



**Massachusetts ME/CFS & FM**

ASSOCIATION

EDUCATION, SUPPORT & ADVOCACY SINCE 1985

***What Sociology and the Illness Narratives Can  
Teach Us About Living with Chronic Illness***

**Helen McGunnigle**

**Sunday Conversations**

**with MassME**

**May 21, 2023**



# Housekeeping

- ❖ We respect your privacy
- ❖ Please stay muted
- ❖ Put questions/comments in the chat
- ❖ A recording of the main presentation and Q&A will be posted

*We cannot answer questions related to your personal or any specific, medical condition.*

*The information in this presentation is for educational purposes only. Please consult with your physician or other healthcare provider in matters pertaining to your medical care.*

*The presenters remarks are their own opinion, and do not represent the views or opinions of Massachusetts ME/CFS & FM Association.*



# Polling questions!

*We invite you to respond to the following poll questions via Zoom when they appear on your screen.*

1. Have you ever had a friend or family member tell you they didn't believe you were really sick?
2. Have you ever had a doctor tell you they didn't believe in your illness?





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# What the Illness Narratives and Sociology Can Teach Us About Living With Chronic Illness

Helen McGunnigle



# Part I

## ABOUT THE DISEASE

Understanding the earlier histories of the diseases and their shared symptoms

*How did we get here?*





ME/CFS

fatigue, PEM, cognitive difficulties

1957

1985



FIBROMYALGIA

pain and tenderness

1904

1940



CHRONIC

LYME

fatigue, pain, brain fog

1980

2004

MEDICALLY  
UNEXPLAINED  
SYMPTOMS

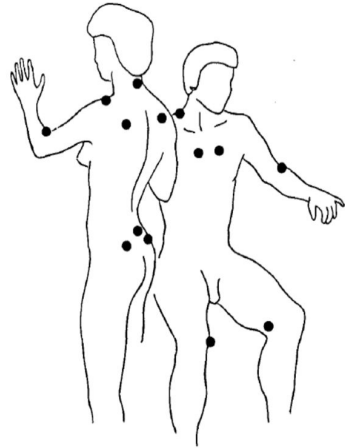
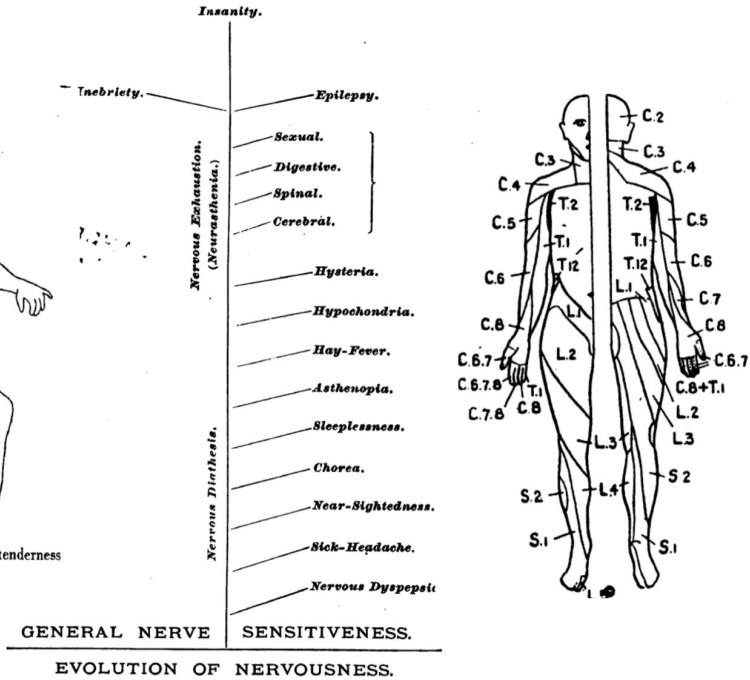
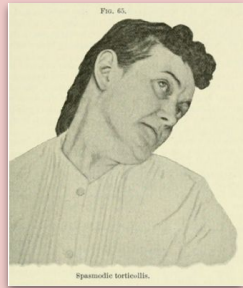
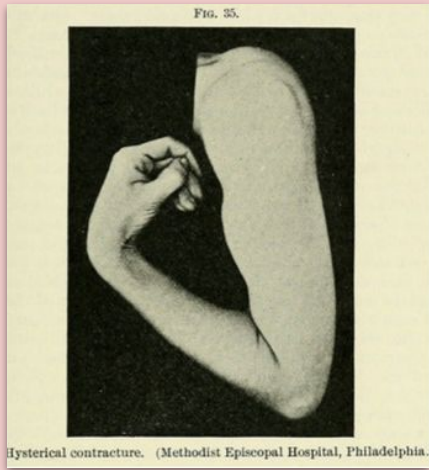
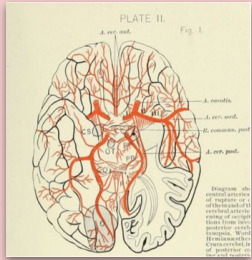
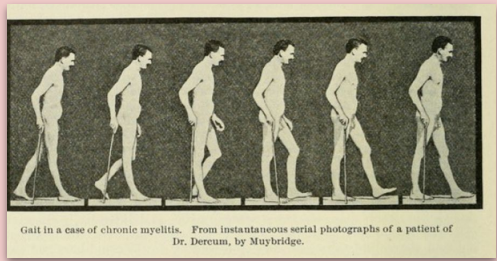
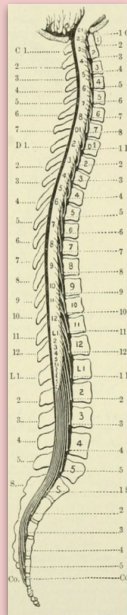


Fig. 1: Location of 14 typical sites of deep tenderness in "Fibrositis".



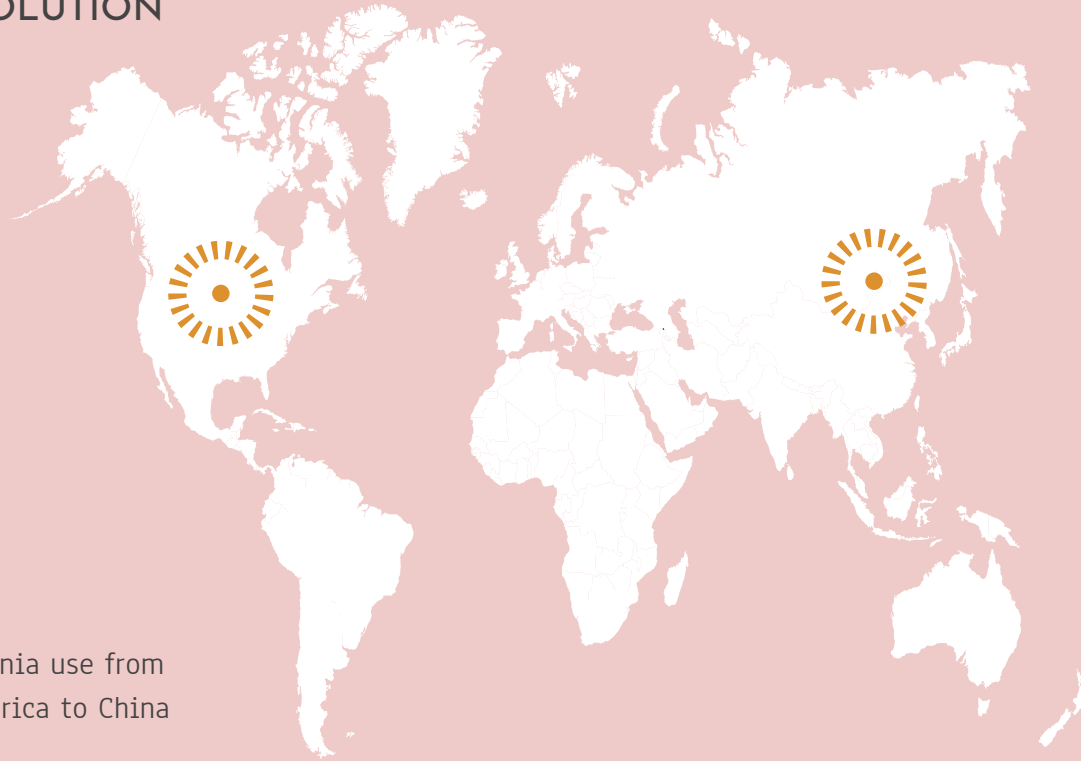
# NEURASTHENIA





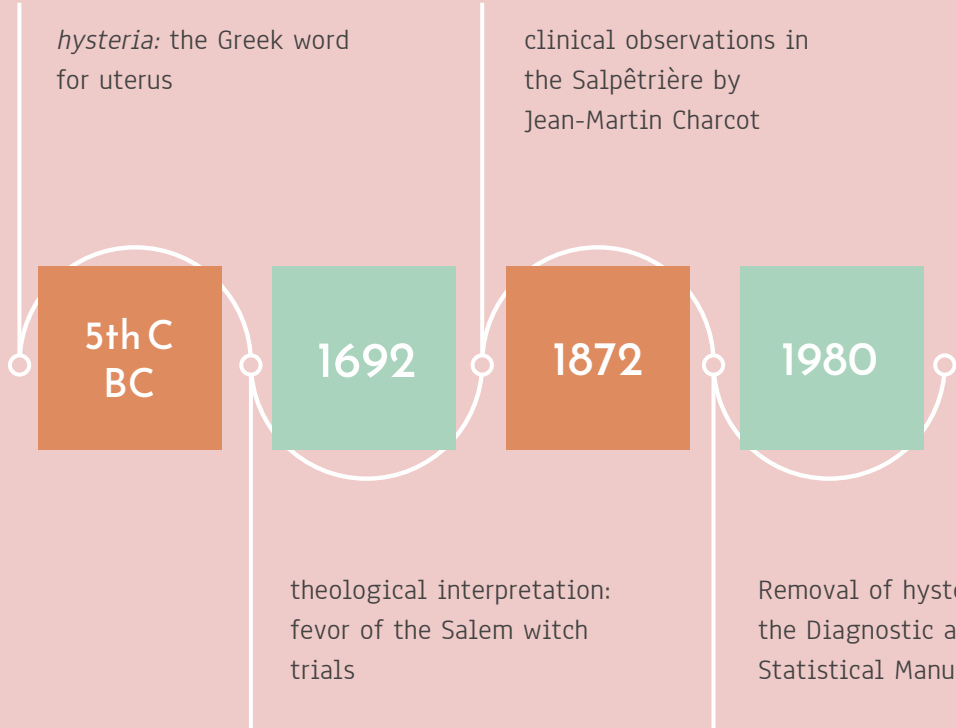
presentations

## EVOLUTION

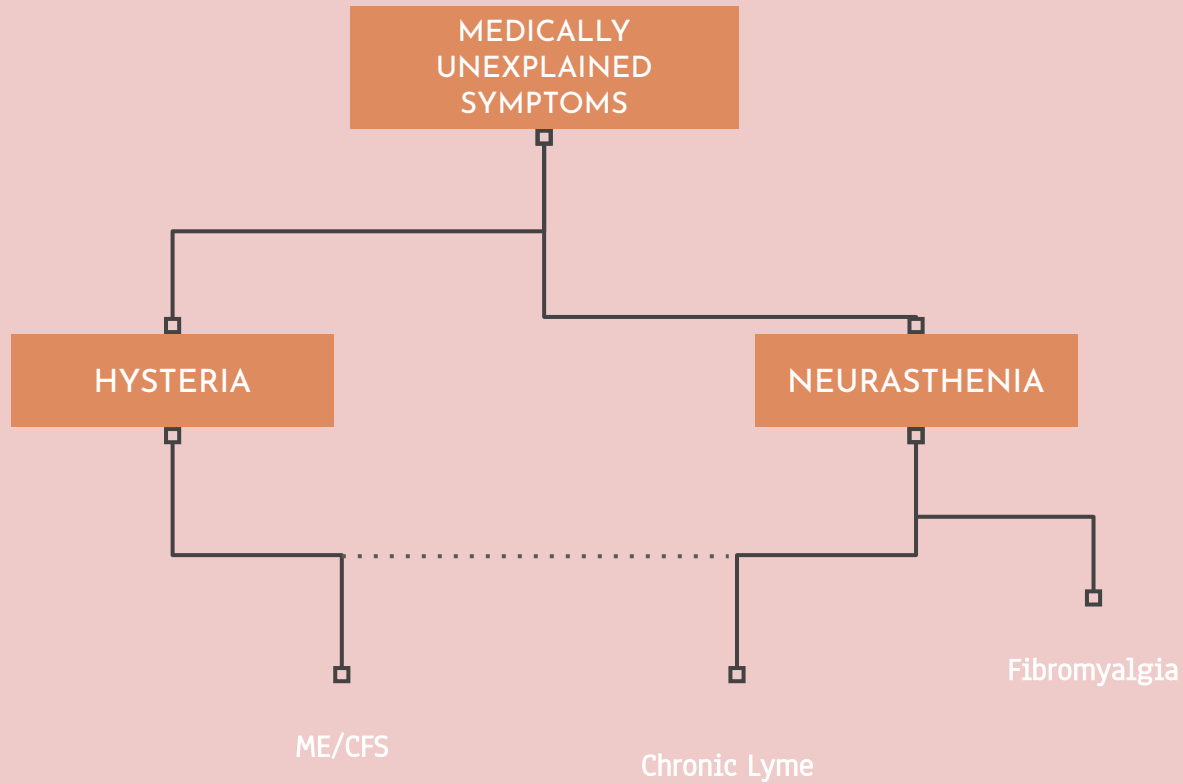


Neurasthenia use from  
North America to China





## HISTORY OF HYSTERIA



CHRONOLOGY

# Part II

## ABOUT THE PATIENT EXPERIENCE

How concepts from sociology  
like the illness narratives can  
help us understand living with  
chronic illness

*Where are we today?*



1 illness narratives

2 goals of medicine

3 typologies of illness and disease

4 unhealthy v. healthy disabled

## CONCEPTS

## DISEASE



physical presentation



confirmed by medicine



quantitative

## ILLNESS



subjective experience



patient reported

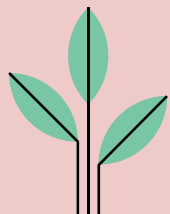


qualitative

Arthur Kleinman's (1988)

## ILLNESS NARRATIVES

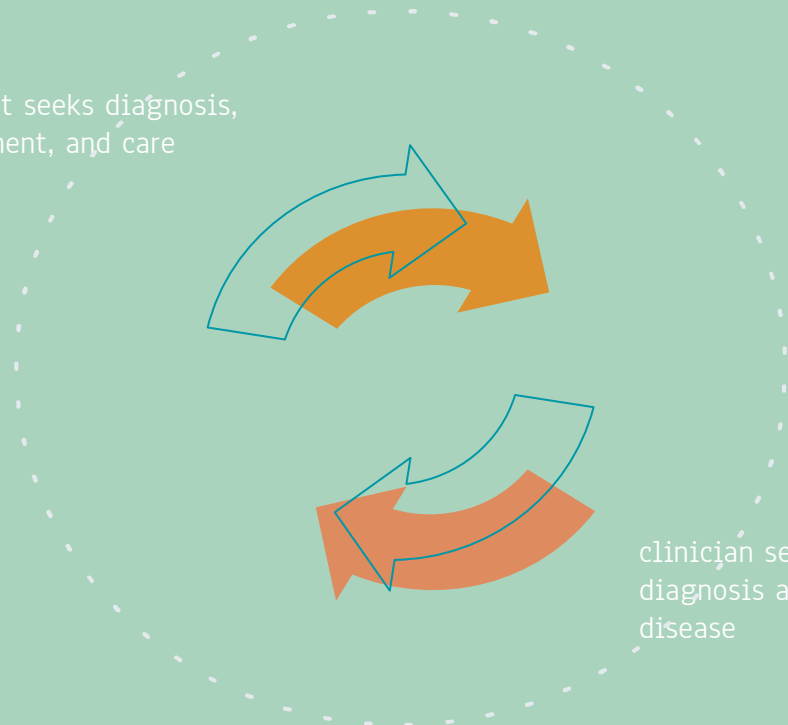




Eric Cassel's (2004)

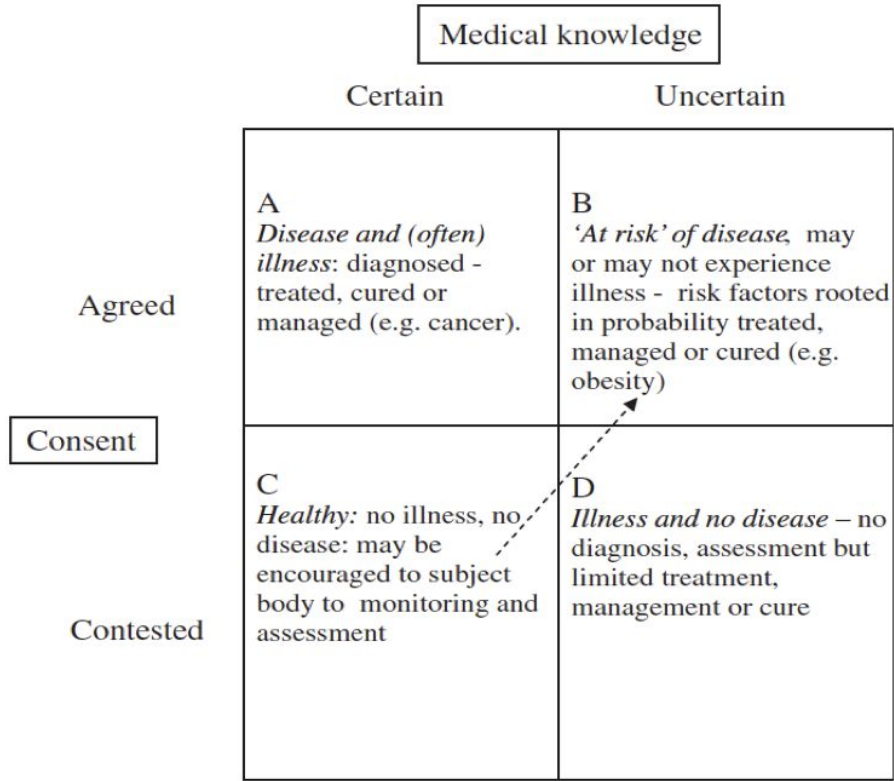
# GOALS OF MEDICINE

patient seeks diagnosis,  
treatment, and care



clinician seeks to  
diagnosis and treat  
disease

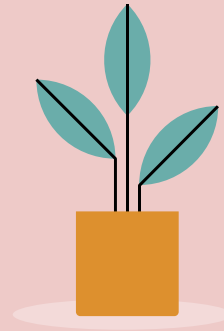
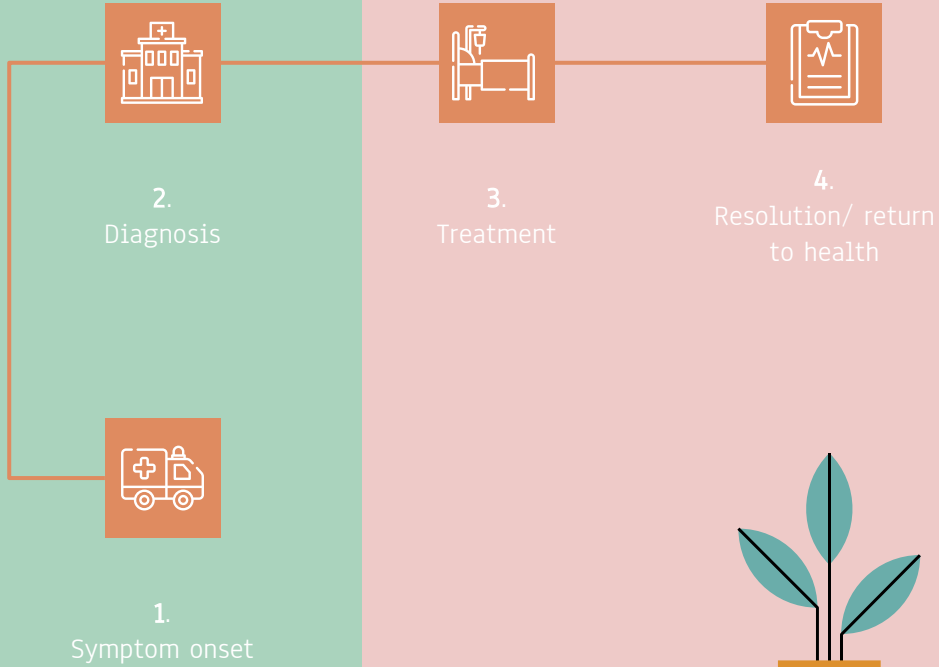




# MANAGING UNCERTAINTY

Sarah Nettleton's (2006) typography of illness and disease

Susan Wendell's (2001)  
unhealthy and healthy  
disabled



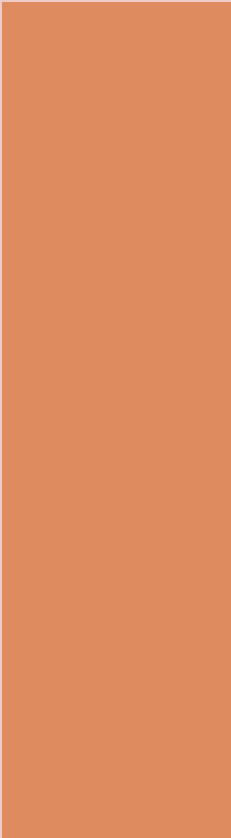
**DISABILITY**

# Part III

## QUALITATIVE RESEARCH

Semi-structured interview of college students living with contested chronic illness

*What do patients report?*





## Doctor/Patient Relationship

How would you describe the relationships with your physician(s)?



## Lived Experience

Can you tell me about a typical day? / How has your daily life changed due to this chronic illness?



## Mental Health

How has mental health been situated in your chronic illness experience?



## Influence of Identity

Do you feel that other parts of your identity influence your chronic illness? (eg. gender, sexuality, race, age, class)

# Ethnographic Methods and the Biomedical Model of Contested Chronic Illness

Helen McGunnigle

**“You Don’t  
LOOK Sick”**

Patient presents with profound fatigue

- Symptom management
- Consider another diagnosis



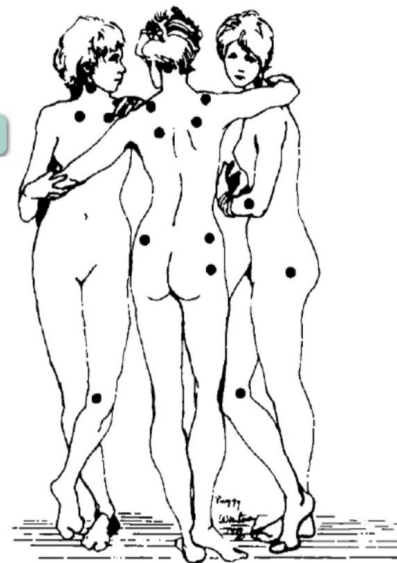
- Symptom management
- Reassess for 6 months
- Consider another diagnosis

- Consider another diagnosis

- Consider another diagnosis



Patient diagnosed with ME/CFS



**“And *YOU* don’t  
look stupid.”**

Collage images from IOM, 2015; Smythe & Moldofsky, 1977; Wolfe et al., 1990.



HYSTERIA



NEURASTHENIA



ME/CFS



FIBROMYALGIA



CHRONIC LYME

CONTESTED  
CHRONIC  
ILLNESS

# THANKS

Does anyone have any questions?

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## Vector

- Medicaments
- Medical
- Hospital line craft
- Hand drawn nurse helping patient background
- Hand drawn nurse taking care patient
- Hand drawn nurse taking care of patient Free Vector
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## RESOURCES



## Images

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<https://doi.org/10.1016/j.socscimed.2005.07.030>

## Works

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Helen McGunnigle

interviewer



Elaine Robinson

interviewee



DISCUSSION

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***No Sunday Conversation in December***

***Sunday Conversations will resume January 21st  
Stay tuned for a series of talks on comorbidities!***

***Have a wonderful holiday!***

