Journalist Primer: How to Report on ME/CFS

(myalgic encephalomyelitis / chronic fatigue syndrome)

ME/CFS is a multi-system disease that causes profound metabolic dysfunction and is accompanied by physical and cognitive limitations. People experience symptoms on a spectrum from severe to mild, but 75 percent of people with the disease are unable to work and 25 percent are homebound or bedridden.

ME/CFS affects all races, ethnicities, genders, and ages—although 75 percent of those with ME/CFS are female.

Most cases of ME/CFS are initiated by an infection. Up to 80 percent of people with ME report an infectious onset, whether it was SARS-CoV-2, MERS, swine flu, Epstein-Barr, or a bacterial infection, and never recovered. Outbreaks have been documented since the 1930s. Unfortunately, this means that people with Covid-19 are at risk of developing ME/CFS. Based on past viral outbreaks, we are expecting 10-12 percent of all people with Covid-19 will go on to develop ME/CFS.

This guide aims to provide journalists with the facts and tools to accurately report on ME/CFS, and to avoid the pitfalls that further stigmatize a vulnerable population.

❌ DON’T recommend graded exercise therapy or “reconditioning”

People with ME/CFS should NOT undertake graded exercise therapies or push themselves to recondition. The CDC does not encourage exercise to treat ME, and has stated that graded exercise may cause harm.

Graded exercise is the practice of regular, gradual increases in activity over time as directed by a clinician until the patient returns to a healthy activity level. While graded exercise may be useful in patients who are deconditioned after recovering from surgery or a severe illness, graded exercise does not address the global metabolic changes and atypical reactions to activity that cause symptoms in people with ME.

Because post-exertional malaise (a worsening of symptoms after physical or cognitive exertion) is the hallmark symptom of ME, programs that gradually increase exercise may do more harm than good. A recent, large-scale survey found that 81% of people with ME *significantly worsened* after completing a course of graded exercise therapy.

There is also growing evidence that people with ME/CFS experience physiological abnormalities in their response to exercise, including reduced blood flow to the brain and heart, reduced oxygen uptake in hemoglobin, reduced oxygen utilization, and abnormal gene expression, which can explain the short-term consequences and long-term setbacks induced by repeated overexertion.

The Workwell Foundation is a good resource for understanding the underlying pathophysiology of exercise intolerance and how overexertion can hurt people with this disease. World Physiotherapy recommends focusing on rest, hydration and nutrition for people recovering from COVID-19 who are showing signs of ME.

❌ **DON’T say that it is rare.** ME/CFS affects more than 1 million Americans, more than MS or HIV/AIDS. There are an estimated 15-30 million people with ME worldwide.

❌ **DON’T say there is nothing known about ME/CFS.** There are many well-documented abnormalities of metabolism, microbiome, immune system, central nervous system, and autonomic nervous system in people with ME. In particular, 2-day CPETs provide irrefutable evidence of the phenomenon of post-exertional malaise—and you can’t fake a CPET. Read our summary of the past 10 years of scientific studies on ME/CFS here.

❌ **DON’T say that it is a diagnosis of exclusion.** While there is no biomarker and differential diagnosis is crucial, there are still positive criteria that must be met for an ME/CFS diagnosis.

❌ **DON’T call it “mysterious”.** Diseases we call mysterious are those we don’t invest in and research: they’re not inherently mysterious, they’re underfunded and understudied.

❌ **DON'T use a picture of someone yawning at their desk.** Using a photo of someone rubbing their eyes or slumped over with a cup of coffee misrepresents the nature and seriousness of the disease. It suggests the disease is the same as being tired, which is both pathophysiologically and symptomatically incorrect. Most people with ME are severely limited in their day-to-day function: 75 percent of people with ME are unable to work, and 25 percent are homebound or bedbound. People with ME have a worse quality of life on average than those with multiple sclerosis, chronic renal failure, and many kinds of cancer. Find arresting artwork by people with ME here, here and here. (*Please contact artist directly to request to use.)*

❌ **DON'T call it "chronic fatigue".** Chronic fatigue is a *symptom* of many diseases. Chronic fatigue syndrome (CFS) was a name coined by the Centers for Disease Control (CDC) in response to an outbreak of "chronic flu-like illness" in Incline Village, Lake Tahoe in 1984 and several outbreaks and sporadic cases in the United States during the 1980s.

The disease had historically been called "myalgic encephalomyelitis" (ME) since the 1955 outbreak at the Royal Free Hospital in London. In 1969, the World Health Organization classified ME as neurological. Today, U.S. federal officials and clinicians typically refer to the disease as ME/CFS.

✔ DO talk about the risk of long haulers to develop ME/CFS

The pathway to recovery or diagnosis for COVID-19 long haulers will not be uniform. Some long haulers will recover, a subset will go on to develop chronic illnesses like ME/CFS or postural orthostatic tachycardia syndrome (POTS), and some will have long-term consequences due to organ damage alone.

Some long haulers are reporting symptoms that resemble ME/CFS, including post-exertional malaise, as well as cognitive challenges and sleep issues.

Historical evidence tells us that a subset of COVID-19 long haulers will likely go on to develop ME/CFS.

Studies show that viral outbreaks often lead to post-viral illnesses, like ME/CFS. In fact, SARS-CoV-2 is not the first coronavirus to result in documented ME/CFS. A study on SARS showed that 27% survivors met the 1994 CFS criteria several years after developing SARS.

A study on Epstein-Barr virus, Q Fever, and Ross River virus showed that ~12% of subjects across the board met ME/CFS criteria 6 months after clearing the infection; and another study of people with mononucleosis produced identical numbers. Read more.

✓ **DO interview people with ME/CFS**, caregivers, and organizations supporting people with ME, such as #MEAction, the Open Medicine Foundation and Solve ME. These organizations can help connect you with patients, clinicians and researchers.

✓ **DO talk to ME/CFS researchers and clinicians.** The US ME/CFS Clinician Coalition is a good place to connect with expert clinicians.

✓ **DO acknowledge that ME/CFS research has been underfunded for decades.** ME/CFS receives few research dollars relative to disease burden. Government agencies haven't made it easier, and even misappropriated funds in the past.

✓ **DO acknowledge that different triggers can lead to ME/CFS.** While 80 percent of patients say they developed ME/CFS after a viral illness, others became sick after accidents, trauma, toxic exposure, or surgeries. Onset can be gradual or acute.

✓ **DO read the Primer on ME/CFS for Journalists from MEpedia.** Educate yourself more on the science and understand the stigma and misconceptions around the disease.

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