

Is It All in My Head?

With diseases like chronic fatigue syndrome and fibromyalgia, what you believe about your illness influences how sick you become.

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In the mid 1980s, Carole Howard was a highly driven academic, simultaneously pursuing a master's degree from Loyola University in Chicago and serving as a college administrator—until the fateful morning when she got out of bed feeling not quite herself. "I woke up one day in a lot of pain," Howard recalls. "I thought I had the flu."

If only it were that simple. Her aching muscles and sluggishness kept her in bed for weeks, and never really went away. Howard was eventually diagnosed with fibromyalgia and chronic fatigue syndrome, two devastating chronic ailments that crippled her academic career and landed her on full-time disability. "You can live with this," says Howard, who now serves as president of the Chronic Fatigue Syndrome, Fibromyalgia and Chemical Sensitivities Coalition of Chicago. "But you have to accept doing half of what you used to do. I have a two-hour limit before I need to sit or lie down."

Beyond accepting her physical limitations, one of Howard's biggest challenges has been dealing with people who doubt that her illness is real. "My family was never supportive," she says. "There were a lot of derogatory comments." Even today, when knowledge about these diseases is much more widespread, Howard still encounters skeptics. A woman helping her around the house dismissively told her: "You're not sick—you don't look sick." "I just went ballistic," Howard recalls. "I was so enraged."

Capping her frustration, Howard cannot be sure to this day why she became ill. But her best guess is that the self-imposed stress of her ambitious lifestyle played a role. "I

didn't know what a vacation was," she recalls. "I never stopped. I didn't realize there was a difference between the Energizer Bunny and me."

Howard's suspicions are confirmed by many researchers, who are coming to believe that psychological factors play a crucial role in perpetuating many physical illnesses, particularly a subset of chronic ailments that defy logic, diagnosis or a cure. It seems that the way you think about your illness can actually affect how sick you get.

These "multi-symptom illnesses"—which include chronic fatigue syndrome, fibromyalgia and potentially others such as Gulf War syndrome, irritable bowel syndrome and the condition known as multiple chemical sensitivity—have provoked intense controversy. Because they have no obvious biological cause, some doctors and researchers dismissed them in the past as hysteria or the "yuppie flu."

Many patients, in response, became equally determined to prove that their disease was just as real and as biologically legitimate as heart disease or breast cancer. Those who have watched a close friend or family member with one of these syndromes can find themselves wondering: Is this real? Is she making this up? Patients themselves fear the worst: Will I ever get my life back? Will no one believe me? Is it all in my head?

"The big challenge is credibility," says Kim McCleary, president of the Chronic Fatigue and Immune Dysfunction Syndrome Association of America, a patient advocacy group. "The illness is still not well understood, and when people don't see anything unusual about you, they question whether you're sick or not."

However, the war between doubters and advocates has waned. The consensus is that these illnesses are truly mind-body diseases, in which biological and psychological causes and dysfunctions are inseparably intertwined. The mind seems to play a key role in kick-starting and perpetuating illness—but it's not that sufferers are simply malingerers. Their bodies are sick, and their reaction to the illness often makes it worse.

"Anybody who has a chronic illness has alterations in biological and psychological mechanisms," says James F. Jones, M.D., a chronic fatigue expert with the U.S. Centers for Disease Control and Prevention. "You really can't separate the brain and the body, because psychology is biology—everything that takes place in the brain is chemical or electrical. You can't have the one without the other."

Diagnosis by Default

For the estimated 800,000 Americans suffering from chronic fatigue and the 3 to 6 million with fibromyalgia, the symptoms are all too physical—as debilitating as flu, and as persistent as tuberculosis. The diseases disproportionately affect women: Nearly 90 percent of fibromyalgia patients, and two-thirds of CFS sufferers, are female. Patients diagnosed with chronic fatigue have endured six months of complete exhaustion, plus a cluster of debilitating symptoms: They grow forgetful. Hurt when they swallow. Suffer throbbing headaches. Toss and turn in their sleep. Those with fibromyalgia may also suffer fatigue, but mainly describe inexplicably aching joints and muscles across their entire body.

But although these diseases are among the more extensively researched of these chronic disorders, patients may still flounder for years searching for an explanation. Symptoms are broad and diffuse, and the diseases have no reliable test, so a diagnosis is usually made by ruling out everything else.

In the search for the cause, researchers have turned up some significant biological abnormalities among chronic fatigue sufferers: Stress hormones, brain scans, and immune system measures often show characteristic differences compared to healthier populations. Researchers haven't given up looking for an underlying infectious cause, since sickness can be misleading—asthma and ulcers, for example, were only recently understood to be primarily physical diseases. At one point, the Epstein-Barr virus, which infects nearly all adults, was thought to be a culprit in CFS or fibromyalgia. But this idea, and others, have fizzled.

Doctors suspect that by continuing to focus on an elusive biological cause, they could be missing out on the other half of the picture—and the chance to find a solution. They have begun to re-examine the role of severe stress, depression and even personality traits in initiating and fostering disease.

Some of the evidence is hard to dispute. For example, those suffering from chronic fatigue or fibromyalgia are significantly more likely than healthy people to have experienced depression, anxiety, physical abuse or a life-altering stressful event well before they developed their disease. In one study conducted by Wayne Katon,

professor of psychiatry at the University of Washington in Seattle, 90 percent of fibromyalgia patients had a prior psychiatric diagnosis. Another study, at the University of Leeds, found that patients who had developed chronic fatigue were nine times more likely to have suffered stressful events and difficulties in the three months before the onset of disease than were healthy subjects. The implication is clear: Unlike other diseases, these disorders are closely connected to psychological distress, whether it takes the shape of a major psychiatric disorder or simply poor coping mechanisms.

More than Depression

Still, it's clear that chronic fatigue is not just a bodily manifestation of clinical depression. While those who are depressed often are tired, and those who battle any chronic illness tend to grow depressed, the two are clearly distinct. Clinical depression doesn't usually result in a sore throat or post-exercise fatigue, and antidepressants aren't generally good treatments for CFS. "Depression and fatigue are fundamentally different," says Leonard Jason, a professor of psychology at DePaul University in Chicago. "If you ask a person who is depressed, 'What would you do tomorrow if you were better?' they say, 'I don't know.' Chronic fatigue sufferers will give you a list of 10 things."

The body's stress response may be crucial to triggering diseases like chronic fatigue. Stress activates the body's hypothalamic-pituitary-adrenal axis, leading to a surge of the hormone cortisol, which suppresses the immune and other bodily systems. If some outside agent such as a viral infection comes along during a period of high stress, the system may overreact or even spiral permanently out of whack.

"Most patients will tell you they had a history of being under a lot of work-related stress, or struggling with anxiety or depression, and against that backdrop, a second event happened—a car accident or a viral infection," notes Dedra Buchwald, an internist at the University of Washington's chronic fatigue clinic in Seattle.

For Laura Hillenbrand, author of the best-selling book *Seabiscuit* and noted chronic fatigue advocate, long-standing sickness began with a common illness—and a shock. While a junior in college, she was traveling with friends down a country road late at night when a deer darted in front of the car. Though the driver swerved and avoided the collision, for passenger Hillenbrand, the traumatic experience was followed almost

immediately by nausea, fever and chills. That night, she was diagnosed with a nasty bout of food poisoning. It was followed by weeks of extreme lethargy, leaden limbs and weight loss—symptoms that have never fully abated.

Did the fright of that evening's near-miss undermine her body, rendering her vulnerable to food poisoning? "I really don't know," muses Hillenbrand, who wrote her best seller largely from her bed. "It is my belief that CFS is an opportunistic disease that preys on bodies that are compromised. It is an interesting coincidence that I began to feel the symptoms just a moment after that experience of extreme stress."

It's the Reaction that Counts

Wayne Katon, whose research focuses on depression, anxiety and somatoform disorders, makes the case that stress and anxiety play a primary role. In his view, personality doesn't just create a hospitable environment—it's an integral part of the diseases. He believes that the initial injury or illness is almost irrelevant. What really matters is the interpretation and emotional reaction. Patients develop what he calls "catastrophic cognitions": beliefs that if they start to get back to their activity, they will damage themselves further.

According to Katon's clinical observations, patients with chronic fatigue or fibromyalgia tend to be highly driven overachievers unaccustomed to feeling any loss of control. When injured or sickened, those who decide that the pain or illness has overwhelmingly and permanently damaged their bodies come to feel victimized and unable to cope. Learned helplessness sets in, and patients can find themselves perpetually depressed and inactive. "They have trouble getting back to that old lifestyle, and what sets in is depression," Katon suggests. "In our modern society, for people who have driven themselves, fatigue becomes a palatable way out of a difficult existence." Although Katon is well regarded in the field, this perspective is still widely debated, at conferences, in medical journals and even by peers at his own medical center.

However, some patients do describe their experience in similar terms. "Stress seems to be the killer," Howard admits. "That's what I think happened with me. I was a superachiever and a perfectionist. I was going to make it, no matter what. I didn't anticipate the consequences."

Fear of further damage and disability may keep patients from trying to get back to an active life. "Whatever caused this impairment is probably not what's keeping it going," Katon says. "What's keeping it going to a large extent are the misbeliefs about getting back to an active lifestyle."

Indeed, Hillenbrand had come to anticipate disaster when she tried returning to a normal life. "I had learned to expect complete collapses each time I overextended myself," she recalls. "As I began to slide into exhaustion, I would anticipate how I would soon be unable to sit up and speak, and I would become very frightened. The anxiety I experienced as I slid into collapse would feed my exhaustion, and I would become still weaker."

It's Not Just a Matter of Will

Hearing talk of "learned helplessness" can be very frustrating for chronic fatigue and fibromyalgia patients, many of whom would like nothing better than to get back to an active life. Accepting that psychology plays a role in these diseases does not mean that patients should just "will" themselves out of illness. The best treatments seem to be highly structured interventions that help patients change the way they think and behave, including cognitive and emotional therapy. For example, graded exercise therapy encourages chronic fatigue sufferers to return to activity at a carefully measured pace, much like physical therapy following hip replacement. Patients are encouraged to try walking a few extra blocks each day, instead of trying to run three miles on a "high-energy" day and risking a relapse.

More than merely instilling a positive attitude, cognitive-behavioral therapy teaches patients to reframe their expectations about what will happen if they exert themselves. Researchers at Oxford found that 73 percent of CFS patients receiving cognitive behavioral therapy for a year returned to relatively normal physical functioning, compared with 27 percent who had standard medical care or relaxation.

Those who refuse to accept the value of psychological therapies can get stuck. Some sufferers continue to seek physical proof that something has gone terribly awry, such as a virus, an environmental toxin or a faulty gene. "Patients seem to think if [their disease] is psychiatric, it makes them less legitimate, it makes their problems less real," says

CFS researcher Arthur Hartz, a professor of family medicine at the University of Iowa. "But nobody with any sense blames this on the patients."

Patients with chronic fatigue who attribute their illness solely to external causes, such as a virus, seem to stay sicker than those who acknowledge the possible interplay of psychological factors. "Your beliefs about the illness are important," says Buchwald. "If you're wedded to an idea that your illness has a single specific cause, your chances of getting better are diminished, because you're not addressing parts of the illness that could be prolonging it." Instead, she suggests, patients should focus on actively following treatment advice and avoiding social isolation.

Because beliefs have such a powerful impact on well-being, the techniques that people use to cope with other diseases can backfire in the case of chronic fatigue. Ironically, patient advocacy groups may be more harmful than helpful, studies have suggested, possibly by reinforcing a sense of victimization or by giving misguided advice, such as actively discouraging all exercise.

"The support groups are very anti-psychological," says Katon. "A lot of times they act to inadvertently reinforce illness beliefs [such as fear of relapse or exhaustion] that are potentially harmful to patients." Those in support groups often report more severe illness, and say that they feel worse since joining the group than do dropouts. Critics dispute these findings, saying that dropouts leave because they feel better. However, research suggests that members are just as likely to drop out because they have grown too sick to attend as because they have improved.

Pat Fero, executive director of the Wisconsin chapter of CFIDS, remains skeptical of the value of psychologically based therapies. She points out that a good attitude alone isn't going to make symptoms vanish, and she doubts that cognitive therapy would improve her chronic fatigue. "If you're feeling negative about everything around you, yes, you're going to feel worse," she says. "But the opposite is not necessarily true: If you improve the state of your mind, it doesn't mean you'll cure yourself."

Hillenbrand, however, credits cognitive therapy with showing her how to reshape her expectations in ways that have made it easier to cope. "I have learned how to replace those fearful thoughts with more positive ones—I don't have to collapse'; 'This will soon pass,' " she says. "As a result, while I still experience those collapses, they are often

less severe and briefer than they once were. I have been able to live a better, happier life."