## **INFLUENCE** | FILM CLUB

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## Unrest Discussion Guide

Director: Jennifer Brea

Year: 2017 Time: 97 min

You might know this director from: UNREST is Jennifer Brea's first feature-length documentary film.

### FILM SUMMARY

Imagine that you are a PhD student at Harvard. You have recently found and married the love of your life. Together, you are travelling the world. Your future looks undeniably bright until a fever sets in, leaving you bedridden for months or years without explanation.

This is Jennifer Brea's story. After enduring severe pain, cognitive dysfunction, sensory sensitivity, and visits to many physicians, Brea was diagnosed with Myalgic Encephalomyelitis (M.E.), commonly known in the U.S. as Chronic Fatigue Syndrome (C.F.S.)—an invisible, stigmatized disease with no known cure. Compelled to document the dissolution of her mind and body, Brea began to film herself. The result is the remarkable UNREST, a medical drama, a love story, and an exploration of the human condition.

Brea's raw, deeply honest video diaries are just the jumping off point. With contextual commentary from medical experts in the field, Brea delves into the historical context of M.E., from the hysteria put forth by Freud, to the fever epidemics of London and Lake Tahoe. Burning for answers, Brea turns to the internet where she discovers thousands of others just like her, with a disease that narrows their world to one room.

UNREST is a deeply personal story. It highlights Brea's struggles with the pain and unpredictability of her disease, and also with the grief and loss of watching her once-full life pass her by. Yet it is also a wake-up call to modern medicine and a rousing call to arms for patients and their allies to fight for better research, treatment, and awareness for a disease that forces millions from the lives they've loved.

## **FILM THEMES**

In documenting her own experience, director Jennifer Brea explores the history of C.F.S. while fighting for a brighter future for people with the disease.

#### **GETTING TO KNOW M.E.**

Myalgic Encephalomyelitis (M.E.), more commonly known as Chronic Fatigue Syndrome (C.F.S.), is a multisystem disease that causes dysfunction in the neurological, immune, and endocrine systems, as well as errors in energy metabolism. Jennifer Brea is one of an estimated 15–30 million people worldwide who have M.E., with hundreds of thousands of new cases appearing each year in the U.S. alone. It is estimated that 80–90 percent of M.E. patients remain undiagnosed, since diagnosis requires multiple tests, some of which may not be familiar to general practitioners.

THE STIGMA OF CHRONIC INVISIBLE DISEASE

Prior to C.F.S. having been defined as such, the disease could be characterized as "hysteria." Brea was initially diagnosed with "conversion disorder" (the modern name for "hysteria") before a more thorough investigation led to her M.E. diagnosis. In Denmark, people suffering with M.E. may be considered mentally ill, and can be forcibly institutionalized. The film explores the theme of stigmatizing that which we do not understand.

**IDENTITY AND MEANING AMIDST ADVERSITY** 

Brea struggles throughout the film with questions of identity, no longer conforming to her previous conception of the roles of scholar, wife, or mother. Exploring the lengths that Brea will go to regain her health, to tragicomic effect, the film also asks: to what lengths would you go in order to return to a life you loved—and to help your partner do the same? Brea ends the film on a hopeful note: through connecting with others, she is able to see that she is not alone, share her stories, and learn from theirs.

#### **TOGETHER, WE ARE STRONG**

When in the trenches of dealing with disease, one can feel incredibly alone in the fight. With this in mind, Brea has created #MEAction to connect fellow sufferers of M.E. via online support groups. The organization also spurs political action while raising awareness about M.E.

"If you say too little, they can't help you, but if you say too much, they think you're a mental patient."

**Omar Wasow** 

"Life was gone, but here, I have this new one, and I have to fight for it."

Jennifer Brea

## **FURTHER DISCUSSIONS:**

- Prior to seeing UNREST, were you familiar with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? If so, what did you know about it?
- 2. As a movie, UNREST is several things at once: a diaristic account of illness, a love story, and a call for action. How do you feel these fit together as a narrative?
- 3. What aspect of the film surprised you most?
- 4. Why do you think there has traditionally been a lack of research done on M.E/C.F.S. in comparison to that of other illnesses?
- 5. A large portion of the film deals with the idea of healthy partners or parents caring for their ill loved ones. How did this affect you?
- 6. There is a lingering stigma that's long been attached to M.E./C.F.S. Why is this?
- 7. Have you or anyone you've known had to deal with a comparably debilitating ailment? If so, how did it affect your/their life?
- 8. Following its debut at Sundance, UNREST won a Special Jury Prize for its editing. Was the editing something you noticed while watching the film? Why or why not?
- 9. UNREST was also produced as a VR experience. What do you think VR might be able to bring to a story like this?
- 10. Do you feel compelled to take some kind of action after seeing UNREST? What might you do?

## **NOTES:**



## FILM FACTS:

- UNREST had its world premiere at the 2017
   Sundance Film Festival where it won a Special
   Jury Prize for Editing. The film went on to screen
   at internationally renowned festivals such as
   SXSW, CPH:DOX, Melbourne International Film
   Festival. Hot Docs, and Sheffield Doc/Fest.
- Reaching out in alternate forms, UNREST was also produced as a VR film which was premiered in the Virtual Arcade at the 2017 Tribeca Film Festival. It was also showcased at Sheffield Doc/ Fest in the Immersive VR section of the Alternate Realities Exhibition, where it won the Alternative Realities VR Award.
- Prior to finishing UNREST, director Jennifer
  Brea gave the highest-rated talk at the 2016
  TED Summit in Banff, Canada, discussing her
  experience with M.E. It was released online in
  January 2017 and has been viewed more than 1
  million times and translated into more than 25
  languages.
- M.E. is an incurable multisystem disease that causes 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, and severe immune dysfunction.

- Though relatively little research has been conducted on the disease, a 2015 Institute of Medicine report on M.E. states that "between 836,000 and 2.5 million Americans suffer from myalgic encephalomyelitis/chronic fatigue syndrome." The Office of Women's Health notes that "women are two to four times more likely than men to develop M.E./C.F.S. Children do develop M.E./C.F.S., but not as often as adults or adolescents."
- No one knows for sure what causes M.E. Many people say it started after a flu-like illness or other infection, such as a cold or stomach bug. It also can follow infection with the Epstein-Barr virus (the virus that causes mononucleosis or "mono"). Some people with the disease report that it started after a time of great physical stress, such as following surgery.
- UNREST was one of two productions to be the first films selected for the Sundance Institute's Creative Distribution Fellowship, "a new initiative to support filmmaking teams seeking a more entrepreneurial approach to the release of their work." The film received grants to fund marketing and distribution expenses, while the Institute worked closely with the film team to devise and execute tactics that allowed them to connect with audiences in new and innovative ways.

## **WAYS TO INFLUENCE**

- 1. **Share** your story of C.F.S. in an effort to raise awareness about M.E. Post a picture of yourself holding a sign with "It's #TimeforUnrest because..." sign and use the #TimeforUnrest hashtag.
- 2. Advocate for those afflicted by signing petitions calling for more research and funding for M.E.
- 3. Make a <u>donation</u> to UNREST to help bring the film to medical schools, leading research institutions, and communities around the world.
- **4. Join** the cause. <u>Volunteer</u> with #MEAction, as they are always looking for patient volunteers and healthy M.E. allies to join their cause to help get the word out.

# We believe a good documentary is just the beginning...

In a world of sound-bites, documentaries provide an opportunity to think, understand, share, and connect with the world.

They are controversial, divisive, fascinating, unexpected, and surprising. They can be thrillers, dramas, comedies, romance, tear-jerkers, and horror films.

Documentaries provide the perfect topic for meaningful conversations. If you want to talk about the things that matter with people that matter then pick a film, invite your friends, and watch & discuss together. It's as easy as that.

Influence Film Club — We are the conversation after the film.