One of the deepest difficulties people with Myalgic Encephalomyelitis (ME) face: the illness itself is profoundly disabling, but the harm from disbelief, dismissal, or misdiagnosis by the medical system often adds a second layer of suffering.

Here's a structured look at the problem and practical steps patients sometimes use to get health care:

Why patients with ME are undermined

* Medical training gap: ME is rarely taught in depth at medical school. Many physicians only learn outdated ideas linking it to "chronic fatigue" or psychosomatic illness.

* Criteria confusion: The lumping together of ME with CFS or "chronic fatigue" has blurred recognition of the specific disease especially PENE.

* Insurance & politics: Some health systems and insurers resist ME diagnoses because recognition implies costly disability benefits and long-term care.

* Bias in practice: Because many patients look outwardly "healthy," their limitations are underestimated, and invisible symptoms (cognitive crashes, orthostatic intolerance, sensory overload) are ignored.

Barriers patients face

* Doctors often disbelieve reports of post-exertional crashes, interpreting them as deconditioning or anxiety.

* Treatments offered (like graded exercise therapy) may harm patients, reinforcing distrust.

* Very severe patients are sometimes left without even basic medical care at home.

Use pacing as a framework

* Explain that you are already using pacing to avoid relapses, and you need the doctor's help to manage symptoms (e.g., pain, sleep disruption, orthostatic intolerance).

* Doctors are more likely to support symptom management than systemic treatment, but this support is often life-saving.

Advocacy & Support

* Take a caregiver, advocate, or printed statement to appointments. This protects against dismissal and ensures important points are not forgotten.

If care is refused or unsafe

* Patients sometimes need to switch doctors until they find one willing to listen.

* In emergencies, be prepared with a medical information sheet that clearly explains ME, PENE, medication sensitivities, and safe handling practices.

* Some patients find more compassionate care through nurse practitioners, integrative doctors, or home-care providers.

* Getting health care with ME often means educating the doctor yourself, using official references, and framing your symptoms in medical terms.

* Focus appointments on specific, treatable symptoms (orthostatic intolerance, sleep, pain, infections), while protecting yourself against harmful "rehabilitation" approaches.

* Advocacy and persistence are sadly necessary, but many patients do find supportive doctors when they present ME as a neurological + immunological disease, not just "fatigue."

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The undermining of patients with Myalgic Encephalomyelitis (ME) has roots in both individual physician beliefsand structural forces like health insurance and public health policy. The two reinforce each other.

1. Physician Beliefs

* Outdated training: Most doctors were taught that ME/CFS is "chronic fatigue" or psychosomatic. Very few have been trained on the ICC (2011) or the neuroimmune/energy metabolism evidence.

* Medical culture bias: Symptoms that are invisible, fluctuating, or not easily confirmed with routine tests are often dismissed as "functional" or "psychological."

* Overreliance on CBT/GET paradigm: In the 1990s–2000s, large trials (like the UK's PACE trial) promoted graded exercise and cognitive therapy. This shaped medical opinion, despite later evidence of harm.

2. Insurance & Health System Pressures

* Financial motives: Recognizing ME as a distinct neuroimmune disease implies long-term disability, expensive investigations, and ongoing support. Insurers and some government agencies benefit from casting it as a psychosomatic or fatigue condition.

* Diagnostic control: Many insurance systems discourage use of ICC or IC Primer, and push for the looser "chronic fatigue syndrome" (CFS/Fukuda) label. That looser category dilutes ME, making it harder for patients to qualify for disability or specialized care.

* Policy inertia: Once health systems adopt a flawed framework (e.g., CFS = treatable with exercise/CBT), it becomes bureaucratically and financially difficult to reverse.

3. Interaction Between the Two

* Doctors often adopt the narratives supported by insurers and public health agencies because those are what appear in guidelines.

* Insurance companies can cite physician skepticism as justification for denial of benefits (“not an organic illness”), while physicians lean on insurance guidelines to justify not investigating further.

* Patients end up in a vicious cycle of disbelief: “the doctor says it’s not real, so the insurer won’t cover it; the insurer won’t cover it, so the doctor says it’s not real.”

4. Evidence of Systemic Influence

* United Kingdom: The PACE trial was heavily funded by agencies with ties to insurance companies. It promoted CBT/GET as cost-saving “rehabilitation” strategies.

* North America: Disability insurers have historically resisted ME recognition, lobbying against stricter definitions (like ICC).

* Medical literature bias: Journals often gave preference to psychiatric/behavioral interpretations over biomedical research, further shaping physician belief.

In summary:

* Physician disbelief comes largely from outdated training and cultural bias in medicine.

* Insurance and health policy have reinforced these beliefs by financially incentivizing psychosomatic explanations and suppressing recognition of ME as a disabling neuroimmune disease.

* The result is a self-perpetuating system where both individual doctors and structural forces undermine patients.

References show:

* Doctors’ disbelief often comes from poor education and psychosomatic bias.

* Insurance and government systems have reinforced psychosomatic frameworks (e.g., PACE trial, avoidance of ICC criteria) because recognizing ME as organic would be expensive.

Physician Beliefs / Medical Culture

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