

What is and isn't ME/CFS?



**EXPLAINING THE
NEUROIMMUNOLOGICAL DISEASE
MYALGIC ENCEPHALOMYELITIS /
CHRONIC FATIGUE SYNDROME**

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@m.e_and_more

MECFS is: Myalgic Encephalomyelitis

ME (ICD-10-G93.3) is a neuroimmunological disease that causes extreme fatigue as well as metabolic, cardiac, gastrointestinal, immunological and neurological symptoms made worse by exertion in a process known as post-exertional malaise or post-exertional neuroimmune exhaustion.

Diagnosis is by symptoms and the International Consensus Criteria requires:

- 1.) Post-exertional malaise
- 2.) Extreme fatigue lasting over 6 months in adults and 3 months in children
- 3.) Symptoms in each of 3 categories
 - Neurological / Pain
 - Cardiac / Metabolic
 - Gastrointestinal / Immunological

If symptoms are only present in 2/3 categories a diagnosis of atypical ME can still be made. ME is not a diagnosis of exclusion and can be diagnosed alongside other conditions.

MECFS is: misnamed Chronic Fatigue Syndrome

The name chronic fatigue syndrome or CFS is sometimes used to refer to ME.

This is confusing because chronic fatigue is a symptom of many diseases and the distinguishing feature of ME is not fatigue but PEM, the cascade of metabolic and neuroimmunological consequences of exertion.

For every 20 people with chronic fatigue only 1 has ME and treatments for chronic fatigue will not fix ME.

The name CFS is also extremely dismissive of the severe disability caused by ME.

"It is the equivalent of saying someone with dementia has a chronic forgetfulness syndrome."

-Dr. Charles Shepherd

MECFS is: defined by Post Exertional Malaise

PEM also known as Post Exertional Neuroimmune Exhaustion (PENE) is an exacerbation of symptoms 24-48 hours after physical or cognitive exertion.

Exertion can be anything from a run in newly diagnosed or very mild patients to rolling over or sitting up in very severe patients. Cognitive exertion can include tasks like reading, math and administrative work.

Symptoms made worse or triggered by PEM include (with prevalence):

- | | |
|--------------------------------|---|
| -Fatigue 99% | -Headaches 78% |
| -Cognitive dysfunction 97% | -Increase heart rate/heart palpitations 77% |
| -Muscle pain 88% | -Ataxia 77% |
| -Muscle weakness 87% | -Nausea 62% |
| -Insomnia 87% | -Trouble breathing 58% |
| -Temperature dysregulation 87% | -Migraine 46% |
| -Flu-like symptoms 87% | -Paralysis 29% |
| -Wired but tired 82% | |

Symptom prevalence from (Lenord A Jason et al, 2019) with less than half of the 39 studied symptoms listed.

MECFS is: a spectrum disability

Mild ME is a severe illness. Severe ME is a life-threatening illness.

MECFS is a fluctuating disability, patients may move between stages of illness, especially during PEM. Cognitive impairment, physical impairment, and impairment from symptoms all vary independently between patients.

@m.e_and_more unofficial severity scale

STAGE 1	1. Chronically ill workers 2. Living in the gap
STAGE 2	3. Fulltime chronic illness 4. Mostly housebound
STAGE 3	5. Mostly bedbound 6. Bedbound
STAGE 4	7. Bedbound Suffering 8. Hospital Level Care
STAGE 5	9. Near-Death Experience 10. Dead

MECFS is not: caused by deconditioning

Patients with MECFS may experience deconditioning as a result of their illness.

However, deconditioning does not explain metabolic and cardiac abnormalities seen on 2-day cardiopulmonary exercise tests and tilt-table testing in MECFS (1, 2). Nor does it explain evidence of neuroinflammation (3) or the abnormal immune response to exercise in these patients (4).

Therefore, treatments for MECFS that simply presume patients are deconditioned such as graded exercise therapy (GET) will not work.

Trying to cure a patient with MECFS through reconditioning is like trying to cure a broken leg by pretending the leg is healed and trying to walk on it. You have not addressed the underlying dysfunction causing post-exertional malaise. Therefore, you will only trigger more PEM potentially causing permanent damage.

GET is not recommended as a therapy or cure for MECFS by NICE, Mayo Clinic, or the CDC. Instead, the opposite is recommended: pacing or learning to live within your energy limits and listen to your body so that you do not trigger post-exertional malaise.

Sources:

- (1) <https://doi.org/10.2522/ptj.20110368>
- (2) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8097965/>
- (3) <https://doi.org/10.2967/jnumed.113.131045>
- (4) <https://pubmed.ncbi.nlm.nih.gov/24974723/>

MECFS is not: depression or burnout

While MECFS may cause someone to burnout or get depressed it is not a mental health problem.

Someone with MECFS may appear similar to someone with depression on the outside. They may stop engaging in hobbies, socially isolate, and spend most of their time in bed. But the cause of this behavior is completely different.

If you ask a person with depression what it is they wish they could they will have few answers. They lack motivation. In contrast, someone with MECFS will have a million plans and activities they are dying to get back to if their bodies would only allow them to.

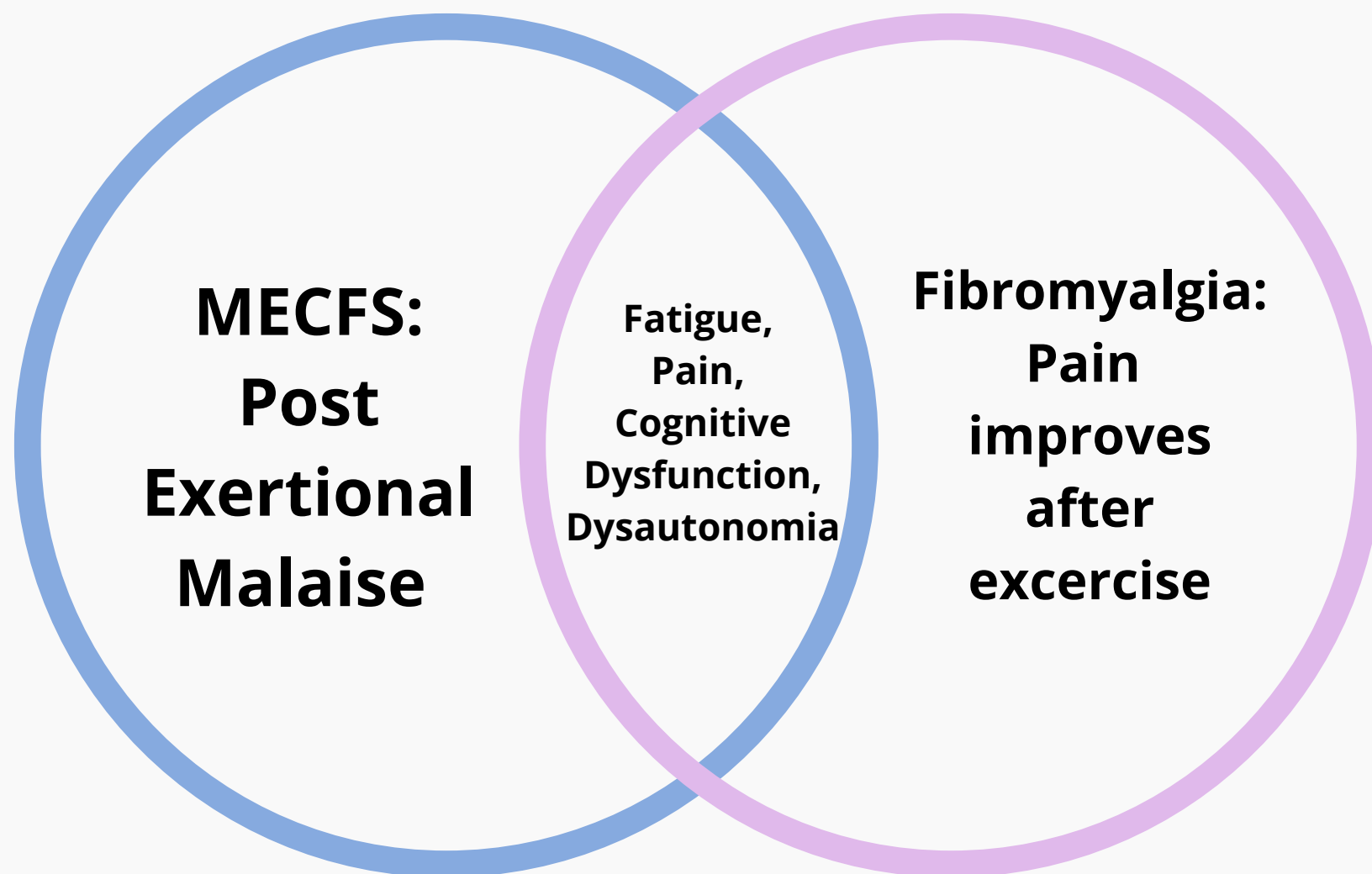
Because MECFS is not caused by distorted thinking or a lack of desire or fear of engaging with activity, cognitive behavioral therapy (CBT) cannot cure it. Therapy can only help patients to mentally cope with their disability and chronic illness.

MECFS is not: fibromyalgia

While MECFS and fibromyalgia share many symptoms they are distinct illnesses and neither is a diagnosis of exclusion. This is important because fibromyalgia responds positively to most exercise therapy whereas MECFS patients must avoid most or all exercise to prevent post-exertional malaise.

Patients may have both fibromyalgia and MECFS in which case care must be exercised to balance treatment for both conditions.

The following ven diagram shows the overlap and differences between MECFS and Fibromyalgia



MECFS is not: curable

There are no FDA-approved treatments for MECFS. Only 5% of patients recover.

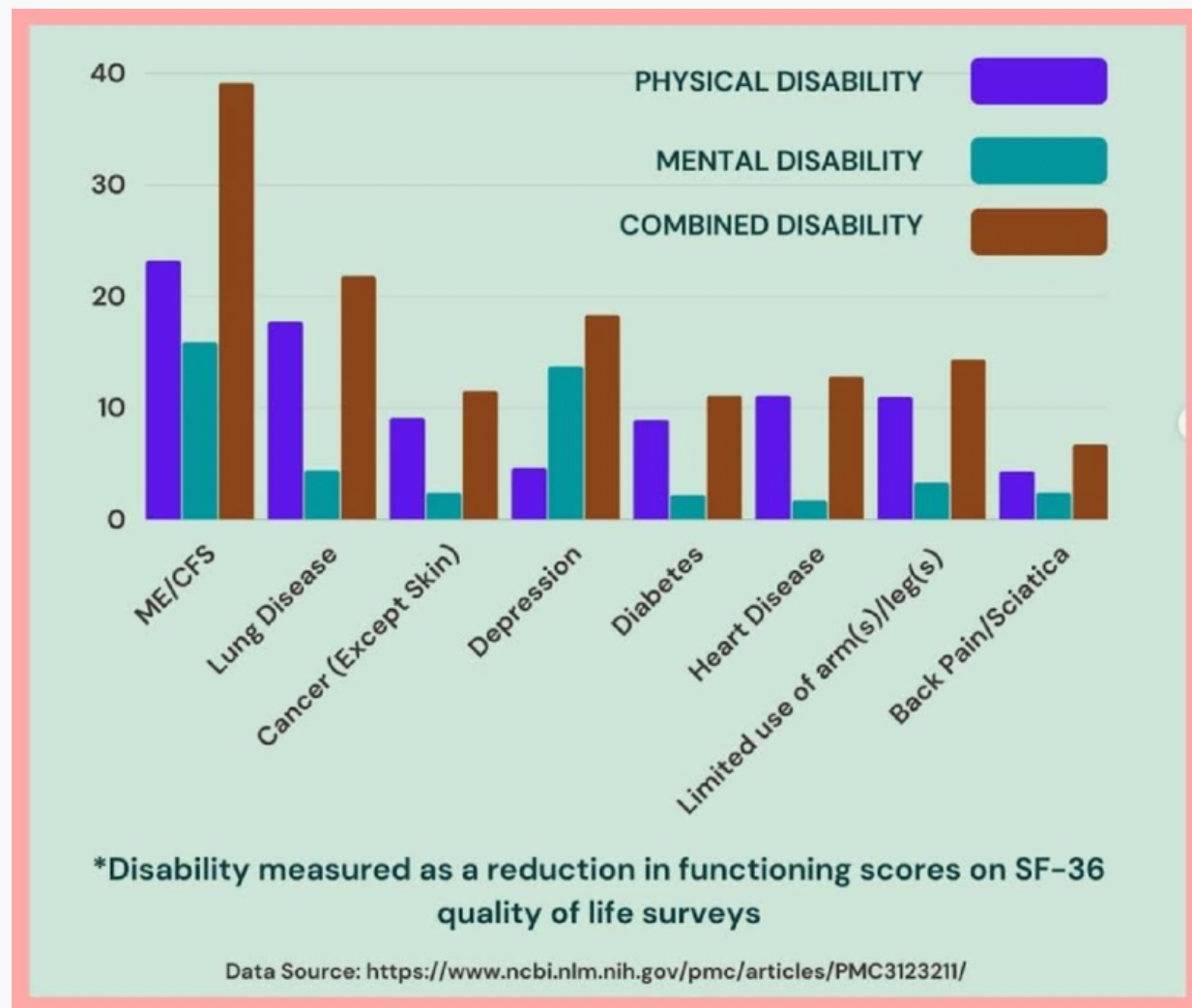
The reason many people online claim to have recovered from MECFS is multifold:

- 1.) 5% of 20+ million people is still over a million people.
- 2.) Recovery from post-viral fatigue syndrome a condition that is essentially equivalent to ME but occurs within 6 months of viral illness is common. Recovery from ME is also likely much more common within the first year.
- 3.) Recovery from chronic fatigue, fibromyalgia, burnout and depression is much more common than recovery from ME and these conditions are often misidentified as MECFS.

The only "treatment" for MECFS is pacing. Pacing means rationing your life. It is not treatment, it is an adaptation for survival.

While there is nothing we can do to cure MECFS, it is still essential that patients follow pacing guidelines to avoid deterioration and maximize their chance of remission.

MECFS is: severely disabling



The above chart shows the functional disability caused by MECFS compared with other well-known illnesses using the WHO's SF-36 questionnaire. This questionnaire is insufficient to measure the extreme physical disability caused by MECFS with 89% of patients hitting the maximum score on role limitations due to physical health (Murdock et al, 2018).

MECFS is not just being "a bit tired." It is not just life-changing bone-aching fatigue. At its most severe it leaves patients tube-fed and paralyzed facing untold years of extreme pain sensory deprivation and solitary confinement.