



# UNREST FILM DISCUSSION GUIDE

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# MESSAGE FROM JENNIFER

*Unrest* is a personal documentary. When I was 28, I became ill after a high fever and, eventually, bedridden. At first, doctors couldn't diagnose me and later began telling me that either there was nothing wrong with me or that it was all in my head. As I began searching for answers, I fell down this rabbit hole and discovered a hidden world of thousands of patients all around the globe, many of whom are homebound or bedridden and use the internet to connect with each other and the outside world.

We were all grappling with a disease called ME, more commonly known as chronic fatigue syndrome. This wasn't a disease I had ever really heard of, read about, or seen films made about, even though it is an extremely common condition. It's a story that's been flying under the radar for the last 30 years.

*Unrest* follows the story of me and my husband Omar. We are at the very beginning of our marriage, of our lives together, when this asteroid hits.

And at the same time, to try to understand what's happening to me, I start reaching out to other patients and documenting their stories. We meet Jessica, a young girl in England who has been bedridden since she was 14, and Ron Davis, a Stanford geneticist who is trying to save his son's life in spite of devastating obstacles.

When I first started making this film, it was just an iPhone video diary. Those first few years, I could barely read or write but needed an outlet for my grief and anger. And so I started creating these intimate videos.

Then, I went online and met thousands of people, all over the world, living the same experience. Many were homebound or bedbound, isolated, without treatment or care, and often disbelieved. I thought, "How could this have possibly happened to so many people?" There was this deep social justice issue at the heart of it. An entire community had been ignored by medicine and had missed out on the last 30 years of science. A part of the problem is that many of us are too ill to leave our homes and so doctors and the broader public rarely see us. That is when I decided to make a film.

# MESSAGE FROM JENNIFER

When we began shooting, I was completely bedridden, so I built a global team, hired crews around the world, and directed from my bed. I conducted interviews by Skype and an iPad teleprompter. We had a live feed that (when it worked!) allowed me to see in real time what our DP was shooting on the ground. Filmmaking allowed me to travel again.

As we started shooting, and I started to get to know these amazing characters, the film became a way to address some of those burning questions that I had. What kind of a wife can I be to my husband if I can't give him what I want to give? How do I find a path in life now that the plan I had is impossible? If I am never able to leave my bed, what value does my life have? I became interested in what happens not only to patients but to our caregivers when we or a loved one are grappling with a life-changing illness. These are questions we will all face at some point in our lives.

Lastly, there was a point at the middle of the edit when we had a very strong cut but I felt unsatisfied with just seeing us, these bodies, from the outside. I knew that there was so much about this experience that an external camera just couldn't capture. So we started bringing in these elements of personal narration, visuals, and sound design in an almost novelistic way, to try to give the audience glimpses of our dreams, our memories. It was important to me to convey that regardless of our profound disabilities, we are all still fully human. That even laying in bed, we have these complex, inner lives.

It's my hope that in sharing this world and these people that I have come to profoundly love, we can build a movement to transform the lives of patients with ME; accelerate the search for a cure; and bring a greater level of compassion, awareness, and empathy to millions upon millions of patients and their loved ones wrestling with chronic illness or invisible disabilities.

-Jennifer Brea

# FILM SYNOPSIS

*Unrest* tells the personal story of Jennifer, a Harvard PhD student about to marry the love of her life when she's struck down by a fever that leaves her bedridden. When doctors tell her it's "all in her head," she goes online and finds a hidden world of millions confined to their homes and bedrooms by ME, commonly called chronic fatigue syndrome.



# ABOUT THE GUIDE

This guide is intended to inspire and facilitate conversation around *Unrest* during your screening. In this guide you will find themes from the film, discussion questions, information about key characters, as well as background and resources on ME. The discussion questions are meant to inspire your conversation, but please do not be dictated by them! You know your audience best — so pick the sections of the guide that suit your audience's needs.

## PRE-SCREENING QUESTIONS

As the host of a screening, we ask that you consider the questions below before your event:

- What is the message you hope to convey through the screening?
- How will you promote your event?
- What do you hope that your screening can accomplish?
- What are three actions you want all participants to do after the screening?
- How many people are you anticipating will attend the event?
- Are the themes you hope to discuss covered in the guide?

# STIGMA & BELIEF

**As explained in the film, there is a large stigma associated with ME, often evidenced by lack of knowledge from doctors and a wide societal misunderstanding of the illness. This section provides a guide for discussion of the false beliefs around the disease and the consequences of this stigma.**

*“Sickness doesn’t terrify me. Death doesn’t terrify me. What terrifies me is that you can disappear because someone’s telling the wrong story about you.” – Jennifer Brea*



- How has this film changed your understanding of invisible and chronic illnesses?
- What are some of the beliefs you had about ME before watching the film? How did your views change?
- Discuss the stigma around ME. Why do you think there continues to be stigma around the illness?
- How does the way the film was made work to change the narrative about ME?
- The film features clips from comedians who have made jokes about chronic fatigue syndrome. How does this type of discourse impact the stigma around ME? How do you think it affects patients?
- What does Karina’s story tell us about how the stigma around ME can impact patients and their families?
- What are concrete short-term steps that you can take to reduce the stigma against ME? What about long-term steps?



# TIME

**As depicted in the film, people living with ME have to adjust to a new experience of time. This section provides a discussion for how time is experienced by the ME patient community and their networks.**

*"I had no idea if it would be months, or years, or decades. It was like I had died, but was forced to watch as the world moved on." - Jennifer Brea*

*"I get to my birthday, and for me that's a very difficult date because I think, it's another year in bed....that's very scary for me because you don't realize, when you're in a bubble quite how much time goes." - Jessica Taylor*



- How is the passage of time represented for each character in the film?
- What role does the passage of time play in the experiences of people with ME?
- Jennifer experiences different incorrect diagnoses when she first becomes ill. How does the way the medical community understands and treats ME impact the experience of time for people with ME and their caregivers?

# RELATIONSHIPS & SUPPORT NETWORKS

**It isn't until Jennifer found an online community of ME patients that she is able to get information about her condition. This section provides a guide for discussion of the importance of support networks for people with ME, and the role that their loved ones play.**

*"I thought maybe I had a rare disease. Maybe I was dying. And then I went online and found thousands of people just like me." – Jennifer Brea*

*"It was scary when he [Randy] left. I was wondering how I was going to do everything, how I was going to cope with everything." – Leeray Denton*



- What role does Omar (Jennifer's husband) play in the film? What were some of the challenges Jennifer and Omar faced as a married couple due to the illness? How did they overcome those challenges? How do you think you would deal with this kind of challenge?
- Why is it crucial for ME patients to have close support networks? What can happen to a patient (i.e. physically, mentally, emotionally) when their caretakers and loved ones may not believe they are ill?
- How can primary caregivers and relatives of a ME patient be supported?
- How can you support someone you may know who has been diagnosed with ME or another chronic illness? How can you support the ME community in general?
- What networks and/or resources do you believe should be created to support the ME community and educate the general public about chronic illnesses and invisible disabilities?

# LOSS & RESILIENCE

**The subjects of the film all experience some type of loss as a result of their condition. This section provides a guide for discussion around loss, as well as resilience in the face of uncertainty.**

*"You have to be able to hold two things in your head: this illness destroyed my life, but what it showed me, I could never give that back... I am still here. I am still here." – Jennifer Brea*

*"I think Casie deals with this disease the way she does because she saw how I dealt with it, and it didn't stop me from being a mom. Having kids [while you have this disease] would be the hardest thing you would ever do, and it would be the best thing you would ever do." – Leeray Denton*

*"[My son, Whitney,] loved traveling and taking photographs. One day he asked us to take his camera out of his room, and then he motioned for me to let him hold it for a minute. And he just hugged his camera and told it goodbye." – Janet Dafoe*



- How do the people in the film with ME cope with the loss associated with their condition?
- How do the subjects of the film demonstrate resilience in the face of loss?
- What role do caregivers and support networks play in helping patients cope with loss?

# MEDICAL COMMUNITY

**Doctors and medical researchers play an important role in the future of diagnosis and treatment for ME. This section provides a guide for discussion around medical professionals' understanding of ME and their treatment of patients.**

*"The doctors had no idea what to do. The nurses were getting frustrated with me for not getting better. They only saw me as a lost cause." – Jessica Taylor*

*"Doctors want to know what to do. But it's not in the textbooks of medicine... So they have to go to the same place you have to go and Google it. In the United States, we are still graduating class after class of medical students that haven't even heard of this illness [and don't know] where to even look for its diagnostic criteria." – Dr. Nancy Klimas*

- How do you think the medical profession can alter its approach to working with patients with ME?
- How can medical students benefit from watching this film?
- How might medical training be changed to reduce disbelief of patients and improve diagnostics?
- What steps can you take in your community to make ME a priority for doctors?
- What would curriculum about ME look like for medical students, university students, high school students, and younger?

# SCIENTIFIC COMMUNITY

**Scientists and research institutions have the capacity to illuminate many of the unknown facets of ME. This section provides a guide for discussion around the role of the scientific community in advancing the knowledge of ME.**

*“Chronic fatigue syndrome is the lowest funded of any major disease by a lot. Many of the people that are at NIH [National Institutes of Health] have in the past not believed it’s real, so why would you fund something that’s not real?” – Dr. Ron Davis*

*“ME was called hysterical paralysis up to the day that they invented the cat scan machine because now we had the capacity to look at the brain and see those great big white spots of demyelination. So it went from hysterical to real.” -- Dr. Nancy Klimas*

- What obstacles have and/or are currently blocking scientists from effectively researching ME?
- How has the field of psychiatry influenced the way scientists think about ME?
- How can we improve awareness among already-established scientists? How can we inspire a new generation of scientists to research ME?
- What might inhibit pharmaceutical interest in ME? What impact would a greater pharmaceutical presence in ME research have?



# GENDERED IMPLICATIONS OF AUTOIMMUNE ILLNESS

**There is a history of disbelief and stigma related to ME, which some in the film suggest is related to its prevalence among women. This section provides a guide for discussion around gender bias in medicine, and how that affects our understanding of ME.**



*"I hear from women all of the time — who were later diagnosed with fibromyalgia, lyme disease, lupus — who were initially told they were hypochondriacs. Eighty percent of autoimmune diseases are women. I can't help but wonder if that's why we're disbelieved." – Jennifer Brea*

*"We used to institutionalize women with hysteria. It's always tempting to look at the past — something strange and distant — to say, thank god we know better now. But what I never could have imagined had I not gotten this disease is that we're still doing this." – Jennifer Brea*

- What are ways in which societal stereotypes about women need to change in order to combat the stigma against ME and other related illnesses?
- How did the diagnosis of hysteria in women contribute to a long history of women's pain being disbelieved and misunderstood?
- An estimated 75-85% of those diagnosed with ME are women. In your opinion, how has this affected the way ME is treated, diagnosed, and researched?

# BIOGRAPHIES



**Jennifer Brea** is an independent documentary filmmaker based in Los Angeles. She has an AB from Princeton University and was a PhD student at Harvard until sudden illness left her bedridden. In the aftermath, she rediscovered her first love, film. Her feature documentary, *Unrest*, premiered at the Sundance Film Festival in January, where it won a Special Jury Prize. She is also co-creator of *Unrest VR*, winner of the Sheffield Doc/Fest Alternate Realities Award. An activist for invisible disabilities and chronic illness, she co-founded a global advocacy network, #MEAAction and is a TED Talker.



**Omar Wasow** met his wife Jennifer when they were both in Ph.D. programs at Harvard. Quickly after getting married, his wife was diagnosed with ME. Omar shows how support and commitment can strengthen when a loved one is suffering from an illness that they themselves are not experiencing. Omar is currently an Assistant Professor in Princeton University's Department of Politics, focusing on race and politics. His co-authored work on the challenge of estimating effects of race was published in the *Annual Review of Political Science*. Omar served as a regular on-air technology analyst and was the co-founder of [BlackPlanet.com](http://BlackPlanet.com), a social network he helped grow to over three million active users.



**Jessica Taylor** has been bedbound with severe ME since she was 15, when she developed after a flu-like illness. After spending four years in hospital, she now lives at home in a village in England with her sister and parents. Shocked to be spending her teens lying flat in bed in the semi-dark, Jessica created a blog called *The World Of One Room* to help her survive. She also founded, from her bed, a charity called *ShareAStar* which does outreach to severely disabled and terminally ill children.



When **Leeray Denton** got sick in the 1980s, she saw 15 doctors. “They all told us it was all in my head,” she says. Her husband, Randy, was overwhelmed by the responsibilities of being a single parent and, putting his faith in experts who told him his wife wasn’t really sick, he left his wife and two teenaged daughters behind. Ten years later, Leeray and Randy’s daughter, Casie, 11 develops ME shortly after giving birth. As, decades apart, Leeray and Casie face the same diagnosis, Randy realizes how wrong he — and the doctors — had been, and sets out to understand this illness and win back his wife and daughter.



The story of **Karina Hansen** and her forced removal from her home shows the harm that can be done when the illness is misunderstood and the wrong narrative is told about how it should be treated. Karina’s story illustrates the widespread and damaging misconceptions of ME. Organizing around the global ME community and their supporters as a result of her story provides inspiration for people looking to enact change.



# TIME FOR UNREST IMPACT CAMPAIGN

***Time For Unrest*** is a global campaign designed to strengthen the growing movement advocating for more recognition, education, research, and funding around ME. Through tailored calls to action worldwide, ***Time for Unrest*** intends to:

- Gain mass and strategic recognition of ME as a debilitating illness suffered by millions
- Mobilize a community of ME patients and allies to advocate on behalf of those with ME and other complex illnesses
- Promote a culture of knowledgeable and empathetic care for ME within the medical community
- Inspire new scientists to the field, and inspire a concentration of work around ME from new scientists and funders

**Keep up to date** with the latest actions as the *Time for Unrest* campaign unfolds. You can learn more about how to stay engaged and spread the word at **[timeforunrest.com](http://timeforunrest.com)**.

**#TIMEFORUNREST**

# BACKGROUND ON ME

**What is ME?** Myalgic Encephalomyelitis (ME) is a systemic neuroimmune condition characterized by post-exertional malaise (a reduction in functioning and a severe worsening of symptoms after even minimal exertion). It causes dysregulation of the immune, nervous, and energy metabolism systems. The effects of ME are devastating enough to leave 25% of patients housebound or bed bound.

ME is a spectrum disease. All people with ME experience a substantial loss of physical or cognitive functioning, but there is a wide spectrum of severity. On average, ME patients score more poorly on quality of life surveys than those with multiple sclerosis, stroke, diabetes, renal failure, lung disease, heart failure, and various cancers. It is important to keep in mind that the onset of ME can be either sudden or gradual and the intensity and frequency of milder symptoms can sometimes increase abruptly. Symptoms can fluctuate significantly from day-to-day, but the unpredictable progression of this disease is measured in years, not weeks or months.

**Prevalence.** An estimated 15-30 million people around the world are suffering from ME; at least [1,000,000 Americans](#), 250,000 British people, 100,000 Australians, and [400,000](#) Canadians have ME. An estimated [75-85% of them are women](#) and 80-90% of them are undiagnosed.

**Symptoms.** Common symptoms include:

- significant physical or mental fatigue
- post-exertional malaise (a reduction in functioning and a severe worsening of symptoms after even minimal exertion)
- debilitating pain
- sleep dysfunction
- cognitive dysfunction
- neurological impairment
- sensory sensitivity
- severe immune dysfunction

# BACKGROUND ON ME

**Diagnosis.** There is no single laboratory test that can diagnose ME. Patients have consistent biological abnormalities demonstrated in research settings. Many specialist physicians use these tests to aid in forming a diagnosis, although the diagnosis is at present most frequently made by excluding other conditions that cause similar symptoms and by using one of several diagnostic criteria. Due to lack of education and awareness about ME, many patients are undiagnosed or, misdiagnosed with other conditions.

**Treatment.** There is no FDA approved treatment for ME. The CDC and other agencies acknowledge treating the disease is complicated by the unknown cause. Because many ME patients' symptoms vary over time, specialists often suggest treatments that are highly personalized and change treatment protocols frequently.

**Name and definition.** ME may be called CFS (chronic fatigue syndrome) or SEID (systemic exertion intolerance disorder) by some patients and clinicians.

## **Resources.**

[ME/CFS Diagnosis and Management in Young People: A Primer](#)

[IACFS/ME Primer for Clinical Practitioners](#)

[Institute of Medicine - Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness](#)

[Myalgic encephalomyelitis: International Consensus Criteria](#)

[Canadian Consensus - A Clinical Case Definition and Guidelines for Medical Practitioners](#)

[CDC Website](#)

**Information courtesy of MEAction. Learn more about ME and how to help mobilize ME patients by visiting [www.meaction.net](http://www.meaction.net).**

# ABOUT SHELLA FILMS

Shella Films is a Los-Angeles-based production and impact distribution company founded by director and producer Jennifer Brea. We make and distribute intimate, character-driven stories across multiple media, with an emphasis on gender, health and the environment as well as works by and about women, queer people, people of color, and people with disabilities.

# ABOUT LITTLE BY LITTLE FILMS

Little By Little Films is a boutique British production company, based in Gloucestershire, UK, and founded in 2011 by creative producer and director Lindsey Dryden. Credits include Close Your Eyes And Look At Me (True/False, 2009), Lost and Sound (SXSW, 2012) and Unrest(Sundance, 2017). Our work has been broadcast on BBC, Channel 4, and featured in Elle and Vogue, with clients and collaborators including Tate, Hyundai, Random Acts, Wellcome Trust, Royal Court Theatre, Royal Shakespeare Company and Kevin Spacey Foundation. We specialise in films and experiences for cinema and digital platforms, and storytelling that's unexpected, uplifting and intimate.

# UNREST

**Director**

Jennifer Brea

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Alysa Nahmias

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