Much of the research conducted today is written by specifically stating that ME/CFS is a poorly understood disease. This is a phrase that many hide behind.

From an advocacy standpoint, the phrase “poorly understood” isn’t just a neutral scientific statement - it’s also a reflection of history, power, and how evidence has been handled. And, there is no disease called ME/CFS. There is the neurological disease called Myalgic Encephalomyelitis (ME) and the thing known as Chronic Fatigue Syndrome

There is a substantial body of biomedical research on Myalgic Encephalomyelitis (ME), especially under stricter criteria like ICC 2011. It covers immune dysfunction, autonomic nervous system abnormalities, mitochondrial/energy metabolism impairment, neuroinflammation, and post-exertional neuroimmune exacerbation (PENE). So advocates often push back on the idea that “we know nothing,” because that’s simply not true.

That said, the claim persists for several overlapping reasons:

1. Fragmented research instead of a unified model

There are many consistent findings, but they haven’t been fully integrated into a single, widely accepted disease model. Different studies highlight immune issues, metabolic dysfunction, or neurological changes—but medicine tends to want a clear, simple mechanism. ME doesn’t fit neatly into that expectation.

2. Case definition problems diluted the science

Broad criteria (like Fukuda or generic “CFS”) grouped together people with different conditions. That muddied results and made findings look inconsistent. Advocates often argue that when you isolate true ME (e.g., ICC), the picture is much clearer.

3. Historical psychologization

For decades, ME was framed by some influential groups as primarily psychological or behavioral. That shaped funding, research priorities, and clinical education. Once a field is steered that way, it takes a long time and strong evidence to reverse it.

4. Chronic underfunding

Compared to diseases with similar disability burden, ME has received disproportionately low funding. Less funding means fewer large-scale, high-quality studies, which then reinforces the “uncertain” label.

5. Lack of a simple biomarker (yet)

Even though there are many candidate biomarkers (immune markers, metabolic signatures, autonomic testing abnormalities), there isn’t one universally accepted diagnostic test used in everyday clinical practice. In medicine, that absence often gets interpreted as “we don’t understand it,” even when patterns are well documented.

6. Institutional inertia and guideline lag

Medical guidelines, textbooks, and training programs update slowly. Even when newer biomedical evidence exists, older narratives can persist in practice for years or decades.

From an advocate’s perspective, the phrase “poorly understood” can be misleading. A more accurate framing might be:

* The disease is biomedically complex and multi-system

* There is substantial but under-integrated evidence

* Progress has been slowed by methodological issues and underinvestment

So the tension is real:

Researchers may mean “we don’t have a complete, unified mechanism yet,” while advocates hear “there’s no solid evidence,” which erases decades of work and patient experience.

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Then there are still doctors who insist that M.E. doesn’t exist but CFS does. That claim isn’t supported by the evidence, and it’s out of step with where much of medicine has moved.

Myalgic Encephalomyelitis (ME) is recognized by major health bodies (e.g., WHO classifies it as a neurological disease), and there’s a large body of research documenting measurable abnormalities such as; Immune Dysregulation, Autonomic Dysfunction, Impaired Energy Metabolism, and the hallmark Post-Exertion Neuroimmune Exhaustions. That doesn’t mean everything is fully mapped out, but it does mean the illness itself isn’t imaginary or attention-seeking.

So why do some clinicians still say that?

Legacy beliefs and training gaps. Some were trained when ME/CFS was framed primarily as psychosomatic or behavioral. If they haven’t kept up with newer evidence, they may still rely on that older model.

Diagnostic ambiguity in general practice.

Because there’s no single, simple test used in everyday clinics, some physicians default to skepticism especially with complex, fluctuating conditions.

Bias and stigma around poorly understood chronic illness. When symptoms don't fit neat patterns, patients can be mislabeled as exaggerating or seeking attention. This happens across multiple conditions, not just ME.

System pressures. Short appointment times and limited specialist access can push clinicians toward dismissive shortcuts rather than careful evaluation.

From an advocacy perspective, it's reasonable to push back firmly but accurately:

* The disease M.E. is recognized and researched, even if not fully understood

* There are objective physiological findings, even without a single diagnostic test

* Dismissing patients as attention-seeking is unprofessional and harmful, and it can delay appropriate care

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