

# ME/CFS – The Devastating Chronic Disease - With No Cure

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## ABSTRACT

The main purpose of this article is primarily to bring much needed media attention and public awareness to the existence of ME/CFS along with Long Covid. Industry respect and legislation support so urgently needed to fund dedicated research for effective treatments and potentially a substantiated cure for the many suffering in silence.

**Abbreviations:** IM: Infectious Mono; NIH: National Institutes of Health

## Introduction

Her eyes dazzled with excitement as she gazed upon her favorite recording artist. Listening to the music, she marveled at how close she was to her #1 idol Taylor Swift. In a baby blue dress reminiscent of Wildest Dreams - she left her seat and began dancing in the aisles of the arena absorbing the thrills of sounds and sights with attending a live concert. Similarly, across town - a young athletic energetic preteen boy at homeplate focuses attentively then swings his bat like his hero Aaron Judge for a base hit. Running effortlessly and swiftly, he slides smoothly into first base as his proud Dad looks on and smiles anticipating a tremendous year for their little league team at school. But that was then. And then came ME/CFS. And then came Long Covid. Putting away her dancing shoes, this young woman became another unfortunate statistic. Dancing at concerts reverted to a lifelong confinement in bed. And while preteens and teens prepare for back-to-school classes and sports activities – that young man's baseball bat is locked away in the bedroom closet as this little leaguer now remains restricted homebound in a wheelchair .....like so many others... .....like too many others...

A top notch teacher suddenly struggles completing his objectives and course outline for his high school class...the laboratory professional who once multi-tasking analyzed test results in stat workflow now lies in a hospital bed awaiting his own test results...the doctor who successfully treated so many kids from colds to cancer now forced into sudden retirement...a mother grocery shopping now naps in the car exhausted before driving home...a neighbor just doing errands around town now requires a drive home...an office worker totally wiped out now spends all his nights and weekends recovering... What happened to all of them? What dramatically changed their lives? What happened is ME/CFS.

### What Exactly is ME/CFS?

Myalgic Encephalomyelitis /Chronic Fatigue Syndrome is real - a legitimate complex debilitating chronic illness unfortunately systemic affecting multiple body systems. This disease "is associated with neurological, immunological, autonomic, and energy metabolism dysfunction" (Institute of Medicine 2015).

• **Note:** Many patients with ME/CFS concurrently are also afflicted with degenerative autoimmune diseases (immune system of the body attacks the healthy tissues and organs) along with POTS (Postural Orthostatic Tachycardia Syndrome – a disorder of the autonomic nervous system) and neuropathies and FMS (fibromyalgia) and now also Long Covid (chronic illness persisting after an initial COVID-19 infection).

All these incapacitating illnesses require comprehensive care for ongoing persistent hindering features. All these chronic disabling manifestations prevent recovery to the once pre-infection health -- and hence thwarting any return to any remnants of a normal life. ME/CFS along with autoimmune diseases and FMS and Long Covid – progressively leave patients critically debilitated with chronic conditions and a most significantly lessened quality of life.

### What Causes ME/CFS?

The mystery continues unsolved as the exact etiological agent unfortunately remains still unknown. To exacerbate focus on a source - there seems to be multiple suspected causes which may trigger responses. These include infections and viral illnesses such as mold, Lyme, Infectious Mono (IM), radiation therapies, surgeries, inflammation, toxins, injuries, and genetics.

### Who is Affected?

Everyone is at risk. ME/CFS attacks from every age, racial, ethnic, and socioeconomic groups. According to the CDC - not hundreds – not thousands – but millions suffer from chronic fatigue syndrome alone with the US noting an estimated up to 3.3 million individuals affected. Additional studies project between 5 – 9 million Americans suffer from ME/CFS with further estimates varying from 17-24 million people with ME/CFS worldwide. Children to adolescents to adults can succumb to this debilitating illness at any time. ME/CFS may begin as early as age 10 and as late as age 77. Those in the public eye battling the ailments of ME/CFS include Americans early retired footballer/soccer player Michelle Akers, authors Ann Bannon and Toni Bernhard, music publicist Howard Bloom, filmmaker Jennifer Brea, founder of ProHealth Rich Carson, early retired racer Ricky Carmichael, singer Cher, singer of Styx Dennis DeYoung, actress Lena Dunham, actress Morgan Fairchild. Fibromyalgia has been reported with singer Lady Gaga and actor Morgan Freeman. Similarly – Long Covid has been associated with actors and musicians from Lena Dunham, Gweneth Paltrow, Salma Hayek and Billie Eilish to athletes such as hockey player Jonathan Toews, and TV personality Chris Cuomo and even bipartisan politicians Sen Jim Inhofe (R) and Tim Kaine (D).

### How is ME/CFS Diagnosed?

Whereas over 70% of medical decisions rely on diagnostic testing in the laboratory – blood/urine and body fluid testing ordered by providers and performed by medical laboratory professionals – for this

insidious disease – laboratory tests can only serve to rule out other conditions. The medical provider instead resolves to rely on physical and mental review and investigation of the patient's symptoms assessing the frequency and severity of symptoms in order to determine the exact debilitating afflictions being experienced. Unfortunately, therefore, too often, ailments remain undiagnosed for years due to the complexity of the symptoms noted and lack of definitive diagnostic testing available.

### What are The Symptoms?

Most patients report a sudden lack of energy - while also experiencing neurological pain. And to complicate the complexity of these undermining conditions – these chronic diseases may affect each person very differently. Overall – ME/CFS is characterized by prolonged severe fatigue with symptoms that worsen after even the most simple physical or cognitive exertion (known as post-exertional malaise, or PEM), sleep disturbances, brain fog, difficulty thinking, dizziness and orthostatic intolerance (the medical term for when standing up causes symptoms), headaches, muscle weakness and pain, and so much more. According to data provided by the CDC - unpredictable symptoms range from 5 core basics: 3 main primary symptoms & at least 1 of the other 2 symptoms:

1. Diminished ability to perform general and routine activities accomplished prior to becoming sick – lasting 6 months or longer. The fatigue is noticeable and can be severe with no relief upon resting or sleeping.
2. Symptoms become seriously worsened after any physical or mental activity – no matter how minimum in extent or nominal the activity may be. This is referred to as PEM or Post Exertional Malaise.
3. Serious sleeping disorders – unrefreshing sleep - from needing sleep to inability to achieve sleep. Even a good night's rest affords no consolation to the constant severe fatigue experienced.

And at least one or two of any of these additional symptoms – although patients may suffer all.

- Problems with memory/ thinking/ concentrating
- Dizziness or fainting when standing upright (orthostatic intolerance)

Other common symptoms include:

- Muscle Pain/Joint Pain/ Headaches
- Lymph Nodes tender/Sore Throats
- GI disorders
- Chills/Night Sweats
- Allergies
- Muscle weakness

- Shortness of breath
- Irregular heartbeat

From a cycle of 'pushing' to do more – the individual experiences what is known as a 'crashing.' The consequential symptoms include severe dizzy spells with migraines and headaches, severe tiredness yet difficulty sleeping, brain fog with inability to think simple. Recovery from a 'crash' takes days to weeks. Most patients - if even able to communicate with others - prefer simple short texting to the strains of listening and speaking. Others revert to 'noise cancelling' options on headphones to requiring 'complete silence' – as there are days 'cannot tolerate sound and just need quite' - any sound can 'make the situation worse' causing 'feeling sicker.' Simple chores from food shopping and cleaning or cooking and even just taking a shower or having a conversation - watching a movie - attending class in person - completing homework - talking - listening to music - may cause a temporary crash to a more permanent set-back situation. Listening to any patient explain their symptoms is extremely overwhelming: 'insanely tired' 'constantly feeling sick' 'having the same symptoms every single day' 'only declining' 'crippling fatigue' 'internal tremors' 'low blood pressure' 'muscle weakness' 'unrelenting migraines' to 'just trying to get through another day' 'doing about the same as always' 'struggling' 'trying to hang in there' 'progressively worsening'. Guilt and stigma abound for young kids confused and conflicted as to why they were targeted.

This continues for young adults incapable to be independent as well as adults from struggling to unable to work and take care of their families: 'wish I could say doing better' 'hanging in there' 'feeling I am not living up to my commitments and responsibilities' 'am so dependent on the kindness of family and friends'. As tough and difficult to deal with physically, mentally, emotionally for so many suffering - so too for the caretakers - families trying to bring some level of comfort to their loved ones experiencing all this every single day. Perhaps the most disheartening is hearing a distraught mother in desperation witnessing her daughter wither away: 'if it were cancer, at least some course of remission could be available'. Once stricken with ME/CFS along with other chronic illnesses and Long Covid – individuals once loving living and energetic – dramatically transform into casualties presented with the forever ongoing dramatic challenges of complicated and enfeebling afflictions.

### Cure? – Treatment?

NONE. Absolutely none. There is NO cure – and there is NO effective treatment. These illnesses are progressive – patients 'will continue to decline unless something is developed to help treat or put diseases into remission.'

Unbelievably heartbreaking – but today's modern advanced medicine still has no medication currently approved to treat ME/CFS. Ironically - while chronic illnesses never let up - many times

the treatments themselves intended to relieve some of the pain and suffering are extremely tough and a strain and in turn cause 'wipe out' episodes. Medical assistance available and provided falls short of any nominal or real relief and is based on the patients' symptoms suffered. Prescribed medications to treat individual symptoms range from a variety of assorted meds including scheduled IVIG infusions, immunosuppressants, antidepressants, pain relievers, and sleep aids. But these are temporary at best and superficial at most - leaving patients yearning 'wish it helped more' or 'that there was something to make a more drastic difference.' In addition, healthcare providers' recommendations can only advise for the limited process of 'pacing/resting,' or the use of wheelchair for any required mobility – and use of noise cancelling aids for sounds around us which most of the general population enjoy listening to.

### Prognosis?

ME/CFS patients patiently anxiously continue to hope for any treatment and any cure to 'make all this go away' - to once again be able to live some form or semblance of a normal lifestyle. Patients are unfortunately continuing to be dependent on limited ineffective medical treatments available only for the symptoms experienced. The cure is still unknown - the etiologic agent remains so much a mystery. According to studies conducted, patients distressed with ME/CFS are dying at a younger age compared to the overall population. All-cause and cardiovascular-related mortality reached statistical significance. The all-cause mean age of death for one research projected only up to 55.9 years.

### \*\*\*\*\*What Does the Future Promise?\*\*\*\*\*

Fortunately - SOLVE ME exists as a prominent American non-profit organization with a resolute mission to enable and encourage extensive research for diagnosis and treatment for ME/CFS and Long Covid and other post-infectious diseases. This premier organization also educates and strongly advocates for increased public awareness and funding along with access to medical care. Emily Taylor is presently the President of SOLVE ME, but she is also caregiver to her mother who suffers ME CFS and her brother who succumbed to Long Covid. "...So many families navigate... misunderstood underfunded disease which there are no FDA approved treatments or cures" – Emily Taylor (CEO/Pres of SOLVE ME). SOLVE ME initiatives "make breakthroughs possible with comprehensive programs": Sim Ramsey grants secured funds for researchers – over 37 original projects; 22 scientific papers published; funds raised for viral diagnostics at NIH; over 1,168 meetings with congressional leadership; over 2,000 organizations recruited; over 30 free webinars and events; funds secured for Long Covid research & clinical trials. The mission of SOLVE ME is to "educate US leaders, grow research funding, and maximize data collection for ME/CFS and Long Covid." Most recently – Due to decades of lack of research funding and limited treatment options - Solve M.E. proudly endorsed and urges quick passage and funding of the Long COVID

Research Moonshot Act of 2024 for all individuals affected by IACCs (infection-associated chronic conditions).

ME SOLVE: "The bill requires that the National Institutes of Health (NIH) conduct comparative research to understand the similarities and differences between Long Covid and other chronic conditions with similar characteristics, including ME/CFS which is mentioned by name."

## Summary

Incomprehensible how so many are experiencing these unimaginable debilitating conditions across this nation in every state and in every city and in every community - with so many grasping for an almost unattainable wish 'for effective treatment and a definitive diagnosis with a cure.' It is most discouraging that more media attention and public awareness and industry respect and legislative support has not been realized in real time - considering the number afflicted and the extent in society affected - from every day citizens to celebrities. Time pauses eerily motionlessly while searching for the needle in the haystack. 'My life is busier than usual with doctors and infusions' - 'just stressful - trying to manage all of it' - 'hoping to get through this day and this month and next' - 'waiting so long on something... anything... to make a difference.' The road is too long and winding for all those sufferers. Effective treatment must be found. And a cure must be discovered. None of these patients should ever be expected to ever live another day in constant fear of no hope. They continue to succumb to these insidious diseases - how much longer can their bodies survive - remaining so devastatingly incapacitated. Let there be a light at the end of the tunnel. Let the young girl put on those dancing shoes again. Let that young boy pick up his baseball bat again and swing into home plate. Let there be some semblance of a normal life for millions afflicted.

As a medical laboratory scientist - calling upon all healthcare and public health and stem and research professionals to focus microscopic attention - put patient care first - someone somewhere find that effective treatment and cure for ME/CFS and Long Covid. Relieve the torment and tribulations for my family and yours, for our friends, neighbors, and colleagues - especially those already homebound senselessly agonizing every single night, every single day, every single hour, every single minute. And... someday... is already too late. Cure ME/CFS and Long Covid - now - in our lifetime [1-25].

## Acknowledgement

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