



NARCOLEPSY GOES TO HOLLYWOOD

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WELCOME!

We are so glad you are here. This toolkit is designed for people living with narcolepsy and their loved ones to offer new tools, tips, and perspectives on navigating narcolepsy. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** series.

Narcolepsy Nerd Alert is an educational series diving deeper into specific topics relevant to narcolepsy. Each month, Project Sleep broadcasts a live event via Facebook, hosted by Julie Flygare, JD, Project Sleep's President & CEO.

After each live broadcast, we create a corresponding toolkit (like this one!) to capture our collective knowledge to help others down the road. Quotes featured in speech bubbles throughout the toolkit are from participants who joined us for the live broadcast.

PLEASE NOTE

The **Narcolepsy Nerd Alert** series is intended for educational and awareness purposes and is not a substitute for medical attention. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your sleep doctor or narcolepsy specialist.



NARCOLEPSY GOES TO HOLLYWOOD

Is all awareness *good* awareness?

On May 26, 2021 we hosted the “Narcolepsy goes to Hollywood” live event to discuss portrayals of narcolepsy in TV shows and movies. This toolkit is a compilation of insights shared by featured panelists Al Jean and Anna Marr, host Julie Flygare, and community members from around the world.

- Watch the [Narcolepsy Goes to Hollywood video](#)
- Learn more about the [Narcolepsy Nerd Alert series](#)



WHAT PORTRAYALS OF NARCOLEPSY STAND OUT TO YOU?

HOW DO THESE COMPARE TO YOUR EXPERIENCE?



DO TV AND FILM PORTRAYALS OF NARCOLEPSY MATTER?



MEET OUR GUESTS & HOST

Two special guests joined our host, Julie Flygare, to talk about portrayals of narcolepsy in TV and film.



Al Jean is the Executive Producer and head writer for *The Simpsons*, and has been working on the show for 32 years, 22 of which have been as a showrunner. He has received 9 Emmy Awards for his work on *The Simpsons*. Al attended Harvard University and as a student wrote for the Harvard Lampoon. He was also a writer for *The Tonight Show Starring Johnny Carson*, and the 2003 movie *Elf*.



Anna Marr is an LA-based actor, writer, and voice-over artist originally from Ohio. She is the co-founder of BlueLaces Theater, a nonprofit organization that creates interactive multi-sensory theater for individuals with developmental disabilities. She is currently developing a dark comedy series called "Walking Through Peanut Butter" based on her experience navigating New York's comedy scene with narcolepsy. Anna is also a Rising Voices of Narcolepsy writer who aims to change how the media represents this chronic neurological disorder.



Julie Flygare, JD, currently serves as President & CEO of Project Sleep. She was diagnosed with narcolepsy with cataplexy in 2007 while in law school. Julie is an internationally recognized patient-perspective leader, an accomplished advocate, and the award-winning author of Wide Awake and Dreaming: A Memoir of Narcolepsy.



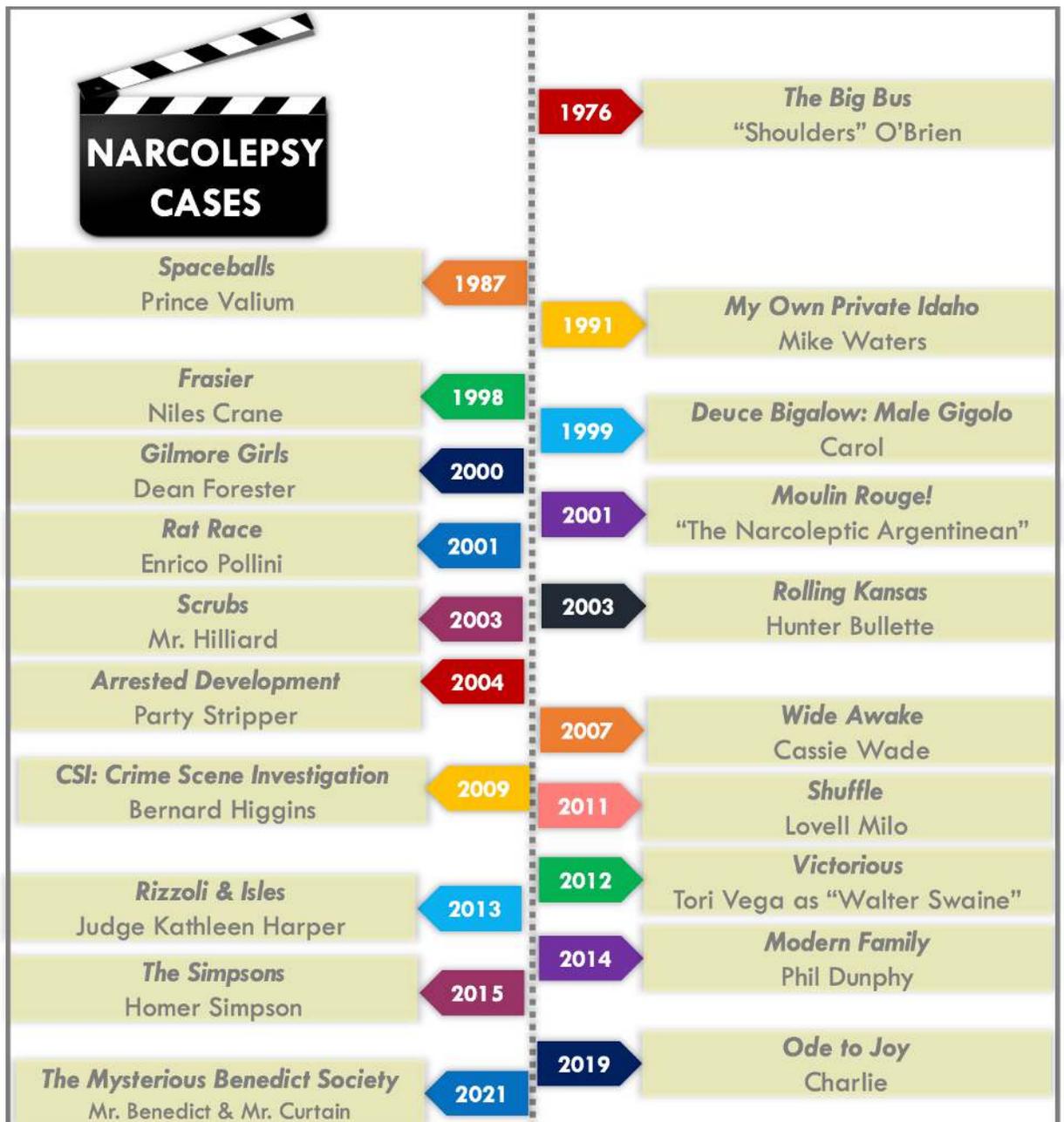
"My sleepiness isn't like the movies."

- MANY PEOPLE WITH NARCOLEPSY



NARCOLEPSY PORTRAYALS IN TV & FILM

Over the years, there have been many character portrayals of people with narcolepsy. If you're familiar with any of these depictions, what have you noticed about them?





DEUCE BIGALOW

Two major developments for narcolepsy occurred in 1999 - the discovery of hypocretin, a key neurotransmitter that helps regulate the boundaries between sleep and waking states, and the release of the movie *Deuce Bigalow, Male Gigolo*, which features a character who has narcolepsy.

"I believe Deuce Bigalow, Male Gigolo, and its impact on what people think narcolepsy looks like, have had a bigger influence on my day-to-day life with narcolepsy than the discovery of hypocretin."

- Julie

"I remember when my doctor said she thought I had narcolepsy, I laughed at her because my first thought was Deuce Bigalow. I was not laughing after my MSLT."

- Gov

"When I was told I had narcolepsy I actually said, 'Narcolepsy? Isn't that people who fall asleep in their soup!!' Oh my! And I was a nurse"

- Sheila

"The portrayal of narcolepsy in Deuce Bigalow stands out, despite the fact that I've never seen it, because it gets brought up to me so often."

- Richelle



"EVERY MAN'S DREAM"

In Season 27, Episode 1 of *The Simpsons*, Homer Simpson is diagnosed with narcolepsy. Julie and Al discussed the episode's development and portrayal of narcolepsy. Highlights from their conversation:

"I think there are parts of the episode that really resonate with the true experience of living with narcolepsy. I was always curious if there was anyone involved with production who knew it more intimately."

- Julie



"A couple people close to the staff have narcolepsy, and we did talk to them as part of the process."

- Al

"Having the pharmacist list the different narcolepsy medications was really interesting. I was curious about some of those specific references, and the mention of hypocretin."

- Julie

"Our writer was really good about finding out what the treatments were. When *The Simpsons* started 30 years ago, you had to go to a library to do research. Now you can Google everything, so there's really no excuse for not researching what you're talking about. It's my hope that by covering [narcolepsy], it will encourage people to take the topic more seriously."

- Al



OTHER PORTRAYALS

Portrayals of narcolepsy in popular media shape public perception and can perpetuate misunderstanding. These are some examples of inaccurate/distorted portrayals of narcolepsy from wide-release films:

"Portrayals absolutely matter... I've actually had people laugh and then ask 'Wait, that's real?' after I tell them I have narcolepsy."

- Ariel

- ***My Own Private Idaho: sleep attack***

"The character falls asleep for long periods of time, and ends up in different places. It's hard to tell exactly, but our assessment is that he is having episodes of excessive sleepiness that lead him to sleep for very long periods of time, so not exactly accurate." -Julie

- ***Deuce Bigalow, Male Gigolo: sleep attack***

"In *Deuce Bigalow*, she's falling asleep in the middle of sentences." -Julie

- ***Rat Race: sleep attack***

"In *Rat Race*, he's falling asleep standing." -Julie

- ***Moulin Rouge: sleep attack***

"*Moulin Rouge*, falling asleep in the middle of activities."

- ***Ode to Joy: cataplexy***

"Narcolepsy is mentioned by name only twice in the movie. It's focused on cataplexy, so the way they simplified is to almost leave the rest of narcolepsy out." -Julie

"Inaccurate portrayals of narcolepsy definitely delayed my diagnosis. I knew all the symptoms but didn't realize I actually experienced them because of what I had seen depicted in film and television."

- Cara

"If you look at what people experience with narcolepsy versus what's being portrayed, it's not representative of the variety of symptoms."

- Julie

As a reminder, there are generally **five** symptoms of narcolepsy: excessive daytime sleepiness, cataplexy, hypnagogic hallucinations and sleep paralysis, and disrupted nighttime sleep.



"Culture change precedes policy change."

- MARYA BANGEE

STORYTELLING AND SOCIAL CHANGE, SSIR PODCAST

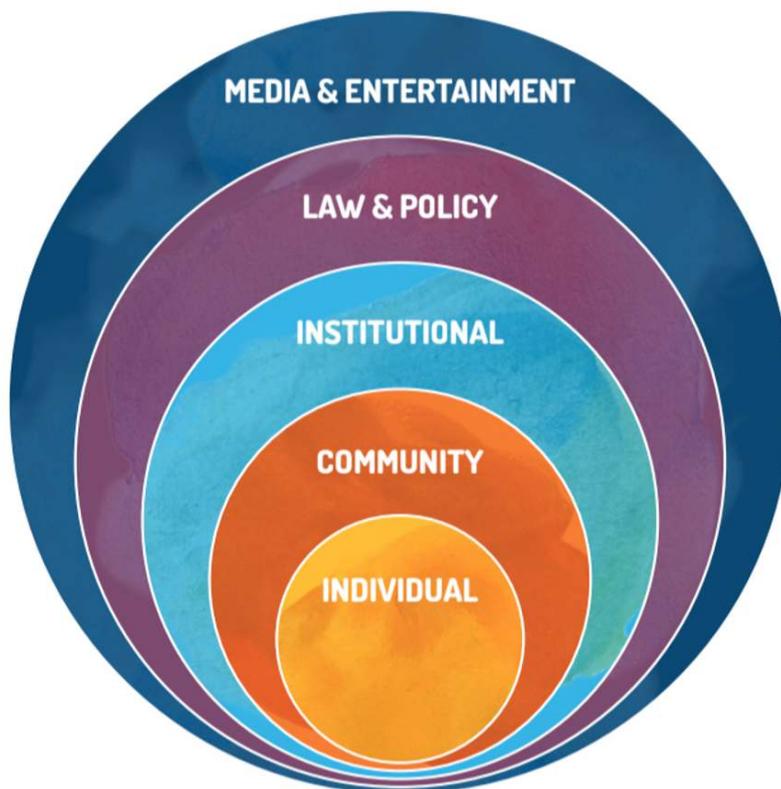


NARCOLEPSY STIGMA

Stigma is a concept of othering people; a belief that they're separate from us and sometimes lesser than us.

"I believe that media and entertainment create the culture that leads to law and policies. So all of these levels of stigma are important. Your story really matters, and you can foster empathy and help reduce stigma through telling it."

- Julie



REMEMBER:

- All of the levels are important
- Stigma operates at all levels at the same time
- Every level is made up of individual people
- Changes are needed at all levels

GRAPHIC BY ELLE WALES



WHAT WE CAN DO: ASK FOR BETTER

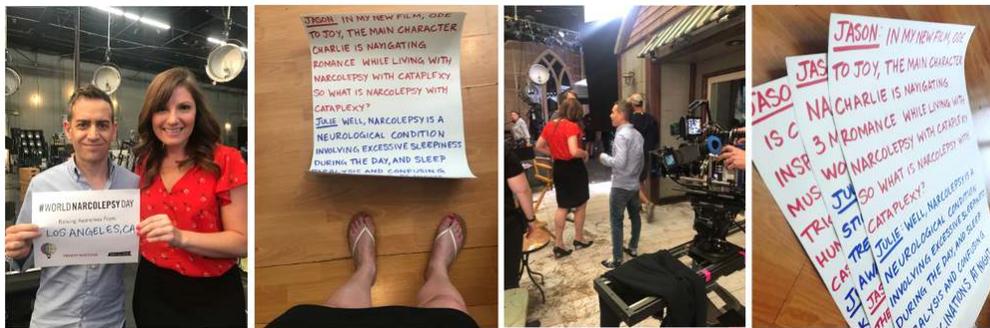
There are ways to make our voices heard in regard to portrayals of narcolepsy. Julie shared the story of her efforts in reaction to the 2019 movie *Ode to Joy*. With very little time before the film's release, these were Julie's requests to the director:

- [Public service announcement](#) collaboration for social media
- Resource information in closing credits
- Media training for stars and director
- Discussion guide



"Thank you for being persistent, Julie! I know it takes a lot of energy!!"

- Sheila



The director and production team met Julie's requests, except that it was too late to add resources to the closing credits. In addition to these collaborations, Julie also:

- Published a [blog post](#) with a [discussion guide](#) and [fact sheets](#) on Project Sleep's website
- Created a "[cheat sheet](#)" for sleep doctors and a [blog post](#) for the American Academy of Sleep Medicine
- Published a [movie review](#) on her personal blog



WHAT WE CAN DO: TELL OUR STORIES

Walking Through Peanut Butter is a dark comedy series our special guest Anna Marr is developing, based on her experience as a comedian living with narcolepsy with cataplexy. The pilot episode has been met with acclaim from several film festivals.

Plot: 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.



"My advice to anyone wanting to break into the comedy world is: stick to your own perspective. In comedy they tell you the more specific, the funnier. Submitting your project to film festivals or script festivals is a great way to make connections, and it can open doors. "

- Anna

"I love this concept of this series, because laughter is my biggest cataplexy trigger."

- Victoria



WHAT WE CAN DO: CONTRIBUTE TO RESEARCH

There is currently **no published research** addressing portrayals of narcolepsy and other sleep disorders, as there is for other conditions such as epilepsy. In an effort to collect information that may help with future research, Project Sleep is launching a platform for community members to submit examples of TV & film depictions of sleep disorders. This is a simple action **you can take** as a step toward improving portrayals of narcolepsy and other sleep disorders. Together, we can create meaningful change!

To contribute examples of portrayals of sleep disorders in TV & film, fill out our [Sleep Disorders in Film & TV Database](#) form. This form takes about 5 minutes to complete.

GO TO FORM



We are excited to see your entries!



RESOURCES

Here are some of our favorite resources. We look forward to hearing what our fellow #NarcolepsyNerds find most useful for navigating narcolepsy!

- **RespectAbility**
 - RespectAbility 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.
 - Summer Lab Program for Entertainment Professionals with Disabilities
- **ReelAbilities Film Festival**
 - ReelAbilities Film Festival is the largest festival in the US dedicated to promoting awareness and appreciation of the lives, stories and artistic expressions of people with different disabilities.
- **SSIR Podcast Episode: Storytelling and Social Change**
- **Rising Voices of Narcolepsy**
 - Fostering a new generation of narcolepsy patient-advocates spreading awareness via speaking and writing while also empowering participants.
- **Ode to Joy discussion guide** and **fact sheets** from Project Sleep
- **Ode to Joy public service announcement collaboration**
- **Ode to Joy Movie Review from a Person Living with Narcolepsy with Cataplexy** by Julie Flygare
- American Academy of Sleep Medicine blog post by Julie Flygare: **New Movie Featuring Narcolepsy with Cataplexy: What Sleep Doctors Should Know**
- Follow **Walking Through Peanut Butter** for updates about the new dark comedy, written by and starring Anna Marr (our awesome guest)!
- Contribute an example of a sleep disorder portrayal to Project Sleep's **Sleep Disorders in Film & TV Database**



RESOURCES

RESEARCH

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THANK YOU!

We are so grateful that you took the time to check out this toolkit!

Project Sleep is a 501(c)(3) nonprofit organization dedicated to raising awareness about sleep health and sleep disorders.

More resources at: www.project-sleep.com

