

DISCUSSION GUIDE

martin
Freeman

morena
Baccarin

He's never been happier.
And that's the problem.



Ode to Joy

IFC FILMS PRESENTS A MOSAIC AND A SMALL DOG PICTURE COMPANY PRODUCTION IN ASSOCIATION WITH THIS AMERICAN LIFE "ODE TO JOY" MARTIN FREEMAN MORENA BACCARIN JAKE LACY MELISSA RAUCH
CASTING BY JENNIFER EUSTON, CSA AND S.J. ALLOCCO MUSIC BY JEREMY TURNER DIRECTOR OF PHOTOGRAPHY DAVID ROBERT JONES PRODUCTION DESIGNER LISA MYERS EDITOR PETER TESCHNER COSTUME DESIGNER CARISA KELLY
EXECUTIVE PRODUCERS JOSH BEARMAN NICK MOGERI MAX WERNER JOSEPH WHITE PRODUCED BY MIKE FALBO JASON WINER MICHAEL LASKER JIMMY MILLER IRA GLASS ALISSA SHIPP PAMELA THUR
WRITTEN BY MAX WERNER **coming soon** DIRECTED BY JASON WINER IFC FILMS

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DISCUSSION GUIDE



On August 9, 2019, the feature film, *Ode to Joy* was released in select theaters and via video on demand to rent at home in the United States. The film features a main character portrayal of narcolepsy with cataplexy, a neurological condition affecting 1 in 2,000 people worldwide.

Project Sleep was not involved in the development or filming of this movie, however we developed this Discussion Guide to assist viewers in talking about the film and learning more about narcolepsy with cataplexy.

About *Ode to Joy*



How does a man who is—literally—paralyzed by happiness find love? Thanks to a condition called narcolepsy with cataplexy—a neurological disorder that causes him to lose control of his muscles whenever he is overcome by strong emotion, particularly joy—Brooklyn librarian Charlie (Martin Freeman) has learned to carefully edit all delight-triggering people, places, and events out of his life. Family weddings, cute babies, adorable puppies, and, yes, romance are all fraught with peril in Charlie’s carefully managed world. But when the beautiful, spontaneous Francesca (Morena Baccarin) falls for him, the risk-averse Charlie finds himself at a crossroads: suppress his feelings of attraction, or take a chance and let love in? Based on a true story originally featured on *This American Life*, *Ode to Joy* is a hilarious and touching look at what happens when we take a chance on love.

A new film portrayal of narcolepsy featuring prominent actors offers a culturally-relevant opportunity to engage with our communities and raise critical awareness.

Why This Matters

Representations of narcolepsy in films provide valuable insight into public perceptions and understanding of narcolepsy. For many individuals, cinematic depictions of narcolepsy may be their only exposure to the symptoms and impacts of the condition. Narcolepsy advocates, patient-driven organizations and medical professionals will benefit from being aware of cinematic portrayals of narcolepsy and joining the conversation as much as possible.

Viewing a cinematic portrayal of any serious illness, especially one that personally affects you or a loved one, may stir strong emotions. Your feelings and reactions are valid. We encourage you to use this Discussion Guide to share about your first-hand experiences.

Hosting a Viewing Party & Discussion

1. Schedule Your Get-Together & Invite Participants: *Ode to Joy's* running time is 97 minutes, so plan for about 2 - 3 hours total. Consider inviting guests to bring a favorite movie snack!
2. As the Discussion Host, review the prompts in advance and feel free to skip questions or add additional topics.

Discussion Introduction

Discussion Host: Read the following statement out loud to kick off your discussion.

Welcome! The non-profit organization, Project Sleep put together this guide to help us discuss Ode to Joy and how it relates to living with narcolepsy with cataplexy.

There are no "right" or "wrong" answers to these questions. Your reactions are valid. Likewise, the responses of others are valid.

One great way to remind ourselves and each other that we are speaking from our own perspective is to use qualifying terms like: "For me," "In my experience," "How that made me feel..." or "My impression was..."

IMPORTANT

Your discussion participants may have varying degrees of knowledge about narcolepsy. The main prompts assume some personal experience with the condition. For loved ones, references to "in your experience" should be interpreted as "in you or your loved one's experience." For those newer to learning about narcolepsy, appropriate prompts are highlighted in "New to Narcolepsy" boxes.

CATAPLEXY: striking, sudden episodes of muscle weakness usually triggered by emotions like humor, surprise, or anger. The severity may vary from a slackening of the jaw or buckling of the knees to falling down. The duration may be for a few seconds to several minutes and the person remains fully conscious (even if unable to speak) during the episode.

- In *Ode to Joy*, Charlie experiences many episodes of cataplexy. How did cataplexy manifest in his body? Which episodes resonated with your experience? Which surprised you?
- In your experience, what does cataplexy look like on the outside? How does it feel internally? What are your strongest emotional triggers?
- Charlie finds creative ways to manage his cataplexy. What are some of the tactics he uses to avoid feeling joy and therefore avoid cataplexy? Did his tactics resonate or surprise you?

NEW TO NARCOLEPSY

- What did you learn about cataplexy from this movie? What surprised you?
- After seeing this film, do you have any questions you'd like to ask someone who has cataplexy?

NARCOLEPSY SYMPTOMS vary by person and may include:

- Excessive daytime sleepiness which often results in difficulty focusing or maintaining alertness
- Sleep paralysis and confusing hallucinations when falling asleep or waking up
- Cataplexy (described above)
- Disrupted nighttime sleep

- In *Ode to Joy*, the symptom featured most prominently is cataplexy. What do you wish people knew about the other symptoms of narcolepsy?
- For those living with narcolepsy without cataplexy, what do you wish people knew about your experience?

NEW TO NARCOLEPSY

- Had you heard of narcolepsy before seeing this film?

TREATMENT

While there is currently no cure for narcolepsy, treatments are available and can reduce symptoms for many people diagnosed with narcolepsy. Treatment approaches vary widely by person and it can take a long time to find an optimal combination. Treatment approaches may include medications, scheduled daytime naps, social support and improvements to general health and wellness (through sleep hygiene, diet, and fitness).

- What treatment approaches did Charlie utilize? What additional tools might Charlie explore more?
- What has been your experience with treatments? How do you weigh the pros and cons of treatment options?

NEW TO NARCOLEPSY

- Have you or a loved one had to navigate treatments for a health condition? What was this experience like?

DISCUSSING NARCOLEPSY WITH CATAPLEXY

Because narcolepsy is an invisible and misunderstood condition, people with narcolepsy often feel alone and hesitant to disclose their disorder to others, fearing the consequences and reaction they would receive.

- Why is Charlie reluctant to tell his romantic interest, Francesca, about his condition on their first date?
- What's been your experience sharing about narcolepsy with new friends, peers or romantic interests?
- Have you found certain word choices or resources helpful to educate others about narcolepsy?
- How would you like people to respond to learning you have narcolepsy? What next steps would you like someone to take?
- Has your experience with narcolepsy influenced how you respond to the adversity of others?

NEW TO NARCOLEPSY

- Have any aspects of your identity (visible or invisible) been a source of stigma, discrimination or uncertainty for you?

HUMOR

Humor can be an important coping mechanism for many people facing serious illnesses like narcolepsy. Also, humor can be a powerful mechanism to educate people about serious matters.

- Has humor played a role in your experience coping with narcolepsy?
- What humor in this film resonated with you? Did any make you feel uncomfortable?

NEW TO NARCOLEPSY

- Has humor helped you cope with adversity in your life?

IN CONCLUSION

- What lessons can we learn from Charlie's evolution as a character?
- How has your experience with narcolepsy evolved over time? Did you experience any denial or try coping in ways that were not optimal? What inspired you to change?
- If you could have a conversation with Charlie and Francesca at the end of the film, what would you most want to tell them or ask them?
- What's most important for people seeing this film to know about narcolepsy?

NEW TO NARCOLEPSY

- What did you learn from this film?
- After seeing Ode to Joy, do you have any questions for someone living with narcolepsy?

QUICK FACTS: Narcolepsy with Cataplexy

Narcolepsy is a chronic neurological condition that impairs the brain's ability to regulate the sleep-wake cycle. It affects 1 in 2,000 people—200,000 Americans and 3 million people worldwide.

NARCOLEPSY SYMPTOMS

Symptoms vary by person but may include:

- **Excessive daytime sleepiness:** Periods of extreme sleepiness during the day that feel comparable to how someone without narcolepsy would feel after staying awake for 48-72 hours. Often resulting in difficulty concentrating and staying alert.
- **Cataplexy:** Striking, sudden episodes of muscle weakness usually triggered by emotions such as laughter, exhilaration, surprise, or anger. The severity may vary from a slackening of the jaw or buckling of the knees to falling down. The duration may be for a few seconds to several minutes and the person remains fully conscious (even if unable to speak) during the episode.
- **Hypnagogic and hypnopompic hallucinations:** Visual, auditory, or tactile hallucinations upon falling asleep or waking up.
- **Sleep paralysis:** The inability to move for a few seconds or minutes upon falling asleep or waking up. It is often accompanied by hypnagogic or hypnopompic hallucinations.
- **Disrupted nighttime sleep:** Unlike public perceptions, people with narcolepsy do not sleep all the time. Timing of sleepiness is “off” with narcolepsy so one may fight sleepiness during the day but struggle to sleep at night.

QUICK FACTS: Narcolepsy with Cataplexy

SCIENCE OF NARCOLEPSY

Recent research suggests that narcolepsy with cataplexy is caused by a lack of hypocretin, a key neurotransmitter that helps sustain alertness and regulate the sleep-wake cycle. Less is known about what causes narcolepsy without cataplexy, the other form of the condition.

DIAGNOSIS

If you suspect that you or a loved one may be experiencing symptoms of narcolepsy, it's important to consult with a board-certified sleep specialist.

NARCOLEPSY TREATMENT

Treatments are available today and can improve symptoms of excessive daytime sleepiness and cataplexy. Symptom management varies widely by person and it often takes a long time to find an optimal combination of treatments.

RAISING AWARENESS

Because of low awareness (even among physicians) and misperceptions, there is an average of 8 to 15 years between narcolepsy symptom onset and diagnosis. It's estimated that the majority of people with narcolepsy are currently undiagnosed or misdiagnosed (common misdiagnoses include epilepsy, depression, and schizophrenia).

Let's Get Social!

If comfortable for you, consider posting about the film on social media. Let your friends know there's a new film about narcolepsy and that you'd love to answer any questions.



@project_sleep · 2h

New movie [#OdeToJoy](#) features main character portrayal of [#narcolepsy](#) with [#cataplexy](#). As a person living with this condition, I'd love to hear what you think of the movie and answer any questions! Learn more: www.project-sleep.com/ode-to-joy/

Resources

FIND A SLEEP SPECIALIST

If you think that you or a loved one may be experiencing symptoms of narcolepsy, it's important to consult a board-certified sleep specialist.

Locate an **AASM Accredited Sleep Center**: sleepeducation.org/find-a-facility

LEARN MORE ABOUT NARCOLEPSY

American Academy of Sleep Medicine	www.aasm.org
Harvard Narcolepsy Education Website	www.healthysleep.med.harvard.edu/narcolepsy
Hypersomnia Foundation	www.hypersomniafoundation.org
Narcolepsy Network	www.narcolepsynetwork.org
Narcolepsy: Not Alone Campaign	www.narcolepsynotalone.com
Project Sleep	www.project-sleep.com
Stanford Center for Narcolepsy	www.med.stanford.edu/narcolepsy.html
Wake Up Narcolepsy	www.wakeupnarcolepsy.org

Learn more about *Ode to Joy*: www.odetojoy.movie

ABOUT PROJECT SLEEP

Believing in the value of sleep, Project Sleep is a 501(c)(3) non-profit organization aiming to improve public health by raising awareness of the importance of sleep health and sleep disorders. Project Sleep educates and empowers individuals using events, campaigns, and programs to bring people together and talk about sleep as a pillar of health.

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