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Chronic Fatigue Syndrome—
Redefinition Raises Hope

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The symptoms of chronic fatigue syndrome (CFS) closely resemble those of depression, sleep disorders, autoimmune disease, and dozens of other conditions marked by chronic, disabling fatigue, muscle weakness, and mental confusion—making diagnosis of the illness difficult.

The result: CFS has often been overdiagnosed and falsely called an epidemic. It's also been underdiagnosed and misdiagnosed. Worse, it's often been trivialized and dismissed as a lifestyle condition that primarily occurs among white, middle-class women who can't cope with their overextended lives—twice as many women than men are diagnosed with the condition.

Consequently, unable to generate the earnest interest of friends and/or health-care providers, countless women and men with CFS have sought relief from dubious and unproven "remedies."

"The impairments of chronic fatigue syndrome are not trivial," insists Keiji Fukuda, M.D., M.P.H., who is at the forefront of CFS research at the Centers for Disease Control and Prevention.

In fact, CFS causes constant tiredness and fatigue that are "so debilitating that no amount of sleep helps," and everyday activity can land you in bed, yet getting out of bed can be nearly impossible.

Besides disabling physical fatigue, women and men with CFS also suffer mental fatigue—confusion, poor concentration, and forgetfulness—as well as never-ending flu-like symptoms, including aching muscles and joints, fever, and swollen lymph glands. The mix of symptoms prompted one sufferer to describe CFS as "endless mononucleosis with a touch of Alzheimer's."

As technically inaccurate as this description may be, it's an

improvement over the derisive, media-hyped "Yuppie Flu" nickname acquired because symptoms were initially diagnosed among young professionals.

But women and men with CFS should not lose hope. The medical community is making strides to end the indifference and misinformation surrounding CFS.

CFS Gains Medical Respect

The CDC recently has stepped up its efforts to distinguish this illness from other fatigue-related conditions. Late last year, it offered this streamlined, refocused definition of CFS: fatigue that has been ongoing for six months, interferes with normal activity, and is not related to another cause. People with CFS also have at least four out of these eight physical symptoms:

- impaired memory or concentration
- sore throat
- tender lymph nodes
- muscle pain
- multi-joint pain
- headaches
- unrefreshing sleep
- post-exertion malaise (meaning you get exhausted even after routine chores, for example)

These criteria provide physicians with a better working diagnosis and should help patients pin down the causes of their

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SELF-CARE

How You Can Control Urinary Incontinence

If you are among the 26 percent of American women who have urinary incontinence (little or no control of your bladder), you've probably kept your problem well-hidden—even from your clinician. Studies show that women with incontinence wait nearly nine years before telling a health-care provider about their condition.

Many women with incontinence become practically housebound—avoiding exercising, socializing, even shopping—for fear of an embarrassing "accident" that can occur from having one of the common forms of incontinence. With **stress incontinence**, for example, urine involuntarily dribbles during sneezing,

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Chronic Fatigue Syndrome

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dog-tiredness and rule out conditions that mimic CFS, such as autoimmune disease, depression, thyroid conditions, and HIV infection. "Unfortunately, there are no brain scans, x-rays, blood tests, or immune work-ups that can confirm or exclude this diagnosis," says James Jones, M.D., senior staff professor of pediatrics, University of Colorado School of Medicine in Denver, and the pioneering researcher who identified CFS in the last decade.

In addition to the CDC's effort, the National Institutes of Allergy and Infectious Diseases and other funding sources have started to support intensive research nationwide.

This move to legitimize CFS has heartened sufferers. "Now when I request a wheelchair in the airport I won't have to pretend it's for a more 'respectable' condition like multiple sclerosis," says Judy Basso, who has had CFS for a dozen years and presides over the Minneapolis branch of the National Chronic Fatigue Syndrome Association.

Many Unknowns Persist

CFS occurs among all races and all age groups, but exact numbers remain a mystery. Some preliminary data from DePaul University in Chicago, however, indicate that the incidence may be "as high as 200 per 100,000 people," according to DePaul investigator Leonard Jason, Ph.D., professor and clinical professor of community psychology.

The causes also remain unknown. One prominent theory is that CFS is "a glitch in the immune system of certain individuals," says Jones. Possibly, their immune systems overreact in response to a trigger, such as infection. This exaggerated response causes fatigue, aching muscles, headaches—all typical symptoms of fighting off a flu virus.

"The problem is, the immune system never shuts off," says Jones. "It remains in attack mode, although we do not really know the enemy." Suspects include allergies, an overgrowth of yeast, pollutants, or even unremitting stress.

Another recent theory published in the *Journal of the American Medical Association* links CFS to an abnormality in the way the body regulates blood pressure. Many

patients with the syndrome respond to treatment involving increased salt and fluid intake in conjunction with standard drugs to regulate blood pressure. Nevertheless, the researchers caution that the findings are preliminary and need to be verified by a larger study.

Other theories suggest that CFS may be a hormonal glitch (which could explain why women are the prime targets) or that it's related to a psychological condition. A single agent or several may also be involved.

Cure Will Be Customized

Researchers investigating treatments are looking into allergy therapies targeted to the immune system and antiviral drugs such as Ampligen®. "Treatment will probably evolve from a variety of fronts simply because the illness varies from person to person," Jones says.

In some people, symptoms come on almost overnight, often after a bout with a cold. With others, symptoms appear gradually. The illness also appears to peak in one to three years but may also persist indefinitely. Some people are able to recover their energy, others are practically bedridden.

If there is any bright spot in this, Jones says, it's that CFS is not life threatening or contagious, and relief is now available to help normalize the lives of people who live with it.

How to Live With It

"It's important to identify the symptoms that cause you the most distress and then target treatments towards alleviating them," according to Jones. If it's joint aches, for example, you may need a regimen of anti-inflammatory pain relievers. If it's depression, some antidepressants such as Prozac® can help you cope better, sleep more soundly, improve your concentration, and even relieve muscle pain.

Here's more advice from the experts:

Beware of the quick fix and "experts" touting cures. According to the National CFS Association's consumer booklet, "Reputable physicians treat symptoms only, and provide educational resources to help people cope with CFS. Improper treatments include IV [intravenous] vitamin C, coffee enemas, Chinese herbs, and blood-warming treatments."

But not everyone is so cautious about unproven remedies. "I would not deter anyone from megavitamins or herbs, for instance, provided they are used in moderation," says Jason. "Look what we have discovered about garlic and its positive effects on the heart." (For information, contact the Chronic Fatigue and Immune Dysfunction Syndrome Association [a patient advocacy group that believes CFS is an immune disorder], P.O. Box 220398, Charlotte, NC 28222; 800-442-3437.)

Adapt to your new state. "People who adapt to the new, reduced energy state and accept their limitations seem to do better—and often improve after two or three years—than those who spend all their effort looking for an immediate cure," says Jones.

Remain active even if you walk only a half block daily. According to Jones, even minimal activity can help you retain—and gradually regain—energy.

Organize your schedule and pace yourself. Plan demanding activities for times when you feel your best, says Basso. Consolidate and simplify tasks. Sit down while cooking, for example. Divide difficult tasks into smaller parts and eliminate unnecessary tasks. Know when to stop and when to keep pushing, says Jones. Discuss reorganizing your work schedule with your employer—taking a day off mid-week may increase your overall productivity. Unremitting stress can turn on an overactive immune system response. Resting, on the other hand, turns it off.

Reach out. Ask others to help with chores so you have energy for pleasurable activities that improve the quality of your life.

Maintain a social life. Advise your friends of your limitations, Brasso suggests, so that their expectations of you will be realistic.

Keep a journal or tape record a diary. This will help you release emotions and learn to accept what you cannot change, says Basso.

For more information about support groups, coping skills, research efforts, and reading materials, contact: National CFS Association, 3521 Broadway, Suite 222, Kansas City, MO 64111; 816-931-4777. 