

Project Sleep Narcolepsy Nerd Alert
Narcolepsy Goes to Hollywood (Season 1, Episode 6)
Transcribed by Mirela Starlight

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Al Jean is a screen writer and executive producer for The Simpsons, working with the show for more than 30 years and receiving 9 Emmy Awards for his work on the show. Al graduated from Harvard University and has been writing professionally since the 1980s.

Anna Marr is the co-founder of BlueLaces Theatre, an actor, writer and comedian living with narcolepsy and creator of the short film Walking Through Peanut Butter. Anna is also a Rising Voices of Narcolepsy advocate.

In today's episode, Julie talks with The Simpsons show runner Al Jean about an episode of the TV show where Homer was diagnosed with narcolepsy and how it is portrayed on the episode, as well as why it is important for media portrayals to include input from people who are living with the conditions being portrayed. Julie and Anna Marr also discuss other Hollywood depictions of narcolepsy and talk about Anna's short film about comedy and narcolepsy, "Walking Through Peanut Butter".

The Narcolepsy Nerd Alert series invites listeners to dive deeper into specific topics relevant to living with Narcolepsy. This is a written transcription of the podcast "Narcolepsy Goes to Hollywood" (Season 1, Episode 6) from Project Sleep.

Project Sleep is a 501(c)3 Nonprofit Organization, dedicated to raising awareness and advocating for sleep health, sleep equity and sleep disorders.

All guests and speakers express their own opinions. While medical diagnoses and treatment options are discussed for educational purposes, this information should not be taken as medical advice. Each person's experience is so unique, which is why it's so important to always consult your own medical team when making decisions about your own health.

Julie in intro: Today I'm thrilled to talk about one of my favorite topics— Hollywood's portrayals of narcolepsy. In this episode I'm joined by Al Jean, the executive producer and head writer for The Simpsons, who has been working on the show for over 32 years. It was such an honor to talk with Al Jean about the development and portrayal of narcolepsy on Season 27, Episode 1 of The Simpsons, when Homer Simpson is diagnosed with narcolepsy. I'm also joined today by Anna Marr, a Los Angeles based actor and writer. Anna developed a dark comedy short film called Walking Through Peanut Butter based on her experience navigating New York's comedy scene with narcolepsy. She's also a Rising Voices of Narcolepsy advocate.

Julie: Hello everybody! I'm Julie Flygare, I'm the President and CEO of Project Sleep and I am here in Los Angeles. And I'm very excited that we have a few guests from Los Angeles today. I reached out to Al Jean, the executive producer of the Simpsons, on Twitter— just as a long shot— just seeing if we could get him to join us. Al has received 9 Emmy Awards, is that—?

Al: It's true.

Julie: Wow. And a Peabody Award, for his work on The Simpsons and so we're just so excited and grateful for him joining us today to talk about the narcolepsy episode which— we just can't wait to get into. And Anna is an L.A. based actor, writer and a voice over artist originally from Ohio. So. These are our two amazing guests— and we're going to go ahead and start with The Simpsons as we said, and this episode from 2015, "Every Man's Dream". Then we will talk more about other portrayals of narcolepsy and looking ahead to the future.

Julie: I'll just maybe read this description that was what we first learned about the episode a few months in advance as it was going to be a premier episode from this description that Al Jean had given in an interview, I think, with Variety. It's discovered after all the years, Homer has narcolepsy, and it's an incredible strain on his marriage. Homer and Marge legally separate and Homer falls in love with his pharmacist, who's voice is Lena Dunham.

Julie: So, Al— I'm just so, so, so super curious, how— the idea came, to do this episode.

Al: Well, you know, well we wanted— after 700 episodes it's hard for us to do things we haven't done before. And we wanted this image where you see this thing that's shocking but it actually, it didn't happen in real life. It's a dream. One of the other executive producers suggested narcolepsy— and we researched it and we, you know, had Homer taking the proper medication — I admit I think we didn't research it quite enough, actually. And talk about what it really is and how serious it is. Thankfully, I had mentioned ahead of the broadcast that we were doing this topic and Julie tweeted me, and said, you know I hope you're not just covering it like any other Hollywood sitcom. [laughing] I said well, what would I do to avoid that? And she gave a suggestion which was you know, really well taken, which was— it is a strain, you know— of course. But with our show Marge is always in the right, so we had Marge less emphatic than she should've been— for this condition. And we wrote that, so— You know, we always just tend to blame Homer for everything. Of course you can't blame someone for this. And that's what we changed, and that made it into the final show and I'm really happy that it did.

Julie: Yeah! Well it's so interesting because I think there are some parts that are— that really do resonate [laughing] with the, with the true experience, so. Right in the beginning when he's being diagnosed in the initial scene, Marge pulls up, you know some pictures from past vacations, you know of Homer sleeping, like, "Oh jeez, this isn't surprising," and here's he's sleeping in all these different— vacation photos, and— I watched this with one of my good friends who has idiopathic hypersomnia, which is very similar to narcolepsy and she's like, "Oh my god, we've done that!" We've gone through her pictures and looked at all of like, all of these pictures of her sleeping. So I'm just, I'm always curious to wonder if there was anyone that knew it more intimately, because that— in particular, was something that stood out.

Al: That being who, a couple people close to the staff have narcolepsy and you know, we did obviously talk to them. So— You know, that was part of the process. The difficult balancing act always is, for anything as serious as narcolepsy if you're making it a comedy topic like, how you make it funny, and then on the other hand not take it— less seriously than you should. So, it's always tricky, but— On the other hand, I hope— that you know, it's my hope, but— That by covering it in a show that actually kids would watch— and you know, that influences people in some way— would encourage people to take the topic more seriously.

Julie: Yeah. And I love this scene that you know you said that you added about Homer saying you know, "Narcolepsy's serious, Marge!" And she says, "Maybe you're not taking it seriously enough." And I think that is a beautiful— that was a beautiful message, so.

Al: Yeah, that's Homer, I mean, you know— [laughing] it's like, everything he does, he doesn't do the right way, but— Yeah, as I said it's balancing the dynamic of the characters with the actual, facts of narcolepsy.

Julie: Right, I mean I thought— like, his part about using narcolepsy card as an excuse for not being able to do things, “narcolepsy! ...narcolepsy!”

Anna: I liked that part. [laughing]

Julie: Yeah, yeah. [laughing]

Al: I'd like, too— I would, [laughing] you know— [laughing] I mean not that I'd want to have it, but I would love to be like him, just to use any excuse just to get through something—

Julie: Yeah. Even like his really mean boss— I'm sorry, I don't know the characters as well as probably anyone else that's ever interviewed you, but— Boss had to be like, “Oops, sorry! Narcolepsy,” you know— [laughs] it's like—

Al: I wish there was such a card that could— and you all had one— [laughs] cause— [laughing] yes.

Julie: I know. And so, then— with the— ending, which is kind of like this interesting twist of dream within a dream within a dream— I just was curious, so it sounds like that was probably maybe the start of, like what got you guys in to it. And it's, it is interesting because dreaming is such a huge part of narcolepsy and not knowing your dreams from reality— and those boundaries that they get so confused. And so I thought that was— really— creative in a way, because of narcolepsy, but maybe that wasn't— necessarily meant to be sort of like, part of the narcolepsy theme? And I didn't see any comments online that seemed to— think that that was part of it. From the public, you know. That they wouldn't probably understand that, but it seemed to me that that was, very in line with narcolepsy.

Al: What attracted to me to uh, to the story at the beginning was, it's a trope to say something was a dream. You know, people hate saying an episode didn't happen, but I thought what would be interesting is if it was several dreams intertwined and you didn't know what the reality was. Not exactly narcolepsy, but— you know, just sort of the way life is sometimes, like you don't know— what's really going on in the past few years, it seemed like. Like, what is reality to me? And the only thing I regret, is I— the last shot should've been— Homer and Marge asleep holding hands in bed. After we aired I said, “Oh! That would've been the way to end it—” that through this they're together and they're holding hands and they're both asleep, but I didn't think to do that. I did it in a later episode.

Julie: Oh, okay. Well, I thought it was pretty creative, and I thought— you know, having Lena Dunham as the pharmacist was really interesting and hearing the name of— you know, that she lists out— the different medications. I was curious about some of those really specific references that— and the mention of hypocretin. Those are so specific and so people with narcolepsy will really know those. But, is it just—

Al: Yeah we did research and, and— the writer, Stuart Burns, was really good about trying to find out treatments for it. And you know, it's funny because— ironically, what our show— 30 years ago, when you researched something— it was impossible. Like, you had to like, go to a library and— read about—

Julie: Yeah.

Al: And now you can google everything, so there's really no excuse for not knowing— at this point [laughing] and you know, you should be googling everything. And finding exactly what it is you're talking about.

Julie: Yeah. Well, I had one more question for you— For people that are looking to get into writing or comedy that have narcolepsy, would you have any advice for them? And I imagine that the— landscape has changed a lot, over the last 30-some years, but. For some of our young viewers that are interested in creative roles, do you have any advice?

Al: I think— You know, having a story that's— that's— fascinating, although, you know, difficult — is always really cool. And I think that the writing advice is the same of course, that I would give to anybody, which is— make a show which you think is really good and write a sample episode of it— write something that you think is really funny, not something you think that other people will buy because it's— you know, hacky. That's the way I got in, you know, initially a while ago and that's the way every writer I know has gotten on The Simpsons is by writing something, like a Bob's Burgers or something— that really catches our attention, and— and we think is clever and funny— and you know it's just, if you're a writer, write.

Julie: I love that. I actually, I lied. I have one more question [laughing] as well. So maybe I shouldn't preface this as last question. Have you felt that people's sense of humor has changed? You've been with the show for so long, and I even, I went back to watch— I have a love for terrible movies so I watched Bring it On again recently and uh, I think that's from like around 1999—

[Al laughing]

Julie: —and— some of the humor you were like, oh my god, like this is really, uh— mmm— not appropriate anymore. You know, people don't say those things. And so I was just kind of curious from your perspective, like, do you feel like, over time— people's sense of humor has changed? And—

Al: Oh, absolutely. Well, I mean, it's pretty well known— in a leading character who— that we thought at that time, at least— that the character we created— was going to be a diverse addition to the characters on the show— we didn't cast him with an appropriate voice actor then, which I would obviously now if we were doing it— so it's sort of like, back pedaling 30 years ago, you go, oh we're— you know— people have been bullied over it, which I regret— nobody should be bullied over anything. You know, I think that— there's no question standards change, and I find myself doing that too except that I kind of go— like, a movie I think is great, The Philadelphia Story opens with Carry Grant hitting Katharine Hepburn on stage— which is horrible— but— I still think the movie is worth watching, even though I don't like that scene. And I think— There's a point where you have to look at intent, or look at the entire picture, before— saying you know, everything should just be like considered un-viewable. Or it could be viewed with a warning, like Gone With the Wind.

Julie: Yeah. Right. But even for new— for creating new content— it just probably seems that people's sense of humor, does— has, probably changed over the years.

Al: Yeah. Sexual jokes are much— more permitted— you know, people really talk about— and obviously, things that, you know, people would make jokes about, a person's sexuality, 30 years ago. Now, you know, we did a show about gay marriage, advocating that it should be legal, and— that seemed, like, controversial in 2005 and it's insane that it's controversial. Like,

nobody says that now. So, it's really weird when you're on 30 years. You just have to learn— to try to listen to people and try to see what people want now, and— I think whatever we've done, we just can't afford to rest on any laurels— we have to you know, be— relevant to the world today.

Julie: Well I think that's really awesome and I just want to thank you so much— you know, coming from such a different perspective where I just— you know, often feel very defensive in these positions— and I just really thank you so much for engaging with the community. It's just, it's just so nice, we've had a lot of times where people just will never write back. Just never even acknowledge, um—

Al: Oh, I completely appreciated your help. I— it really made me— so happy that you felt that it improved the episode, and uh— any more or last questions?

Julie: I don't think so— I know you have to run to do something else, so we're just so grateful for you being willing to join us and it's so nice to meet you and thank you in person.

Al: Thank you for inviting me.

Julie: Of course! Bye for now.

Anna: Thank you!

Al: Bye.

Julie: I feel like every day, literally— there seem to be new mentions of narcolepsy that are happening. Anna seems to be finding these— often these new—

Anna: I watch a lot of television, and— I would say— there will be months on end where the only conversation between Julie and I in text threads is just like, "Did you see this? Did you see this? Did you see this?" From me, and yeah— I do call them out on— not, I wouldn't say call them out because I don't— feel that way, I feel like it's just— calling them in, as the phrase is, in terms of us tweeting about it. And I'll tweet at the show and— Yeah, like you said nobody ever answers [laughs] or recognizes it, so— the fact that Al Jean did any of that really goes to show what kind of a show runner he is. 'Cause that's the show runners job is to respond to criticism and be the face of the show, and— I mean obviously he's been doing it for so long for a reason.

Julie: Yeah. I think a lot of old series are back on Netflix and stuff. So, um, I went through the West Wing— which says— well actually it does have one mention of narcolepsy but obviously their portrayal of multiple sclerosis with the president— so I think it's interesting and I think Gilmore Girls is maybe back on Netflix and so— people have been sending— some examples from that, so.

Anna: If any show's had a long run— it'll be in there. It doesn't matter what year it was made.

Julie: Right. So, I'm just going to start with this question— do TV and film portrayals of narcolepsy matter? You might guess, by us having a whole broadcast about it, that we do think it matters. So we're going to probably try to convince you, too. That it matters. So I love this quote, "Culture change precedes policy change." And I have always believed this— it seemed intuitive to me, back after I was diagnosed, that there weren't a lot of— what I had seen in— in movies, just— weren't, what I had experienced. And so that's why I wanted to write my book, to try and open peoples hearts and minds to the real condition. But also because of policy that

I had learned in law school that I felt that legal shifts often change after society. So if you got people in society to understand and care about something first then you could get them to be more open to policy change. So, you know, as you think about Project Sleep and often we're talking about policy and trying to change policy. At the same time culture and society is still so important to us too because, you know, those things go often hand in hand and sometimes culture precedes policy change.

Julie: So I just want to start with a quick story that, you know narcolepsy in 1999— most people if you ask them, you know, what's the big thing that happened for narcolepsy in 1999, would point to the discovery of hypocretin— the neurotransmitters that help to regulate the boundaries between sleep and waking— that were first discovered to be connected to dogs in narcolepsy and then eventually to humans in narcolepsy. And for narcolepsy type one it's this loss of hypocretin that brings on the onset of the symptoms and— so, narcolepsy was on the cover of *Cell* magazine— but there's something else big that happened in 1999. To narcolepsy, that most people in the community don't talk about as— quite as much. And that is— [laughs] the esteemed Deuce Bigalow Male Gigolo! So, how could I say that a movie that literally most people think of is, kind of like— I don't know how to describe it— kind of like a really bad movie, it's almost so bad it's good I gue— I don't know. I actually have not, I must admit, I have not watched it— in full.

Anna: I have not either, I've only seen— [laughs] the narcolepsy scenes. It came out when I was 8, so I was not watching this type of film back then. [laughs]

Julie: Yes. I've seen the narcolepsy scenes and read enough about it. So I do believe those still, even though I've never even seen this movie. And— it's not even a good claimed movie, I still to this day believe that that movie has probably had a bigger influence on my day-to-day life, living with narcolepsy, than the discovery of hypocretin. I hope that changes— I think as new hypocretin treatments come out, maybe that will change. Um, but I do want to underscore that culture and movies really do play a big impact. And so, often a lot of TV shows also mention narcolepsy, or make narcolepsy jokes— I've stuck this with just character portrayals— depictions. Where they actually have a character that, you know, is believed to have narcolepsy. And so, also— I didn't include any reality TV— or people that are actually living with narcolepsy on reality TV— I kept that out. This is just character portrayals.

Julie: So, there's a lot on here. I just want to highlight a little bit— 1999 of Deuce Bigalow. And then we have Moulin Rouge in 2001 and Rat Race in 2001. So I'd say that those three movies are kind of a big— those were— kind of all major movies.

Anna: The most commonly referenced.

Julie: Yes. Kind of had a little trifecta [laughs] for those couple years. And of course, the— My Private Idaho was another big one back from 1991. Kind of an obscure movie. And then more recently of course we just have a lot of TV, and then— we'll talk about this a little bit later— Ode to Joy, and The Mysterious Benedict Society, which is a book series that's now a TV series on Disney.

Anna: I am not aware of this. I was kind of aware of the book series— I hope that they have somebody with narcolepsy on that writing staff.

Julie: One would hope, but— I mean, I'm just hoping the world is changing. I just want to point out, too— although there are a ton of portrayals of narcolepsy as we've just shown you, there is actually no research yet in this area. And that's too bad. And I hope that, maybe we can inspire someone that's— watching, to start doing some research. There is wonderful research

in a lot of other areas of TV and film portrayals. And this includes epilepsy, there's quite a few papers about epilepsy portrayals, in TV and film. Along with that, seizure first aid— which is kind of like— basically like, if a seizure happens— on the shows like ER and Grey's Anatomy, how do— the medical professionals on the show respond to the seizure. And multiple sclerosis, turrets syndrome— there's quite a few papers. Autism, cancer, HIV/AIDs— CPR and coma, and how people in our public, like— perceive these things, based on TV and film.

Julie: And of course it's not just disease communities. There are a lot of other areas where people are watching portrayals. I believe it's— is it, GLAD that looks at a lot of perceptions of LGBTQ TV portrayals, like they like, almost every year I believe, come out with a report [laughs] showing how the portrayals have been. Which is really wonderful— to keep track of, and to continue to— hopefully, be in contact with Hollywood and, influencing the entertainment industry. When these different research projects analyze the portrayals, there's a lot of different aspects to— talk about. So, it's how the symptoms are portrayed— for these conditions. Some people focus also on how are people's interactions with doctors— and treatments. And often, treatment's not really mentioned at all— and interactions with doctors are seen as very negative. Which is, you know, can be true to experience, but sometimes also— maybe makes people even more distrusting of doctors, possibly.

Julie: Also, how are these conditions impacting people's social lives, their work lives— the character's— social, work and school. So that's another thing that people looking at. The characters' disclosure, and other characters reactions. For example, in West Wing, when the president, you know he keeps his multiple sclerosis private for— many years, and it's kind of like, this hidden secret, right. And then it comes through that he has this, and— so you see other characters react to that. And the characters were very upset. Mostly that it had been hidden information, you know. But some of those reactions are really interesting to look at. Some of these analyses look at characters, like their nature or likability. Which are things like whether the character is considered sympathetic, whether they're like, a violent or dangerous character. In epilepsy a lot of the characters with epilepsy are kind of these violent, dangerous, strange people, sort of. Which doesn't often make you think, probably— great things about people with epilepsy, if you're— the characters you see are kind of like, dangerous you know, seeming.

Julie: And so, that's one way to look at it and also the characters' complexity which is— what else you know about the character. None of us are just people with narcolepsy— we have many different facets, like Anna's love of weird ice cream flavors, which— totally appreciate. [laughing]

Anna: That's the only other thing about me. [laughing]

Julie: No— [laughing] well, maybe a cute dog named Ralph. [Laughing]

Anna laughing

Julie: But you know, there's just— everyone is, has other roles in life of being a family member, a friend and whatever, there's so much more to everyone and so. Often when a character is distilled down to just a disease or just one aspect of their identity, it can almost make them a little bit less— someone that you can relate to. Because, if you don't share that same identity with them. But if you learn that they also like weird ice cream flavors, and you like weird ice cream, then you're like, oh, that person's like me. 'Cause we both like ice cream. Maybe I don't have narcolepsy— so it's kind of interesting about characters complexity, is another thing to look at. And so just from this research I just wanted to point out some of the really cool themes that just come across I think are important, when we talk about narcolepsy. That movies and

TV are a visual art form— there's no way around it. You have to be more creative to think about, how could you make a hypnagogic hallucination come to life on screen. I don't think it's impossible— I think it's very possible, but if you're not as familiar with these conditions, you probably wouldn't be able to creatively think of how to do that. So very few of these depictions of other diseases, too, kind of try to take the inside the person's perspective, maybe. There was like, one seizure where they took you inside the person's head, before they lose consciousness— to kind of give you an idea of what they're experiencing and I think that could be something that's really powerful, seeing behind the eyes of a person with narcolepsy.

Julie: So you know it's our human nature to simplify things. That's just something we should always keep in mind that, our capacity to understand complexity about other condition is somewhat limited if you think about what you even know about other conditions. Portrayals often reference other portrayals. When— entertainment is just talking to other entertainment and just looking at other media— they might base like, in the epilepsy they said that some seizures looked like they were based on other depictions of seizures. Never like, going back to source material of real seizures. So there's also like, you can examine these for accuracy. Whether these are, you know, the symptoms are displayed accurately. But there's also self comparison, which is that people that have the conditions, like us— compare ourselves— to what we see. And how do we— you know, evaluate our experience, based on— what, you know, we see in these characters.

Julie: And that there's no single you know, accurate portrayal because everyone's experiences are different, with different conditions. Remember there's always some of this tension, between realistic and serious portrayals— and positive portrayals. And so, the wonderful paper about West Wing and the president being diagnosed with multiple sclerosis is that— some people with multiple sclerosis said, I don't know how he could be president, you know— his schedule and everything, it's unrealistic. And then other people who have multiple sclerosis said, I love seeing that a president can have multiple sclerosis. Just remember that that's some of the tension that we might see, is that we might see that some people would prefer to see portrayals that show it realistically and seriously and others might like to see— positive portrayals, and also in peoples responses— so how people respond, the president having multiple sclerosis— some people do want to see that there was misunderstanding, and that people— his friends weren't getting it.

Anna: Right, right.

Julie: Some people loved that 'cause they're like, that's actually true to life! You know, that social experience was true to life. Other people are upset by that 'cause they'd rather see the friends and family in the characters' show, and the characters' role— respond well. Because it would show other people in reality how to model behavior from the show.

Anna: Well and it's also like, the tension that we experience in real life as well. Especially in terms of like, portraying myself coming out in to the world as a person with narcolepsy, publicly on social media for example. Or even pitching myself to— in rooms, in meetings. And it's like, I want you to know that I have narcolepsy and that it's serious, and that it impacts my life— but I also don't want you to think that I can't work. I want you to know what my real experience is, but I don't want you to justify me that way. So it's— it's a tough balance.

Julie: It really is, that was very well said. [laughs] I just want to read a few of these quotes from these papers. The epilepsy organization, the major one in America has like, three things to do and three things not to do. There are very clear guidelines of things you should not do and things you should do— when someone's having a seizure. And so this amazing paper that

goes through all of these examples of, often medical professionals' characters, responding to someone having a seizure in a TV show— they said the first aid management of seizures performed by actors portraying healthcare professionals, was inappropriate— in nearly half of all cases. And just about why this is important, you know, for most people a cinematic representation of epilepsy may be the only seizure they'll ever see. This will inevitably shape their attitude toward this disorder. I think that's probably really true for narcolepsy, because— the sleepiness of narcolepsy is just, isn't so— maybe they've seen someone fall asleep but often in social situations we kind of rally, right?

Anna: I would say hands-down almost all of my friends would say that they don't see how it impacts my life. Which, you can take as a good or a not good thing.

Julie: Right. And so if all they see are these portrayals in movies— that can be their only visual references sometimes, to what we have. This is also kind of really— as treatments for epilepsy continue to improve, the number of people who have actually seen seizures may continue to decline. At the same time the public's images of seizures will increasingly be informed by portrayals on TV and movie— that bear little resemblance to epileptic seizures. As you think about narcolepsy too I think there's somewhat of a similar storyline, that as our treatments do get better— there's going to be a little less likelihood that you're going to see people having a cataplexy attack in public. Or, you know, an episode of sleepiness. Hopefully, you know— as treatments improve. But I think that's just kind of a really interesting thing to think about, too.

Julie: One last one. The entertainment narratives do more than educate or misinform people about diseases. Depictions such as the West Wing's portrayal of MS play a role in the social construction of illness and this process may influence perceptions of self and the experience of social interactions for people with chronic illnesses in a variety of complex ways. So, just again pointing out how there's a lot of self reflection or self comparison. I've heard people say this so many times— my sleepiness isn't like you've seen in the movies. You know, I got diagnosed and I couldn't think I had narcolepsy because— I didn't recognize my experience— based on what I'd seen in movies. However, when I have tried to point this out, sometimes, and saying that I think the movies are showing— sort of like a myth, or not a real version, that this isn't really happening, I do seem to get push back from our own community to say, no I have fallen asleep while standing. So the only way I can figure out how to put these two kind of things together is that, possibly at an extreme version— and a severe experience, that people can be — you know, falling asleep without warning in a public situation. Probably not like this because I don't think you could still be standing, you'd have to be like leaning against something, probably.

Anna: I still think that there's a variety of experience. I wouldn't— I don't know. I don't know. I've heard people say—

Julie: But this is certainly not the most typical thing that—

Anna: No! [laughing]

Julie: —a doctor would be looking for, because if doctors were looking for you to stand up— to be falling asleep while standing in the middle of a—

Anna: Right

Julie: —conversation— you wouldn't get most people diagnosed. Mine was very, very invisible, but also I think I also wanted to push it out of my head. So I might've repressed—

Anna: Yeah.

Julie: —that it was.

Anna: Totally.

Julie: And— the only other thing I can think about these depictions, too, is that it's a lot of this misunderstanding of being in the middle of a conversation and maybe like, laughing— and then collapsing over and that that could actually be cataplexy—

Anna: Yeah.

Julie: —that people are somewhat showing, as opposed to sleepiness.

Anna: Yeah— I— I think it's really difficult, to— communicate it. And I'm not giving an excuse, by no means. I just think that people tend to take the easy route out.

Julie: Right. Totally. So just to really quick look at— the basic, of what symptoms do you even see in these— Deuce Bigalow, she is falling asleep in the middle of sentences. Rat Race, he's falling asleep standing. Moulin Rouge, falling asleep in the middle of activities. Ode to Joy is just pretty much, is just cataplexy— narcolepsy is mentioned by name only twice in the movie, but barely, and it's just focused on cataplexy and so the way that they simplified is almost to leave the rest of narcolepsy out. They put the definition on the screen once at the beginning but they probably define cataplexy six or seven times throughout it, just to make sure you get it, because— it is kind of complex.

Julie: Just to remind you guys, that there are five major symptoms, generally, of narcolepsy— excessive daytime sleepiness. And cataplexy— and then we have of course hypnagogic hallucinations and sleep paralysis and then disrupted nighttime sleep, so. If you look at the variety of symptoms that people experience, with narcolepsy versus what's being portrayed, it's not representative of the variety of symptoms.

Julie: I just, a few other really quick kind of interesting theories or things I wanted to bring to your attention from the research world is this concept of disparagement humor. And it's basically that a non-serious humor mindset suspends the usual like, serious critical mindset— and so that allows you to, possibly, have different standards for what's allowable you know to say somewhat. So if you were to say something, you said a joke to me and the recipient, I'm receiving the joke— if I reject what you've said as a normative standard, so— if you say something that I don't think is okay— the source, the person that said the joke, can just say— oh, it was just a joke. Not serious, I didn't really mean it. And so this can— disparagement humor can justify a wider range of negative responses, towards members of a targeted group — and in the context of disparagement humor, discriminatory behavior can be easily rationalized as falling in with the boundaries of socially acceptable. So, humor is not bad. Humor is also medicine— there are wonderful things about humor, but sometimes humor is uhh- inside, outside group— and sometimes can be used to— be a little bit more discriminatory towards marginalized populations.

Julie: Just to look at narcolepsy stigma and understand that stigma is at many levels, and some people have, you know— media and entertainment are sort of, like— create the culture that leads to law and policies. And all levels of stigma are important— which is, stigma is a concept of othering people— you know, that they're separate from us— and then sometimes lesser than us. Just some context for that, and— you can look up more about stigma— and

you know your story really matters and can help to reduce stigma, and— you can foster empathy, and storytelling is such a powerful vehicle for doing good, too, so.

Julie: And so what can we do? We have some reactive efforts, I'm just going to quickly go through what we worked with, on— for *Ode to Joy*, which is a movie that came out in 2019, and then— *Walking Through Peanut Butter*. Which is Anna's amazing project! So just really quickly there was This American Life segment, so this is, as Anna said it's based on a true experience of a man, Matt Frerking, who I've actually met— a wonderful scientist— that the episode of This American Life on NPR was based on his experience, so— real man! And he does talk about having narcolepsy and cataplexy— and how his sleepiness affects his relationship and his cataplexy, he had very severe cataplexy— affected his relationship. And so, from that NPR segment— actually a few movies were inspired by that. A short movie called *Cataplexy*, which is on Amazon Prime. And then also this movie and the announcement came out just the next year— that a *Modern Family* director and a Colbert writer were teaming up to make a comedy called *Joy*, that was based on this NPR segment. And basically that you know, the thought of— joy, as a trigger— that can be problematic in a relationship.

Julie: And, so— I had started reaching out as soon as I heard about it, in 2012— reaching out to people who knew people, that— were involved with this, and did speak to them, they said that they would get in touch with me later, when they were closer. I offered to do free consulting. However I could help. And the movie kind of shifted around from a few different production houses, I believe, and so it came back on my radar in early 2018. I saw it had a new home, I guess— in Hollywood. And I started looking for a connection— gathering advice and research examples, which is why I got into all the research of, how do other communities deal with this kind of stuff. And I realized at that point it had already been filmed. So they'd already done the filming in 2017. I found that via Instagram. So, it had been filmed, but what else could be done? Right. Eventually, I tried many different things. I made contact in early 2019, and— this was by guessing email addresses!

Anna: [laughing] Oh, my gosh.

Julie: Eventually, how I made contact— my first guess was wrong. My second guess was right. And the person wrote back very, very quickly. Which was nice. But, said— they would kind of be in touch later, I was like how 'bout now?— and then— the film was going to be in the Phoenix Film Festival and we have two board members now in the Phoenix area so I went, flew to Phoenix to see it there— 'cause this was one of the first places you could actually see it. And so I watched it there. In a packed audience, for the first time. And the narcolepsy community really, you know more broadly found out about all this in that same time period 'cause the movie was starting to be reviewed as people were watching it in film festivals. So people with narcolepsy started to get really concerned about this, what was happening— there were some delays in the production and then on— I'll never forget, July 8th, finding out— alright, it's a go. It's going to be released with IFC Films. And so, it took about a week to get a call with IFC Films. And then another week, I was able to actually speak to the director, and the movie came out August 9th, so it was just— exactly a month from when we found out, and then it was going to be opening. And this was the timeline of the opportunity to try and work with them. At such a late stage. And I have to say, very thankful that it was a woman with idiopathic hypersomnia who actually worked in the film industry who helped me make the connection to the director. And I asked him to do a PSA together, a public service announcement about narcolepsy, for social media, to create resource information for the closing credits— that basically like, if anything that you've seen in this movie, seems similar to an experience of you or a loved one, please find a sleep specialist— so it wasn't even about Project Sleep, it was just about— getting people to see a sleep specialist, because none of that behavior is— well, he does have a sleep specialist in the movie, but, still— just to like, reinforce

that this is a real condition, and— to do media training for the stars and the director— and to do a discussion guide. And have the ability to use the poster on the cover. So we were able to do most of that except for the credits. They said it was too late. You know, those had been locked for many months. Which is disappointing because I had been trying for many months. But we were able to do the other things, which is really great. In addition we did some more of our own things, I made like a, cheat sheet for, um— sleep doctors, so they could understand about the film, like what they needed to know was depicted, so they could talk to patents about it. And publish a review and put up stuff on our website and this discussion guide. And we did do the PSA. I just really want to quickly mention that I was talking about this with my best friend, and she has a friend that works at Netflix, and that friend said that they thought never— would the director do this with me. That this would be unheard of, to do something like a PSA— with an organization like mine. Just really interesting to see that even still in 2019 that — someone else in the industry would say, never, ever would someone do a PSA with an organization— when their whole movie is based about a condition that we live with.

Julie: And— now— we get to talk about *Walking Through Peanut Butter*, Anna's amazing project.

Anna: So yeah, so a very basic synopsis is— 22 year old workaholic Jessie moves to the city that never sleeps to be a stand up comic. She also has narcolepsy, a chronic sleep disorder even she knows little about. In this short pilot, Jessie discovers a new symptom— sudden muscle weakness, triggered by strong emotions. Her trigger? Laughter.

Anna: So, in general, it's about a stubborn, over achieving new college grad, Jessie, who dives head first into the comedy world of the city that never sleeps, which is— the perfect place to— adapt to her newly diagnosed narcolepsy. And, I had originally wanted to write a full 22 minute pilot— comedy pilot— and you know, resources— I was living in New York City at the time, I'm now in L.A. and— I'm a writer and an actor, so— I wanted to have something written and I also wanted to have footage. It's really important, as an actor to, to make your own work, so. I ended up shortening it down, to— more of like a, digital content length. Which is great because when I produced the film, essentially it is a 10 minute short film. So, it's really easy to just slip into film festivals that way. But it is a dark comedy— based on my own experiences navigating the New York City comedy world— while living with narcolepsy, and— the wonderful irony and conflict of being a stand up comedian who's cataplexy trigger is the punch line of her jokes, that aside— Hollywood loves a story about— a really nice person, who unravels, into— a mess. And we've gotten into a few festivals, which have or have not happened— [laughing] given the state of the— pandemic. And yeah, we won an award. Our first award was at the Independent Shorts Award, here in L.A.— for best women's short.

Julie: How do those awards play into the process? I mean it seems like a very, I know it's very common place to you, but, I'm a little outside of that world, and so, can you explain to us sort of how this process— happens?

Anna: Yeah! I mean, so— it's one of the many ways that you can gain— recognition and exposure— just to get your story on the map and to the eyes of various gatekeepers and players in the industry. You know, especially for me as somebody who had just moved to Los Angeles— from New York City, and is still making connections here— submitting your project whether it's a script or a film or a web series— to film festivals or script festivals is a— is a great way. To, to make those connections, and— it can open doors and also help you— we've gotten you know, some good film festival recognition. It can help you pitch yourself to, various — industry people.

Julie: I think that there are a lot of really interesting— and that's why I wish Ode to Joy had included some more experts, or— consultants, from the narcolepsy patient community, because— I think there were opportunities there to see a character develop— one of my favorite quotes is, “We’re always evolving,” and some of that evolution is what draws you to different characters from TVs and movie— is the shared humanity of evolving, right.

Anna: Yeah. I think that so many shows, especially with young adults— I think that there’s a lot of shows about identity, right? And like, it doesn’t matter how specific the story is, in fact in comedy, they tell you that the more specific— the funnier. If you’re writing, say for example like the fact that— in that Simpsons episode, they invol— they used the word hypocretin, like literally how much more specific could you get? Like you said, only a small percentage of people watching that episode knew what that word meant— but it was funny probably to hear that— a funnier sounding word. But when you list out specifics, it tends to be more universal, than if you just try to generalize. Because people can find their way through a really nuanced, specific, niche story more than they can through something that's trying to be, just like, appealing to everybody.

Anna: Something that's really exciting to me, that I've spoken to you about before, Julie, in terms of pitching this show— because, it can be hard— you know, you’re not sure if people are going to want to hear about the specifics of narcolepsy, or what I just talked about, and you— you need to have sort of a different angle in terms of theme and message, and. I think that part of the younger generations right now who are simultaneously members of the burnout generation, and also constantly the targets of the self care industry, who better to talk about that than a person with narcolepsy or idiopathic hypersomnia, or a sleep disorder in general.

Julie: I want to know if you have any advice for people that are interested in telling their story through comedy or writing— similar to what I asked AI.

Anna: Yeah! I think— for me, my vehicle is— is humor and comedy, so I’m going to stick with that lane. Just going to echo the specificity and sticking with your own experience. I think it's really easy to get lost in— is this going to be representative of all people with narcolepsy? What about people with severe cataplexy? There’s no such thing as like, one accurate portrayal. To stick to your own perspective, because that's all you can speak for with your own story, while also being responsible. And respectful of other people’s experiences and not making general, over generalizations. Find other people who celebrate your story. If you are in a community of people that don’t want to hear about it, if you’re in a community of people that— is not going to accommodate any of your access needs— who aren’t interested in having conversations about ableism, thinking about using more responsible language— you know, it’s okay to— to find a new community. And they’re out there, we’re out there. Find people online who are doing things that— you really relate to, and reach out to them, and— it’s just good to find other like-minded people to support you, so you feel emboldened to— to share.

Julie: One more question, then— how do you manage the process and knowing that you’re making progress and hold yourself, like, accountable over time to— get this done?

Anna: The best piece of advice is to— do your best to not beat yourself up. It’s really tempting, to look at, how much— someone on Instagram has written in a day. If you feel this constant pressure, it’s a structural issue within the industry— and within culture at large.

Julie: Wise words.

Julie: Let’s just go through a few of these additional resources— I think this one we didn’t mention yet, but it's a great one— [RespectAbility](#). They do a lot of great things, but some of

what they do is reaching out to entertainment professionals to promote positive, accurate, diverse and inclusive media portrayals, on TV and in film, both in front of and behind the camera. And they have a very cool summer lab program, for entertainment professionals with disability.

Anna: They had a ton of great content, that they still have online, on their website. They had different stars of different TV shows on, and it was just great to hear from everybody, so. I recommend checking that out.

Julie: Oh, cool. Alright. So that's a great one. And then, ReelAbilities Film Festival— I think that they, last time I saw, it's something like 14 different cities across the country—

Anna: Oh, wow.

Julie: —but they have the largest film fest in the U.S. dedicated to promoting awareness and appreciation of the lives, stories and artistic expression of people with different disabilities. This is just one of my favorite, more general podcast episodes, from the Stanford Social Innovation Review, I think is what the name of that— SSIR, stands for. And it's this "Storytelling and Social Change" episode, and there's a lot of great quotes, but you know, one of them is— "It's about how you create ecosystem that can allow for authentic stories to be told." And they have some really cool people from entertainment, talking about different communities and representations.

Julie: And of course, Rising Voices of Narcolepsy! Our program to foster a new generation of narcolepsy patient advocates, spreading awareness via speaking and writing, while also empowering the participants. So Anna was one of our early— I think you were 2017— were you a first year?

Anna: Indeed.

Julie: Yes! And she was a writer, and the name of her first essay I think was Walking Through Peanut Butter?

Anna: No, it was, um— "Laugh at Me, Not My Narcolepsy".

Julie: Yes. But then it was a line in there where you talked about walking through peanut butter.

Anna: Yes!

Julie: Yes.

Anna: Well thank you everybody, it really truly means the world. I would not have been able to finish the project without— Julie's help, and— and, her wider network and— all of the incredible people of narcolepsy who really came out and— were the predominant, like hands-down, largest majority of the supporters for our crowd funding campaign, and I truly cannot thank you enough.

Julie: Alright guys, thank you for tuning in and being part of this community and we're just hoping to share many more portrayals of narcolepsy that move towards some that resonate more with our experiences. Alright, bye for now!

Anna: Bye!

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