



# Please believe ME

Ignorance about ME is still blighting lives, but new research might change that

What's it like having a debilitating illness that some people don't believe exists? When it leaves you too unwell to leave the house, how do you tell your boss or your friends? Over 30 years after it was cruelly dubbed "yuppie flu", ME is still little understood, and some doctors fail to acknowledge it even in the face of official guidance from NICE (the National Institute of Clinical Excellence). Now, US researchers, led by Stanford University, believe they've found a test to diagnose ME for the first time. Using blood samples from 20 people with ME and 20 without, the test was 100 per cent accurate. This, the researchers say, proves the illness is real. But, of course, those diagnosed with ME have never needed convincing.

## More than tired

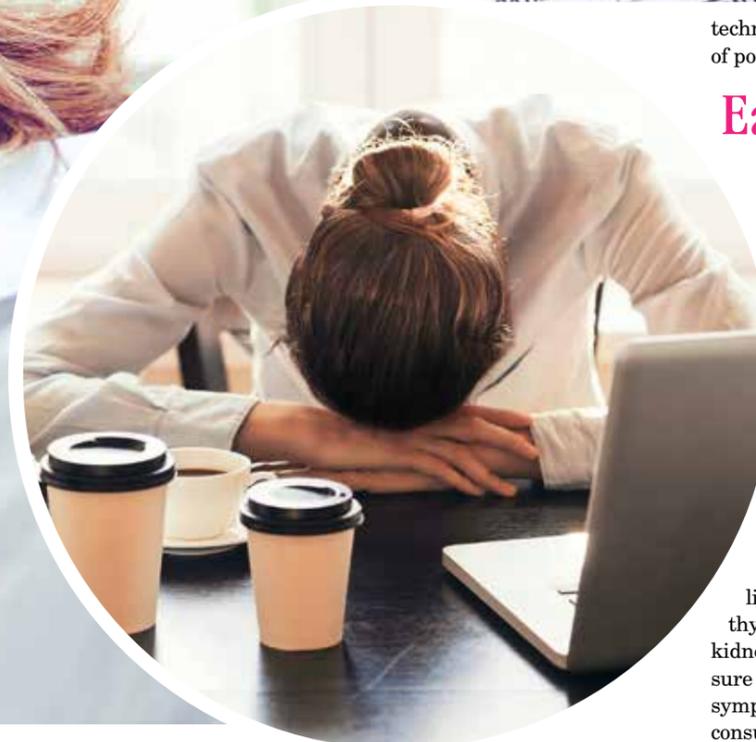
It's estimated that ME (short for myalgic encephalomyelitis) affects 250,000 people in the UK and 17million worldwide. It's more common in women, and usually starts in the mid-20s to mid-40s – although it can affect anyone, including children. It's not known what causes it, but it's often triggered by an infection, such as chickenpox, and typically affects the nervous and immune systems. The illness is sometimes called chronic fatigue syndrome (CFS), and doctors will often use that term as a diagnosis. But tiredness just doesn't cover it. In

The condition affects around 17million people worldwide

fact, the range of symptoms can vary hugely and change over time. The key symptom is "post-exertional malaise". This means that even minor physical or mental activities can lead, often a day or two later, to intense, debilitating exhaustion and a rise in other symptoms. Crucially, resting doesn't help. Other symptoms might include pain in the muscles and joints, back, chest or head; hypersensitivity to noise or light; dizziness and balance problems; a recurrent sore throat or glands; a general feeling of being unwell; sleep problems; brain fog – issues with

concentration, thinking and memory – and digestive problems, such as nausea or IBS. How severely you're affected varies, too. People with mild ME are able to go to work or school and carry out light tasks. But they may need days off when symptoms flare up, and socialising and hobbies could be beyond them. At the other end of the spectrum, around one in four people with ME are severely affected. They may manage basic tasks, such as brushing their teeth, but be unable to walk and spend much of their time in bed. In some cases, they'll need 24-hour care. According to Clare Ogden of the charity Action For ME, "Even in its mildest form, ME can have a significant impact on your life, and not just on your health. Many people face isolation as friends

and family struggle to understand its true impact." **New research** One reason ME is so often dismissed as an illness is that there's no diagnostic test for it. Professor Ron Davis, who worked on the new research at Stanford, explained, "Too often, this disease is categorised as imaginary. When individuals with chronic fatigue syndrome seek help from a doctor, they may undergo a series of tests. These would normally guide the doctor towards one illness or another, but for these patients, the results all come back normal." For their research, the Stanford team found a way to measure minute differences in



technique to test the effects of potential drug treatments.

## Easing symptoms

Without a test, diagnosis isn't straightforward. But doctors are given guidelines – they should ask for a detailed history of your symptoms and give a physical examination. They may take a blood test to rule out other conditions, like anaemia, an underactive thyroid gland, or liver and kidney problems. If a doctor isn't sure about the diagnosis, or if your symptoms are severe, they should consult a specialist. You may be referred to a specialist yourself if there's one in your area.

electrical signals given off by cells in the immune system. They then isolated immune cells and plasma from blood samples, added salt to create "stress" and measured the response. In samples from all 20 ME patients tested, there was a clear spike in electrical energy, suggesting that the immune cells were struggling to cope. That didn't happen with the samples from any of the healthy people in the trial. Professor Davis, who's own son has ME, says, "We don't know exactly why the cells and plasma are acting this way, or even what they're doing, but there is scientific evidence that this disease is not a fabrication of a patient's mind." It was a small study, and more work needs to be done, but the team is already using the same

There's no cure, but treatments might ease symptoms. Medication could include a low dose of tricyclic antidepressants – not for your mental health, but to help you sleep and ease pain. Then, there's a technique called "pacing". This is about striking a balance between activity and rest to help you avoid an energy crash and surge in symptoms. Sometimes it's used to help stabilise your condition, then build up your activity levels, but it doesn't work for everyone. There's also cognitive behavioural therapy (CBT). Again, this doesn't imply ME is a mental health condition. The therapy is used to help people manage their symptoms. "Some people make good progress and may recover, while others can remain ill for years,"

says Clare. "Ask your doctor for advice as early as possible, so you can make informed decisions about how to manage your symptoms. An approach that works for another person may not work for you."

## Living with ME

Georgina, now 22, developed ME when she was a student in 2016. She'd had glandular fever and never fully recovered. It was about a year before she was diagnosed. "Time after time, I went to doctors complaining of all these symptoms, and they said I was stressed with uni, or 'a bit tired' after the glandular fever," she says. "I was told to exercise more, which made things worse.

"Now, I never have a day without symptoms. Sometimes I have extreme fatigue with intense pain in my muscles and joints, and stomach problems. Other days, the fatigue isn't strong, but the pain is unbearable. My

brain fog can get so bad, I can't speak properly, or I'm too nauseous to stomach food. Other times, my sound sensitivity is so intense, I can't bear to be in a room with my family. The exhaustion is probably the most challenging. It's like my body is stuck in concrete – everything is heavy. My symptoms are so overwhelming. Nothing helps, no amount of sleep, vitamins or food makes it better. "This illness is hard for people to understand, as so many of the symptoms are invisible. Friends only see me on low-symptom days, so they don't really know the full extent of it. It's very isolating." With support from her university, Georgina managed to finish her degree at home, but she's not well enough to hold down a job. "I get upset at the thought of people thinking I'm lazy," she says. "I want to work. I have so many ambitions and goals, but my health controls my life."

There is currently no diagnostic test for ME

For more information and support, contact Action For ME at [Actionforme.org.uk](http://Actionforme.org.uk) or call 0117 927 9551