Even though it was going to be episode two, like after my prologue episode, it was going to be the next episode. We didn't release it because I had concerns about some ableist and sanest language. And as a new podcast host, I'm still figuring out how to address certain types of content when it pops up during an interview. You know, because I don't want to be wrong. But people are messy. I'm messy. And talking about care and disability and racism and ableism is messy. Fostering connections and speaking in public is messy. It's beautiful. We don't learn by being perfect. I was a teacher, I know this. I always encouraged my students to make mistakes and to make big mistakes because then it's easier to to notice and to fix them and to learn. Like if you're going to make a mistake, make it loud. I cannot take my

own advice. We don't learn by being perfect. I am figuring out how to be accountable without being absolutely terrified of saying something wrong, which I will do at some point. Since this is an epilogue of sorts, I needed to tie it back to the prologue of episode one, I suppose, right? Make a neat little package out of an otherwise ADHD-fueled season of what exactly is this podcast and what will it be? *ahem* Everything is connected anti trans legislation, a rising eugenics discourse, attacks on reproductive rights, mass shootings, police violence, even the ridiculous uptick in the use of drugs like Ozempic for off label uses, like weight loss is all connected. And it can feel overwhelming; it is overwhelming. The idea of a public arena where we can safely gather as whomever we are, is under attack. And the commons are shrinking. And our autonomy is chipped, chipped, chipped away. What do we do about it? Can a person with major depressive disorder have hope? Apparently I can. I've found my little place to pull on the giant knotted ball. And that helps. If we each do our part to pull on our little thread in our little corner. We can unravel it, and then maybe knit up something cool. But it takes all of us pulling together. All these attacks are designed to isolate us and sow mistrust among neighbors. What could we accomplish together, creating something different collaboratively, each with their own thing. Chaotic bisexual artists teaming up with the anti racist ecologists teaming up with the gay retail workers. What could we do? As Diane de Prima wrote, no one way works, it will take all of us shoving it the thing from all sides to bring it down. Thank you for joining us for Hoorf Season One. We hope to see you back here in the fall for season two. Thank you for joining us on this episode of Hoorf. To view the complete show notes and all the links mentioned in today's episode, or to get a full transcript of that episode. Visit [Hoorf podcast.com](http://Hoorfpodcast.com) that's H O O R F podcast.com. Before you go make sure you subscribe to the podcast so you can receive new episodes right when they're released. And if you're enjoying our podcast, I'd love to have you leave us a review in Apple podcasts. Reviews are one of the major ways that Apple ranks their podcasts. So even though it only takes you a few seconds, it really does make a difference for us. Become a patron for \$3 a month you can support the creation of this podcast, pay my editor and join a community of fellow caregivers out here just doing our best. Thank you again for joining me, Elle Billing, in this episode of Hoorf. Until next time, be excellent to each other. Hoorf is hosted by Elle Billing at [elleandwink](http://elleandwink.com) audio editing by Ricki Cummings at [rickiep00h](http://rickiep00h.com) music composed by Ricki Cummings. Hoorf is a production of Elle & Wink Art Studio all rights reserved. Hoorf Podcast can be found on social media channels at Hoorf podcast at H O O R F podcast.