ASBURY PARK PRESS
NEPTUNE, NJ
D - 158,623
S - 221,449
DEC 11 2001

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GARDEN STATE PRESS
CLIPPING BUREAU

With no definitive diagnosis or treatment, physicians and patients look to researchers for answers to chronic fatigue syndrome.

Dr. Christine Petty, a family physician in Rockford, Ill., treated a patient for an illness that lasted six years.

During that time, the man, then in his 40s, became so disabled that he couldn't leave his home. He took a leave of absence from his job. His wife divorced him.

Petty's patient had chronic fatigue syndrome (CFS), an illness that is often as devastating as it is puzzling, and one for which there are more questions than answers.

Story By
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HEALTH AND FITNESS
NEWS SERVICE

Estimates of those with the illness have reached 800,000 in the United States alone, according to recent research. But pinpointing its exact symptoms can be as perplexing as CFS itself.

Fatigue is a common complaint. But in the case of this patient, Petty could pick up signs that his difficulties were different. This patient's fatigue was bone-crushing and unexplained. He also complained for at least six months of a host of other ills: low-grade fever, muscle aches, sore throat and sleep problems.

While there is a definition for CFS that was developed in 1994 and used by Petty in her diagnosis, most researchers and clinicians find it flawed. A new one is in the works. It is expected to be ready by 2003.

At present, there is no definitive way to identify CFS.

"It's a diagnosis of exclusion," said Dr. Kenneth Wasser, a rheumatologist with a practice in Tinton Falls.

"The first steps are a thorough history and physical examination. Physicians must rule out viral causes, depression, cancer, thyroid disorders or any other chronic illness."

The U.S. Centers for Disease Control and Prevention recommends a series of about 15 tests physicians can use to screen for CFS. They include a complete blood count, measures of total protein in blood plasma as well as glucose levels.

Unusual findings in any of the tests could

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point to a disorder that a physician may successfully diagnose and treat.

But 90 percent of CFS patients will test at normal levels, according to the CDC.

Treatment concerns

After ruling out all other diseases, doctors should consider chronic fatigue syndrome. But, as with the diagnosis of the illness, there is no definitive treatment.

"I try to get them to exercise, to get more quality sleep," Wasser said. "Medicines, such as muscle relaxers and antidpressants, can improve the quality of sleep. A lot of these patients have pain and we try to avoid narcotics."

For Petty, treatment included providing a lot of support for her patient. Holistic management of patients' lives also can be a central element of care, Petty said. Eating right, controlling stress and maintaining social ties are important considerations.

Cognitive behavioral therapy in skilled hands may also be included in treatment, said Dr. Anthony Komaroff, a professor of medicine at Harvard Medical School in Boston.

A common-sense clinical approach is best, said Dr. William Reeves, principal investigator of CDC's chronic fatigue syndrome program.

The U.S. Department of Health and Human Services' newly formed Chronic Fatigue Syndrome Coordinating Committee identified primary care physicians as those most likely to care for patients with chronic illnesses such as CFS.

The syndrome also poses a quandary in a medical climate that emphasizes a scientific basis for prevention, diagnosis and treatment.

"While it is pretty clear there are objective, biological things wrong with many patients," Komaroff said, "the problem is that none has been found to be present in every patient. So, we don't yet have the two things that the average doctor and patient are looking for — a diagnostic test that is sufficiently accurate to be useful and a proven treatment."

As a result, patients with the syndrome must often endure the skepticism of family and friends and some physicians. Patients and their advocacy groups have become vocal defenders of the physiological basis, even if unknown, of CFS.

Dr. Arthur Barsky, a psychiatrist at Brigham and Women's Hospital in Boston, received a rash of angry letters after he and a colleague published a study suggesting that the responses of physicians and others to the diagnosis of a controversial illness such as CFS could cause patients to exaggerate and maintain their symptoms.

Most letter-writers assumed Barsky was saying that the illness was more a state of mind.

Researchers gear up

Komaroff said attitudes in general seem to be changing. He said there is much less skepticism among physicians now than there was a decade ago, before research evidence began to roll in.

Nonetheless, treating patients with CFS might not be every physician's cup of tea, Reeves noted. Patients with CFS are often articulate. They don't look sick, and they have a lot of complaints, he said. Common complaints and symptoms of patients are often cognitive, so a physician may have a patient who just can't stay on track.

"These are hard patients to deal with," he said.

The pursuit of a cause and proper treatment for chronic fatigue syndrome is heating up

with a new emphasis by the Department of Health and Human Services on research.

"We are trying to reinvigorate the field now because there are so many new methods for doing genetic analyses and studying the brain," said Eleanor Hanna, a senior advisor at NIH's Office of Research on Women's Health, which is coordinating the department-wide CFS initiative.

Researchers are already using imaging technology to measure brain hormones and are examining the functioning of the immune system.

"There is considerable evidence already that the immune system is in a state of chronic activation in many patients with CFS," Komaroff said.

The CDC will soon begin a national survey to determine prevalence rates.

Recent research findings by Leonard Jason, a psychology professor at DePaul University in Chicago, threw into question a long-held belief that CFS is most common among white women. His survey of nearly 29,000 Chicago residents found that the illness occurred across all ethnic groups.

"Latinos had rates almost twice as high as Caucasians, and African Americans had rates similar to Caucasians," Jason said.

The search for specific infectious agents that may trigger or perpetuate symptoms of the illness is also ongoing, Komaroff said. "Although it is still unproven that any infectious agent is the cause of CFS, a number of us think that is a very plausible possibility in many if not all patients."

When the dust finally clears around CFS, few researchers believe a single, infectious agent will be found to explain all the cases, Komaroff said. And many believe that a variety of poorly understood syndromes — ranging from CFS to fibromyalgia — may turn out to be one and the same illness.

ON THE WEB

Centers for Disease Control and Prevention, Chronic Fatigue Syndrome information
www.cdc.gov/ncidod/diseases/cfs/

Diagnosing the syndrome

Patients are classified as having chronic fatigue syndrome if they meet the following two criteria:

- Unexplained fatigue that is not due to ongoing exertion, is not relieved by rest and results in a substantial reduction in previous levels of activity.
- Four or more of the following symptoms are concurrently present for six months or more: impaired memory or concentration, sore throat, tender cervical or axillary lymph nodes, muscle pain, multijoint pain, new headaches, unrefreshing sleep or post-exertional malaise.

Centers for Disease Control and Prevention