

ME International Video Script (Long)



Intro Slide:

The information provided is not intended to diagnose or treat any illness and is not to be considered medical advice.

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WHAT IS MYALGIC ENCEPHALOMYELITIS?

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Myalgic Encephalomyelitis, commonly known as ME, is characterized by immune and neurological dysfunction with severe exacerbation of systemic illness following any exertion.

It is understood to be an inability to properly generate energy within cells, which often prevents sufferers from working, studying, or otherwise living a normal and functional life.

There is currently no official cause or cure for this disease.

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After an outbreak at the Royal Free Hospital in London in 1955, Dr. Melvin Ramsay described ME and laid the groundwork for recognizing ME as a distinct disease.

Over the years the ME patient population was lumped in with other patient groups, with a focus on fatigue and psychological causes, ignoring many of the original characteristics of ME.

ME typically has an acute sudden onset and currently affects about one million American men, women, and children.

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In 2011, a panel of experts, who had over 500 years of combined experience, collaborated to create the International Consensus Criteria known as the ICC.

The precursor to the ICC was the Canadian Consensus Criteria, commonly known as the CCC.

ME: THE LIVED EXPERIENCE

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What is it like to have Myalgic Encephalomyelitis?

The 2015 PLoS One journal article titled "The Health-Related Quality of Life for Patients with ME/CFS" showed the quality of life for ME/CFS patients is lower than breast cancer, colon cancer, lung cancer, chronic renal failure and many other diseases.

Those with ME are often disabled, and some are so ill they must remain in bed in darkened rooms to manage the neurological issues, including paralysis, with full time caregivers.

The key feature of ME is a post-exertional exacerbation of symptoms affecting immune function, impairing heart function and circulation, as well as impaired cognition.

Sometimes labeled as "a crash", this post-exertional neuroimmune exhaustion is not going from "well to sick" but going from "sick to sicker".

Many patients are forced to live outside their energy production system to take care of daily living tasks, which leads to periods of being homebound and/or bedbound with multiple debilitating symptoms.

Seeing someone with ME out in the world does not mean they have recovered.

It usually means they have rested up for days and will likely be forced to rest for many more days following this activity.

There is no getting around the damaged energy production of ME.

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Patients are often forced to live in a push/crash cycle, and that has long-term damaging consequences.

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This quote from the Hummingbirds' Foundation for ME website by longtime advocate Jodi Bassett, now deceased, paints an accurate and devastating picture of living with Severe ME.

"For people with severe M.E. even the smallest movement, thought, touch, light, noise or period upright can make their already very severe symptoms far worse. Thus few illnesses demand such isolation and loss of quality of life as severe M.E. Very often people with very severe M.E. can barely communicate, or even tolerate the presence of another person. This is what makes M.E. such a cruel disease and such an isolating disease. The illness can cause an unrelenting level of disability, suffering and isolation that is just unimaginable to anyone not familiar with very severe M.E."

HOW DOES ME RELATE TO CFS?

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So if that is Myalgic Encephalomyelitis, then what is Chronic Fatigue Syndrome?

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Chronic Fatigue Syndrome, commonly known as CFS, has inappropriately become synonymous with ME.

CFS was defined by the Fukuda criterion in 1994, encompassing many fatigue patients as well as those who were previously recognized as having ME.

In 2015, the Institute of Medicine (now known as the National Academy of Medicine) created a revised criterion known as ME/CFS-SEID.

SEID stands for Systemic Exertion Intolerance Disease.

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This criterion, as was done with CFS, ignored many of the distinguishing characteristics seen in myalgic encephalomyelitis.

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Doctors are being taught to diagnose SEID based on the following symptoms:

A greatly lowered ability to do activities that were usual before the illness, persisting for more than six months, with required symptoms of post-exertional malaise and sleep problems.

In addition, the patient must have either problems with thinking including memory issues, and/or a worsening of symptoms while standing or sitting upright.

This last symptom is also known as Orthostatic Intolerance, or OI.

Because ME has not been widely recognized, most patients have received the diagnosis of chronic fatigue syndrome and have obtained disability under that label.

ME International recommends that patients who have been given the CFS, ME/CFS, or SEID diagnosis be evaluated for ME.

This reevaluation should not affect a disability judgement, as disability is based on functional capability.

GETTING A MYALGIC ENCEPHALOMYELITIS DIAGNOSIS

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For a diagnosis of ME, symptom severity must result in a significant reduction of a patient's pre-illness activity level.

A patient's symptom severity can range from mild to very severe.

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The CFS-Fukuda, Canadian Consensus Criteria, as well as the newer ME/CFS-SEID, require a wait-time of six months before a diagnosis is reached.

The ME-ICC criteria dropped this six month wait, and the disease can now be diagnosed at the onset of illness.

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Diagnosis according to the International Consensus Criteria consists of the following:

The patient must have Post-Exertional Neuroimmune Exhaustion (PENE), which is the physical inability to produce sufficient energy on demand.

The following are signs you have PENE:

1. Marked, rapid physical and/or cognitive fatigability in response to exertion. The exertion it takes for this symptom to manifest may be minimal. Activities of daily living or simple mental tasks can be debilitating and cause a relapse.
2. Post-exertional symptom exacerbation such as acute flu-like symptoms, pain, or worsening of other symptoms.
3. Post-exertional exhaustion - This may occur immediately after activity, or be delayed by hours or days.
4. Prolonged recovery periods, usually taking 24 hours or longer. A relapse can last days, weeks, months, or be permanent.
5. Low threshold of physical and mental fatigability (lack of stamina) that results in a substantial reduction in pre-illness activity level.

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Post-Exertional Neuroimmune Exhaustion is a more specific description for the crash experience and should be used in place of Post-Exertion Malaise, commonly known as PEM.

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Diagnosis requires at least one symptom from three of the following four symptom categories, under the classification of Neurological Impairments.

The first Category is Neurocognitive Impairments.

This includes difficulty processing information such as slowed thought, or impaired concentration such as confusion, disorientation, cognitive overload, difficulty with making decisions, slowed speech, as well as acquired or exertional dyslexia.

Other neurocognitive impairments include: short-term memory loss, such as difficulty remembering what one wanted to say, what one was saying, retrieving words, recalling information, or poor working memory.

The second category is Pain.

This includes headaches, which can be chronic, generalized headaches-- often involving aching of the eyes, behind the eyes, or back of the head-- and may be associated with cervical muscle tension, migraines, or tension headaches.

This may also include significant pain experienced in muscles, muscle-tendon junctions, joints, abdomen, or the chest.

It is noninflammatory in nature and often migrates.

In other words, it is generalized hyperalgesia, myofascial or radiating pain, or widespread pain which may meet fibromyalgia criteria.

The third category is sleep disturbance.

This can include disturbed sleep patterns such as insomnia, prolonged sleep or naps, sleeping most of the day and being awake most of the night, frequent awakenings, awakening much earlier than before illness onset, and/or vivid dreams/nightmares.

Another symptom of disturbed sleep patterns is unrefreshed sleep, which can include awakening feeling exhausted-- regardless of the duration of sleep-- and/or day-time sleepiness.

The fourth category is neurosensory, perceptual, and motor disturbances.

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This includes neurosensory and perceptual issues such as the inability to focus vision; sensitivity to light, noise, vibration, odor, taste, and touch; or impaired depth perception.

This also includes motor disturbances such as muscle weakness, twitching, poor coordination, feeling unsteady on one's feet, and/or loss of control of bodily movements.

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Diagnosis requires at least one symptom from three of the following five symptom categories, under the classification of Immune, Gastro-intestinal, and Genitourinary Impairments.

The first category is flu-like symptoms, which may be recurrent or chronic, and typically activate or worsen with exertion.

This may include sore throat, sinusitis, and cervical and/or axillary lymph nodes may enlarge or be tender on palpation.

The second category is susceptibility to viral infections, with prolonged recovery periods.

The third category is issues with the gastro-intestinal tract.

Symptoms include nausea, abdominal pain, bloating, and/or irritable bowel syndrome.

The fourth category is genitourinary, which includes urinary urgency or frequency, and/or nocturia.

The fifth category is sensitivities to food, medications, odors, and/or chemicals.

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Diagnosis requires at least one symptom from the Energy Production / Ion Transport Impairments section.

The first symptom is cardiovascular, which includes the inability to tolerate an upright position-- orthostatic intolerance-- neurally mediated

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hypotension, postural orthostatic tachycardia syndrome, palpitations with or without cardiac arrhythmias, and/or light-headedness/dizziness.

The second symptom is respiratory, which includes air hunger, labored breathing, and/or fatigue of chest wall muscles.

The third symptom is loss of thermostatic stability, which includes subnormal body temperature, marked diurnal fluctuations; sweating episodes, recurrent feelings of feverishness with or without low-grade fever, and/or cold extremities.

The fourth symptom is intolerance of temperature extremes.

Many patients with ME experience a majority of these symptoms with little relief.

It is important to note that neither the CFS-Fukuda nor the ME/CFS-SEID criteria include many of these immune, neurological, or cardiac symptoms.

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The International Classification of Diseases code for ME is currently G93.3, under "Diseases of the Nervous System - Other Disorders of the Brain".

This is also known as its ICD code, which is in its 10th revision.

The upcoming ICD 11 revision will relabel ME as 8E49, "Diseases of the Nervous System - Other Disorders of the Nervous System".

CONFIRMING A DIAGNOSIS OF MYALGIC ENCEPHALOMYELITIS

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If you have been diagnosed with CFS, ME/CFS, CFS/ME, Fibromyalgia, POTS, Chronic Lyme, or other immune dysfunction diseases, it is important to be evaluated for ME.

Finding a qualified expert that can definitively diagnose myalgic encephalomyelitis is difficult.

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Most doctors do not understand the reality of ME, or been educated on diagnosing ME using the International Consensus Primer.

The IC Primer provides clinicians a one-stop, user-friendly reference for ME.

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An easy to use questionnaire can be found at www.MEadvocacy.org/resources, and is labelled "ICC Questionnaire for patients over 18".

This resource can help patients and doctors make a preliminary diagnosis.

Then, doctors can follow the International Consensus Primer (IC Primer) to definitively diagnose myalgic encephalomyelitis and pursue symptom treatments to help improve the patient's quality of life.

A link to the ME IC Primer can also be found on the resources page at MEadvocacy.org.

Many diseases and conditions can be mistaken for ME by doctors who have minimal experience with the disease.

If treatment of these conditions resolves the symptoms, patients have been misdiagnosed and do not in fact have ME.

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Some of the conditions that need to be tested for include:

Infectious Disorders such as: TB, AIDS, chronic lyme, chronic hepatitis, and endocrine gland infections.

Neurological conditions such as: multiple sclerosis, myasthenia gravis, and B12 issues.

Autoimmune disorders like polymyositis, polymyalgia rheumatica, and rheumatoid arthritis should be considered as a possible cause.

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Thorough testing for endocrine conditions like Addison's, hypo and hyperthyroidism, and Cushing's Syndrome is needed.

It is important to thoroughly screen for spinal issues like stenosis, chiari malformation, and craniocervical instability.

Other conditions that may be overlooked are cancers, anemias, iron deficiency, diabetes mellitus, poisons, and treatable sleep dysfunctions.

WHAT IS NEEDED?

So what needs to be "done" about ME?

Patients with ME need to be screened for infectious agents, including viruses and bacteria often associated with ME that are reactivated, or opportunistic infections that develop due to an impaired immune system.

Doctors, supervisors, judges, and others who are in a position to affect the patients, must understand the serious damage that a push/crash cycle can cause.

As a society, we need services in place that help patients prevent the push/crash cycle if these patients are to have an improved quality of life.

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For many years Graded Exercise Therapy, known as GET, and Cognitive Behavior Therapy, known as CBT, was the recommendation by doctors--with the expectation that these patients would gradually recover.

We now understand that this is not the reality for those who have ME.

Forcing patients to do GET has led to a serious exacerbation of the illness, and the damage caused by pushing exercise is known to have led to death.

Patients need society to understand the danger of pushing to gradually increase activity.

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Medical professionals should encourage patients to rest as much as necessary to avoid Post-Exertional Neuroimmune Exhaustion (PENE).

Severe ME patients are even more isolated due to the severity of their symptoms, and are often unable to leave their homes even to seek medical care.

They often require full-time caregivers.

Unfortunately, due to the lack of recognition about the reality of ME, full-time caregivers are not provided under the current health care systems in most countries.

HOW TO IMPROVE QUALITY OF LIFE FOR ME PATIENTS

The question you may now be asking yourself is...

"What can be done right now to help patients with Myalgic Encephalomyelitis?"

ME International believes that worldwide adoption of the ME ICC, to diagnose and treat, is the fastest way to improve the quality of life of people with ME.

This would be effective in getting doctors, governments, and other organizations to properly support ME patients.

ME International supports worldwide adoption of the International Consensus Criteria, with education based on the International Consensus Primer-- which provides quality guidance for medical professionals.

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Many patients have found improvement in quality of life from various treatments including supplements, antivirals, IV fluids, low dose naltrexone (commonly known as LDN), and most importantly-- pacing activities to avoid going outside their energy production capabilities, which would exacerbate all symptoms.

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Specific treatment information can be found in the ME International Consensus Primer.

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