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# MECFS



What your sick loved  
one needs you to  
know.

**PART 1**



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# What does MECFS stand for?

Starting from the name Myalgic Encephalomyelitis means

My (muscle) algic (pain)

Encephalo (Brain and spinal cord) myel (muscle) it is (inflammation)

So in short our muscles and neurology are inflamed and in pain. When your body attacks itself like this, it is called an autoimmune disease. Other autoimmune diseases you might have heard of include arthritis, MS, or lupus. ME is classed by the world health organization as a neuroimmunological disease which means an autoimmune disease affecting the brain.

ME also has the name CFS or chronic fatigue syndrome because it causes severe energy deficiency leading to severe chronic fatigue. But chronic fatigue is only one small part of MECFS and 20× more people have chronic fatigue than have MECFS.

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# What symptoms does MECFS cause?

MECFS causes a massive number and variety of symptoms. Its normal for people with ME have between 50 and 100 distinct symptoms!

Some of the most common symptoms include:

- |   |  |
|---|--|
| -Chronic Pain                             | -Sensitivity to Light, Sound, Motion and Touch |
| -Chronic Fatigue                          | -Sensitivity to Medication, Chemicals or Food  |
| -Muscle Weakness, Spasms or Tremors       | -Sudden Mood Swings                            |
| -Stroke or Seizure Symptoms               | -Headache & Migraines                          |
| -Brain Fog                                | -Low-Grade Fever                               |
| -Sleep Disturbance                        | -Sore Throat                                   |
| -Dysautonomia and Orthostatic Intolerance | -Frequent Infections                           |
| -Stomach Symptoms                         |  |

However, the one symptom most unique and important to MECFS is PEM / PENE. Which stands for Post Exertional Malaise or Post Exertional Neuroimmune Exhaustion.



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# **What is PEM? What does it mean when you crash?**

Post Exertional Malaise is the primary and most important diagnostic symptom of ME/CFS.

You can think of it like an old car battery. When you let the battery run down to nothing, it can damage the structure of the battery. For people with ME if they do too much activity it makes all of their fatigue and symptoms worse. They breakdown in a crash.

It's important to know that crashing the body like this can do long-term damage. That's why it's important for people with ME to avoid overexertion. Not just to avoid the symptoms it causes, but to protect their future health.

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# Isn't fatigue just a fancy word for tired?

While fatigue can feel similar to being really tired (to approximate how tired someone with ME is every day you would have to pull 3 back to back all-nighters) it isn't the same.

When you are tired you can rest and that rest makes you feel better. Tiredness is also the result of doing something. You used up energy and your body is making more to refill your tank.

In contrast, when someone with fatigue wakes up in the morning they do not get more energy. While sleep is still necessary for people with fatigue, it doesn't alleviate their tiredness. Your body can't make enough energy no matter how long you wait around.

Fatigue in ME is the result of a lack of chemical energy or ATP. When people ingest cyanide it kills them instantly by stopping the production of ATP. The fatigue from ME is like always being slightly poisoned with cyanide.

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# WTF is "brain fog"?

Brain fog is a general term used for the many cognitive dysfunctions that occur in people with ME. These cognitive dysfunctions can be confusing because they fluctuate and manifest in many different ways.

Common brain fog problems include:

Suddenly forgetting what you were saying

Getting lost in familiar places

Forgetting to do routine actions like locking the door or turning off the stove

Being temporarily unable to recall well-known names, facts and dates

Forgetting whether you just completed an action

Brain fog varies by person and how well someone is able to cope with brain fog may also depend on their level of cognitive functioning before getting sick. In highly intelligent people brain fog can be distressing despite appearing minimal to an outside observer due to good compensation. In people with severe brain fog, these cognitive difficulties can make navigating beurocracy in order to receive help impossible.



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# Will you get better?

There are currently no FDA-approved treatments for MECFS and only 5% of patients recover. Therefore you should expect your loved one to remain sick for the rest of their life or until a cure or treatment is found.

However, around 80% of patients with ME have what is called relapsing and remitting disease. This means that even though the disease never goes away they will have periods where they are a lot healthier and periods where they are much sicker. Relapses and remissions can come with a lot of emotional baggage so it's important to remember to support your loved ones regardless of whether they are doing well or poorly.

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# Chronic Fatigue Treatments Aren't A Cure For ME

There are a lot of experimental treatments for ME. There are also a lot of doctors who claim to be able to cure ME without evidence.

It is important to know that chronic fatigue is very treatable and many people recover from it. Sometimes these people will get confused or will have been misdiagnosed and claim that they have been cured of MECFS. But the treatments for chronic fatigue won't cure MECFS.

Chronic fatigue and MECFS are two very different things. Chronic fatigue can be caused by lots of different factors many of which are treatable. But we don't know how to treat chronic fatigue itself, only the underlying causes. We don't understand the underlying cause of ME yet, so we can't treat the chronic fatigue it causes. Remember only 1 in 20 people with chronic fatigue has ME.



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**I'm worried my loved one is depressed or deconditioned.  
If they don't get out of bed they will never get better!**

You are right. Depression and deconditioning are problems faced by people with ME. However, the reason your loved one will not get better has nothing to do with depression or deconditioning.

Think of it this way: imagine someone is grieving for the death of their father. This is bad, grief sucks. But their grief didn't cause their dad to die and it would be really insulting to insinuate that it did.

Lack of orthostatic tolerance (ie. Needing to spend time lying down) in patients with ME has been scientifically shown not to be caused by deconditioning. Instead, deconditioning happens because ME forces patients to remain in bed. Trying to get the patient out of bed won't help unless the ME was resolved first.

Likewise, patients with ME become depressed because they are unable to do the things they want to do. In contrast, patients with depression stay depressed because they have no motivation to do things. Simply ask your loved one "if you were better tomorrow what would you want to do?" They will almost certainly have a laundry list of desires, a drastically different answer from someone who is depressed to the point of being bedbound.

In the case of deconditioning, it is almost always extremely hard to prevent as patients will already be trying to do as much as they sustainable are able and doing any more would lead to faster degradation of health rather than prevent it. However, depression can be helped with therapy or antidepressants, as long as it is understood by the treating doctor that the patient suffers from secondary depression (ie. Depression due to circumstance, like grief)

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## **Whats the worst that can happen?**

It's important to know that while any level of ME is scary and massively life-changing, protecting your loved one's health has never been more important.

Often times when people are newly diagnosed it can seem like everything in their life has disappeared. They probably can't work (3 in 4), they feel awful every day, and their functional abilities have been decreased by half even in mild cases. But severe, very severe, and extremely severe ME are a whole new level of living death.

If you do not support your loved one in being able to #StopRestPace, if you push them to go back to work too soon, to overexert, or to not listen to their body they risk becoming severely ill.

Patients with severe ME have a quality of life comparable to those undergoing chemotherapy or late-stage AIDS. They are often reliant on 24/7 caregiving and may have complex nursing needs like feeding tubes and central lines in order to receive adequate nutrition and hydration.

Severe pain and sensory sensitivity are common and can lead to patients needing to survive in essentially solitary confinement and sensory deprivation in order to reduce suffering.

Severe patients can also develop MCAS a potentially deadly condition where the body begins to have anaphylactic reactions to basic medications and foods.

The extreme frailty of severe ME patients also means they are highly susceptible to death from infection.

All this is to say that "what's the worst that can happen" is death. While ME is rarely deadly, the actions your loved one is taking to avoid overexertion and listen to their body is the reason why. They are protecting themselves from a progression of disease that if not controlled leads towards death. They are not "overreacting" or being "lazy" they are trying to stay alive.