Having recently been diagnosed with multiple sclerosis, I thought I understood fatigue, the kind that settles into the bones and lingers like fog. Later, when my younger sister began complaining of general tiredness from college, I half-joked that she might have “chronic fatigue syndrome”. I did not yet realise how misplaced that comment was. I had mistaken a symptom I knew for a condition I did not, neglecting the severity of post-exertional malaise (PEM), the hallmark of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), where even minimal activity can trigger a disproportionate and prolonged crash.

For decades, ME/CFS was framed as psychosomatic. As Weir (2021) notes, historical models emphasised behavioural or psychological causes and encouraged harmful interventions such as graded exercise and cognitive behavioural therapy (GET and CBT respectively). Both GET and CBT are no longer recommended by modern guidelines (NICE, 2021). Even the name, “chronic fatigue syndrome”, conceals the condition’s multisystem nature, and downplays its defining physiological feature of PEM. The persistence of misunderstanding has caused deep harm: patients were urged to push through symptoms that were, in fact, evidence of systemic dysfunction (Weir, 2021). While emerging research continues to uncover metabolic, neuroimmune and autonomic irregularities, the absence of a validated diagnostic biomarker perpetuates doubt (Maksoud et al., 2023).

This is further complicated by the growing recognition of long COVID’s pathophysiological and symptomatic overlap with ME/CFS. A recent meta-analysis found that roughly half of Long COVID patients meet ME/CFS diagnostic criteria (Dehlia, 2024). There is humility in acknowledging that our definitions are provisional, and long COVID’s relationship with ME/CFS challenges medicine’s tendency to separate diseases by rigid labels. It reminds me that listening to patients often precedes understanding them.

That is why patient-centred research is so important. For instance, surveys have been used to better understand PEM, and how it encompasses a constellation of delayed symptoms (such as cognitive fog, sleep disturbance, and immune-like relapse) that can last days (Chu et al., 2018). Such patient accounts enrich scientific inquiry by grounding it in lived experience. This could be used to inform education of both medical students and clinicians, teaching them to validate rather than dismiss patient narratives, which could protect patients from persistent epistemic injustice (Blease et al., 2017).

As someone who has also wrestled with invisible symptoms, I have learned that empathy is not just imagining someone's suffering, but believing them even when you cannot measure it.

Thus, my greatest learning point has been humility: humility in admitting that I once trivialised a condition I did not understand; humility in recognising that medicine evolves and evidence shifts; and humility in knowing that effective practice starts with listening. Learning more about ME/CFS has reminded me that to treat illness well, we must first believe in the reality of what we cannot yet explain.

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