



Ode to Joy: About the Movie and Key Talking Points for Narcolepsy Community Leaders, Clinicians and Researchers

On Aug. 9, 2019, the film, [Ode to Joy](#) opened in select theaters (in New York and Los Angeles) and released via video on demand across the United States. Ode to Joy is a movie about a man, Charlie (played by Martin Freeman) navigating romance while living with narcolepsy with cataplexy.

Project Sleep was not involved in the development or filming of this movie, but we aim to help provide the narcolepsy community and film audiences with appropriate educational tools and resources to discuss the film and raise awareness about narcolepsy.

About the Movie	Key Talking Point
<p>CATAPLEXY: The physical manifestations of cataplexy ranged from accurate (i.e. a knee-buckling and crumbling downward to the ground) to inaccurate (i.e. rigid plank tumbling backward).</p> <p>Viewers will likely get the impression that emotions cause Charlie to fall asleep or “pass out,” which makes cataplexy seem more light-hearted than the real-life experience.</p> <p>Charlie tries to avoid “joy” to avoid cataplexy. His tactics included listening to classical music, thinking of tragic world events, and putting thumbtacks in his shoes on a date.</p>	<p>CATAPLEXY: is sudden episodes of muscle paralysis often triggered by emotions like humor, surprise, or anger. The severity of these episodes vary from a slight knee buckling or neck weakness to falling to the ground for a few seconds to several minutes. During a cataplexy episode, the person remains conscious and aware of their surroundings, even if unable to speak or move, which can be terrifying.</p>
<p>NARCOLEPSY: During the film, narcolepsy is mentioned once or twice, but it’s not explained that cataplexy is a symptom of narcolepsy.</p> <p>The other symptoms of narcolepsy are not depicted or defined (perhaps besides one very short clip of Charlie lifting his head off his keyboard at work, as if from a nap.)</p>	<p>NARCOLEPSY: Importantly, cataplexy is a major symptom of narcolepsy, a chronic neurological condition that involves other symptoms such as excessive daytime sleepiness - that can result in difficulty focusing and maintaining alertness, along with sleep paralysis and confusing hallucinations when falling asleep or waking up. And some people have a form of narcolepsy without cataplexy.</p>

<p>TREATMENT: Xyrem is mentioned early in the film. Charlie says this caused bedwetting and he gets similar benefits from exercise.</p> <p>Other treatment options are not mentioned and lay viewers may not realize treatments exist because if you don't know "Xyrem" as the name of a narcolepsy medication, this quick exchange may fly over one's head.</p>	<p>TREATMENT: Treatments are available and can reduce symptoms of narcolepsy with cataplexy. Approaches to treatment vary by person and it can take a while for each person to work with their sleep specialist to find an optimal combination.</p>
<p>AFFECTS MANY PEOPLE: The opening definition and film synopsis describe cataplexy as a "rare disorder" and do not mention narcolepsy. Since the portrayal is exaggerated and inaccurate in certain ways, viewers may get the impression that this condition is a "unicorn-like" oddity impacting few real-life people.</p>	<p>AFFECTS MANY PEOPLE: Charlie is not alone! Narcolepsy is a chronic neurological condition affecting 1 in 2000 people, about 200,000 Americans and 3 million people worldwide, including many children.</p>
<p>SEEKING MEDICAL SUPPORT: Despite inaccuracies, the film raises significant awareness about the emotional triggers of cataplexy and has enough accurate pieces that some viewers might recognize themselves or a loved one as possibly having cataplexy.</p>	<p>SEEKING MEDICAL SUPPORT: If you think that you or a loved one may be experiencing symptoms of narcolepsy with cataplexy, please consult a board-certified sleep specialist. Locate a AASM Accredited Sleep Center.</p>

For More Information:

- [Ode to Joy movie website](#) (how to watch the movie at home!)
- [Julie Flygare's Review of Ode to Joy](#) (for more details about the film's depiction)
- [Project Sleep's Ode to Joy Resources page](#)
- [Project Sleep's Ode to Joy Discussion Guide](#)
- [Project Sleep's Narcolepsy Quick Facts](#)

