

## **Video Transcript**

### **Life with a Low Battery: Living with ME/CFS**

Hello! I'm Mito, and I want to take a moment to share an interesting perspective about our bodies.

This may seem like an unusual connection, but did you know that the human body operates in many ways like your cell phone?

Think about it: your phone runs numerous apps in the background, seamlessly working together as long as its battery has enough power.

However, if you forget to charge your phone overnight, you may find yourself in a predicament the next day. Suddenly, you'll need to prioritize which apps are most important for you to use.

For instance, you might need to call or text a few people and respond to some important emails.

Unfortunately, you may not have enough battery left to scroll through social media or watch videos during your lunch break.

But that's okay; you can charge your phone tonight and manage to get through one day without those distractions.

Now, remember how I mentioned that your body operates like your phone? Just like your phone needs energy to run its apps, your body requires a variety of systems to be "open" each day to function properly.

Basic functions like seeing, hearing, eating, breathing, walking, pumping blood, and thinking are like essential apps that constantly run throughout our daily lives.

All of these bodily systems need energy, similar to how the apps on your phone need battery power.

So, how do we recharge our body's battery?

Typically, we rely on sleep, hydration, food, oxygen, and even certain medications to replenish our energy reserves.

Waking up refreshed the next morning allows us to take care of all our bodily needs without much thought.

However, some days you might wake up feeling exhausted, prompting you to postpone energy-draining tasks for another day.

Fortunately, this isn't a daily occurrence for most people.

Sadly, there is a significant population whose bodies do not fully recharge each night.

Many individuals never regain a full battery, as they experience a condition known as myalgic encephalomyelitis/chronic fatigue syndrome, or ME/CFS.

This chronic and disabling illness affects various body systems, including the nervous and immune systems.

While I won't delve into the full science behind it, I want to highlight some key points.

People with ME/CFS experience a range of debilitating symptoms that make daily activities incredibly challenging, if not impossible.

Simple tasks that most of us take for granted, such as showering, sitting upright, or even holding a conversation, can completely drain their energy.

Their batteries cannot hold a charge like they used to, requiring them to recharge frequently throughout the day.

In essence, an ME/CFS battery has limited energy reserves that drain quickly and may take much longer to recharge—sometimes double, triple, or even quadruple the time required compared to those without the condition.

Many days, they can only run critical functions.

So how can those with ME/CFS manage to accomplish anything?

They often have to shut off unnecessary "apps" that drain their battery.

For instance, if they want to have a conversation, they might need to lie down, dim the lights, close their eyes, find a quieter space, take breaks during the discussion, or elevate their legs.

These adjustments can help conserve some much-needed energy.

There are patients whose energy levels are so low that they are confined to their homes, or worse, their beds.

They are battling invisibly, requiring so few "apps" to be operational that they are merely surviving.

Thankfully, ongoing research is helping us understand this condition better.

While we still don't know exactly how many people suffer from ME/CFS or post-COVID ME/CFS, we do know that millions of individuals around the world are affected by it.

In fact, this may be the most common disease you have never heard of.

So how can you help? It's quite simple. Believe those who are suffering.

Understand that they did not choose this condition; they are not faking it, and they do not wish to live confining lives.

If you have a functioning battery, take action to help others understand and learn about this disease.

Help offload tasks that may hardly drain your battery, but could overwhelm someone with ME/CFS, allowing them to attend their child's birthday party, join you for dinner, or simply hold a conversation.

Share videos, spread awareness, and be part of the movement to educate so that all individuals impacted by ME/CFS and post-COVID ME/CFS can receive the care and understanding they deserve.