

## **MGH Institute of Health Professions**

### **Invisible Disability: Providing Compassionate Care for a Person with ME/CFS January 15, 2019**

#### **Questions submitted by the 600 graduate students and additional audience members, for the ME/CFS panel at this event**

##### **Daily Function:**

- How do you know when it is going to be a good day?
- How much assistance do you typically need during the day?
- How are your sleeping patterns?
- Are patients able/allowed to drive? How do you or other ME patients commute when necessary?
- How has this diagnosis impacted your family? What changes have been made at home?
- Do you follow a certain diet?
- What does a typical day look like for you?
- What tools have you found that help you communicate/use technology day to day? (for example, we saw people using video chat or vlogging. What helps makes this possible?)
- What is the toughest part of living with ME?

##### **Symptoms and Comorbidities:**

- What percentage of the ME population is bedridden?
- Does ME lower life expectancy?
- What is the suicide rate for people with ME?
- Is there any connection between ME and migraines? Guillain Barre Syndrome? Multiple Sclerosis? Any related pathophysiology that we can look out for to separate ME from these illnesses?
- Are all patients different in their constellation of symptoms?
- Have your symptoms changed/evolved overtime?
- Other than a slowed rate of speech, what are other speech/language differences you have noticed after having ME/CFS?
- Is it true that ME patients often present with inexplicable elevated WBC counts?
- Could you describe the pain that you experience?
- Would you say that ME/CFS is similar to the cognitive impairments patients who have obsessive compulsive disorder (OCD) experience? Why or why not?

##### **Causes of ME/CFS and Diagnosis:**

- Is there any understanding of the cause?
- Is it latent in a person and an infection triggers ME, or does the severe infection cause ME?
- Have any links been found in past medical history that would explain a trigger?
- Is ME contagious?
- What sort of physical trauma can cause ME?
- I understand that ME/CFS does not have any diagnostic test or studies and is basically a diagnosis of exclusion. Based on your experience, how do providers come to this diagnosis of ME/CFS?
- How did you become aware of your diagnosis since a lot of health care providers are not knowledgeable of the disease?

- Is the diagnosis genetic? Do you either of you have children?
- Are there common triggers (i.e. viruses) among the data for patients with ME?

### **Health Care Practitioners' Role:**

- What do ME patients do after seeing their primary care practitioner and become rejected? Usually we rely on and trust our doctors' opinion when we are feeling sick.
- Do you have any experience working with rehab services (i.e. SLP, OT, PT)? If so, can you describe their role in your treatment? Was this intervention helpful?
- Is accessing rehabilitation services (OT, PT, SLP) difficult? What resources can help patients access these resources?
- Have you ever experienced interprofessional care? If so, could you describe your experience?
- For the healthcare providers that have been helpful/ beneficial to you, what qualities have they possessed and what have they done that has set them apart from others?
- What modifications would be helpful during health exams?
- What advice do you have for recognizing and advising more mild ME/CFS patients?
- What specialists do you recommend connecting an ME/CFS patient with?
- What type of specialist ultimately diagnoses ME? If so, do you see them regularly?
- Who coordinates your care?
- How do we teach future clients about pacing?
- Has PT been involved in your care? If yes, how so?
- How can health care practitioners accommodate patients with ME in the health care settings (medical offices, hospitals, outpatient clinics)?
- Have you received home care services from any health professional for ME? If so, what did their services entail and was it helpful?
- Do patients with ME qualify for services like power wheel chairs for energy conservation?
- How can institutions such as the MGH Institute of Health Professions or other workplaces, support students and employees that are diagnosed with ME/CFS?
- As a healthcare provider, how can we convey to ME patients that they are believed and they can trust us with their care?
- Can you elaborate on how we as health care professionals can better accommodate ME/CFS patient needs in our facilities and care plans?
- What do you think could be a nurse's role in your care?
- For a disease with limited treatment options, what are the most comforting words and actions your healthcare providers can give you?
- What are some things you would like the people educating us (future health care professionals) to consider about ME?
- Where should we direct our colleagues for information on ME/CFS if they are unfamiliar?

### **Treatment Approaches and Coping Measures:**

- Does diet have a significant impact on your ME symptoms? Are there any current dietary recommendations?
- What kinds of treatments or interventions (such as medications, supplements, therapies) have been helpful for alleviating your symptoms? (if any)
- What treatment helps most improve your day to day function?
- What treatments and management plans have been especially difficult for you?

- In light of people sharing experiences with “brain fog”, our group wonders if stimulant medications are ever tried? If so, was there any success?
- Are there any non-pharmacological interventions that have worked for patients?
- What is the best medical advice (treatment, medication, etc.) that improved your quality of life?
- Which medications have been the most helpful and which have been the most hurtful/detrimental?
- Do different treatments tend to work best for those with post-viral onset versus post-symptomatic onset? Or is treatment similar regardless of the origin of illness?
- Much of what we do as therapists requires participation from our patients, which could be detrimental to people with ME. What treatments, if any, are on the horizon for you?
- How would you like to see clinicians improve the treatments of ME?
- What interventions can healthcare providers offer to manage symptoms for ME acute phase patients in the setting of active PEM?
- Are there any medications that have been helpful during a crash?
- What strategies, other than pacing activities, did you find helpful in coping with ME?
- Have you found any comfort measures that have allowed you to cope with this disease?
- Have you tried traditional Chinese medicine? Acupuncture?

**Research:**

- Have you participated in any research for ME/CFS?
- Is there any involvement with mitochondria depletion?
- What is the current research for ME focused on? Are there any current research trials?
- Is there any ongoing research that excites you or makes you hopeful for better treatment in the future?
- Has any research been conducted about ATP creation or ATP depletion in connection to ME/CFS?
- Does “hyper” ATP depletion exist?
- Has research found any connection between patients pre-illness level of activity and rate of disease?
- Can you speak about the current and future efforts/ focuses of the ME/CFS collaborative research center at Harvard/MGH?

**Financial Management:**

- What and how much does insurance cover regarding rehab services?
- How do people with ME/CFS receive support if they are living alone and have no family/friends available to help in the area?
- Are there any resources for financial support?

**General:**

- What gives you hope?
- What keeps you motivated?