



Chronic Fatigue Syndrome (ME/CFS) Information for Family, Friends and Caregivers

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Chronic Fatigue Syndrome (CFS) is a serious, complex and often disabling illness, which affects at least one million American men, women and children of all races and economic backgrounds. Four times as many women as men are affected. The illness is also called Myalgic Encephalomyelitis (ME) and Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) and it is found worldwide. The acronym ME/CFS is now increasingly being used.

Many people with ME/CFS are very ill and need a lot of help and support from family and friends. The value of caregivers support is immense and should not be underestimated. Most caregivers, are wholehearted in their wish to help, but to provide effective assistance, they also need to know about the illness and how it has affected their friend or family member. When the patient is too ill to act for her/himself, caregivers have an important role acting as advocates and facilitating communication between the patient and healthcare provider.

What is ME/CFS?

Profound fatigue lasting at least six months in adults, or three months in children, is a major component of the illness. This debilitating fatigue is accompanied by a wide array other symptoms. ME/CFS symptoms are made worse by physical and mental activity, are not relieved by rest and result in a substantial loss of ability to function. The pattern and number of symptoms varies among patients, and symptoms may change in severity from day to day, or hour to hour.

ME/CFS symptoms include:

- After exertion, malaise, muscle weakness and other symptoms worsen. Recovery is delayed 24 hours or more
- Unrefreshing sleep, daytime hypersomnia (excessive sleep) and/or nighttime insomnia
- Widespread migratory muscle or joint pain (without swelling) or headaches (a new type or more severe)
- Neuro-cognitive symptoms include impaired short-term memory, difficulty in concentration, difficulty finding words and/or numbers, inability to multitask, disturbed balance, hypersensitivity to noise, light or emotional overload.

- Autonomic symptoms include facial pallor, dizziness, palpitations, inability to stand up for any length of time (orthostatic intolerance), urinary frequency and bowel symptoms (irritable bowel syndrome.)
- Neuro-endocrine symptoms include sweating, feeling feverish, intolerance to heat and cold, low body temperature, abnormal appetite, symptoms that worsen with stress.
- Immune manifestations include tender lymph nodes, recurrent sore throats and flu-like symptoms, or a new sensitivity to food, medications or chemicals.

The illness usually starts suddenly with fever and flu-like symptoms, but the onset can be gradual. Some patients improve slowly and can return to work part or full time; others have relapses and remissions; some remain housebound; and some are bed-bound. Up to 15% of patients recover within 10 years.

Because there is no diagnostic test for ME/CFS, the diagnosis depends upon the patient's symptoms meeting the criteria of one of several case definitions. The 1994 International Case Definition is the most commonly used. However, it excludes some patients with genuine ME/CFS who do not exactly fit the criteria. The 2003 Canadian Clinical Case Definition was produced to overcome this problem. A Pediatric Case Definition is available for diagnosing children and adolescents. All definitions require ruling out other fatiguing illnesses before declaring it ME/CFS. Although there is no cure for the illness, medication can be useful in the relief of individual symptoms. Illness management is aimed at helping patients adapt their lifestyle to their existing capabilities (pacing).

How ME/CFS Affects patients

ME/CFS affects every aspect of the patient's life and her/his quality of life is often very poor. Once-active adults find themselves needing to rest instead of caring for others. They are forced by the illness to spend time away from their responsibilities at work, at home, or at school (for children). Functional impairment may induce feelings of anger, sadness or guilt. Patients frequently focus on their symptoms, their treatment and their hopes for recovery. ME/CFS

takes a significant toll on families. Some spouses may be unable to cope with the illness.

Financial concerns can create serious personal hurdles for patients with ME/CFS. Inability to work, leading to unemployment, together with ongoing financial expenditures, force the patient to apply for disability benefits. This process is difficult, time consuming and saps energy.

Inability to function or malaise may cause the patient to avoid making advance plans, cancel planned activities and become socially withdrawn.

ME/CFS patients typically do not look ill, so friends, family, and some healthcare providers may think that they are malingering. Consequently, many patients experience unkind reactions from those who think the illness is “all in their heads” and it may lead to a lack of confidence or self-esteem.

Obtaining suitable healthcare is difficult, even if the patient has not lost her/his medical insurance. The illness is not part of any medical school curriculum. Many healthcare providers are ignorant about ME/CFS, or deny it exists. It may be difficult to obtain a diagnosis or proper treatment for symptoms.

A prime diagnostic feature of this illness is a worsening of symptoms after exertion. Well-meaning friends or uninformed healthcare providers may encourage a patient to do more than she/he is able. This can cause a relapse of the illness. Patients need to learn to pace themselves.

How Caregivers Can Help

Support and Communication

- The top priority for caregivers is to offer physical and emotional support. Caregivers should keep an open line of communication with patients, by being non-judgmental toward both patients and the professionals with whom they must collaborate.
- Validate the patient, confirming your belief that they have a serious illness, even if a healthcare provider shows doubt. (Then, offer to help find a supportive healthcare provider.)
- Ask the patient, what they need and how you can help. Listen to the patient rather than providing suggestions on how to “fix” things.
- Offer support and be understanding when she/he cancels plans due to illness or fatigue.
- Offer positive responses such as, “I’m sorry you’re feeling so bad” or “You’re handling things so well,” or “I know this is difficult for you.”
- Avoid comments such as, “You can beat this thing, if you try hard.” Avoid negative comparisons such as, “You walked for a longer time yesterday” or “You used to have such energy.”

Education

Caregivers should learn about ME/CFS and how it affects the patient. Learn where to find valid information about the illness and where to turn when help is needed. Information about ME/CFS can be found at The New Jersey Chronic Fatigue Syndrome Association (NJCFSA) website, www.njcfsa.org, or Help Line, **888-835-3677**. A large library of books and periodicals about ME/CFS is also available to members. Caregivers are welcomed at local support group meetings and NJCFSA conferences. For information about these, contact the NJCFSA.

Healthcare

ME/CFS patients may need help navigating the healthcare system. Finding a healthcare provider who is able to diagnose and manage this devastating and puzzling illness can be difficult. The NJCFSA maintains a **list of ME/CFS knowledgeable healthcare providers**. Some patients may be unable to drive and may need someone to attend medical appointments with them. The caregiver can help the patient to report her/his most pressing problems, ask appropriate questions and take notes about the doctor’s recommendations and comments. ME/CFS treatment is symptom-based and supportive.

Practical Things You Can Do

Notice what activities of daily living the patient has difficulty completing, such as getting dressed or balancing the checkbook. Offer specific help, such as laying out clothing, assistance with organizing bills, or computing bank balances. Suggest that the patient keep needed items, such as keys, in a specific place. Write down directions or instructions.

Things You Can Do for Yourself as Caregiver

Caregivers need to know their own limitations and how to care for themselves. They also need support and “down time.” Caregivers can sometimes feel angry or guilty and may need to talk with a friend or another support person. It’s a good idea to set reasonable expectations for the care you are able to offer. Let the patient know when you need a break. Continue to enjoy your life, friends and activities. Give yourself credit for what you do for the patient.

For More Information on ME/CFS

Visit www.njcfsa.org. Call **888-835-3677**.

E-mail: njcfsa@njcfsa.org

References

Berne, K. For those who care fact sheet. www.cfids.org
What is CFS? www.njcfsa.org