ME/CFS

ME/CFS Prevalence

This disorder affects roughly 1 percent of the population

Accordingly, here are some conservative estimates: 3 million in the USA, 4 million in the European Union, and 200 thousand in Australia.

2015 IOM Diagnostic Criteria

The presence of three of the following symptoms for more than six months.

The intensity of the symptoms should be moderate or severe at least 50 percent of the time.

Fatigue

Post-exertional malaise

Unrefreshing sleep

Criterion for diagnosis requires all three of the above-mentioned symptoms plus one of the two symptoms below.

Cognitive impairment

Orthostatic intolerance

What Causes ME/CFS?

The exact cause of this disorder is unknown.

Most people report some combination of a significant viral condition, overwork, anxiety, challenging life events, exposure to toxins, or Lyme disease from a tick bite as contributing to the development of their illness.

It has been established that certain physical markers are associated with CFS. A review of the literature in the Journal of Clinical Medicine in 2021 noted that homeostasis of the immune system is dysregulated in CFS. Individuals with this condition also experience increased oxidative stress following exercise.

Treatments

Medical- There are numerous medical conditions that can cause fatigue. All possibilities should be ruled out or treated. CFS is diagnosed when no other explanation for the symptoms is found. Unfortunately, there are no tests for CFS, nor are there accepted medical treatments.

Pacing- Pacing is one aspect of treatment that most agree upon. The level of activity must be reduced to avoid PEM. Each person must determine the baseline level of activity that they can tolerate and work from there.

Diet- Most people make some changes to their diet. Individuals with CFS seem to do better when they decrease their intake of processed foods, sugar, fatty meats, and alcohol. A Mediterranean diet that includes more fruits, vegetables, whole grains, and healthy fats may well represent a healthier choice. There is no supplement that has been proven to help people with CFS, but there is a great deal of experimentation by sufferers.

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Treatments Continued

Movement - Graded Exercise Treatment (GET) has been shown to be harmful to most people who participate in this method. GET advocates participating in walking or some other exercise and then increasing the time or distance by a certain percentage each week. The originators of this model hypothesized that CFS fatigue was caused by physical deconditioning and fear of activity.

*Most people who report recovering generally do some type of exercise. More attention should be given to studying the best ways to do this.

Psychological - Cognitive-behavioral therapy (CBT) has been shown not to be effective. CBT theory holds that individuals with CFS avoid activity, get deconditioned, and focus too much on symptoms. Treatment consists of helping patients stabilize their patterns of activity, rest, and sleep. (Ignore what your body is telling you and push ahead?)

Brain retraining is the other main psychological treatment. The theory behind this method is that the nervous system becomes overloaded by a combination of environmental and psychic stressors. The amygdala incorrectly interprets further symptoms as threats and gets stuck in "fight or flight" mode. Treatment consists of relaxing the body and mind through meditation and other methods, providing safe messages through self-talk and visual imagery to avoid overreaction to symptoms, improving coping skills, and dealing with trauma and other emotional issues. Most programs do train people about pacing, as the thought is that it takes considerable time for the mind to adjust its patterns.

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Treatments Continued

Limited research-based investigation has been done on brain retraining. Ashok Gupta conducted a clinical audit of 27 individuals who had been in his program for 6 months or more, and two-thirds of the participants rated themselves as being within 80 percent of their pre-illness functioning. Alexandra Batty conducted a survey of 139 people with CFS in Gupta's program, and the average score increased from 28 before treatment of 3 months or more to 48. The threshold for full recovery was 80.

Some other well-known programs are DNRS by Annie Hopper, ANS Rewire by Dan Neuffer, and Re-Origins by Ben Ahrens. There appear to be many anecdotal reports of some success with brain retraining among the CFS community.

It appears that brain retraining is a useful tool in combating CFS. However, it does not seem to work equally well for everyone, and it may not fully account for the physical aspects of the disorder. John Sarn and other functional medicine providers have achieved good results in reducing pain and other physical complaints through mind-body approaches. The same reasoning may not be fully applicable when treating CFS, where the primary symptom is fatigue.

So, What Should My Plan Be?

There is hope. Five to eight percent recover, and that number is likely higher for those who go through programs.

It appears that the majority of those who recover do so by working in five main areas- medical, pacing, diet, mental health, and exercise. It is for each person to decide which areas they need to focus on the most.

The Power Up program offers some exciting new ideas to consider, along with dynamic tools.