



For Those Who Care About Someone With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Myalgic encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a serious, poorly understood and often disabling condition. It is an invisible illness, meaning there are very few obvious signs that the individual is ill. The cause(s) and cure remain unidentified, although symptomatic treatment is available.

Routine medical tests usually yield normal results and there is not yet a specific diagnostic test. However, it can be diagnosed by an ME/CFS-knowledgeable physician. ME/CFS follows an unpredictable cycle, often waxing and waning, and the symptoms are worsened after physical or mental exertion – a cardinal symptom of the illness called post-exertional malaise.

Treatment is symptom-based and individualized, since symptoms and responses to medications vary from person to person. Although many patients improve over time, most do not recover fully and a significant number of patients are so severely affected that they are largely home and/or bed-bound. For this reasons, it's vitally important for them to have the support of family and friends as they integrate the challenges of living with ME/CFS into their lives.

Effects on the Patient's Life

- **ME/CFS affects every aspect of an individual's life.** Formerly secure and self-confident people may lose self-esteem due to lack of productivity and difficulty engaging in pre-illness activities. These changes may cause friends and family to perceive them as "acting different" and can often upset the balance in relationships.
- Although the primary effects of ME/CFS are experienced by patients, the illness impacts everyone around them.

Effects on Relationships

- ME/CFS presents new challenges to relationships and may worsen existing relationship problems. Sudden changes in health and activity levels can make people with CFS very unpredictable. It is difficult for CFS patients to make advance plans and plans often must be canceled at the last moment. Because overexertion leads to relapses, previously enjoyed activities must often be altered or given up. This places a tremendous strain on partners and friends.
- People with CFS may be unable to work because of the debilitating symptoms and the unpredictability of their health. Financial problems can be a significant relationship stressor, as patients often are unable to contribute financially.
- Patients may become more dependent, more preoccupied with personal needs and less able to meet the needs of others. Others may feel neglected when former caregivers now need more help than they can give. Abandonment issues are common also. Feeling inadequate and unlovable, people with CFS may be afraid of losing friends, partners and families.



- Due to lack of understanding, and acceptance by some professionals, insurers, employers and the general public, CFS patients may feel the need to "prove" their illness. This should not be perceived as a request for special treatment or attention, but rather as a request for respect, understanding and support, and a need for acknowledgement that they are, in fact, quite ill - although they may not look sick.

How to Help: General Suggestions

- Educate yourself about ME/CFS. Stay informed by subscribing to Research1st (SMCI's monthly e-newsletter) at <http://solvecfs.org/get-involved/newsletters/> and following us on Facebook by 'liking' www.Facebook.com/CFIDSAssn
- Validate and acknowledge the seriousness of the illness. Be as patient, caring and understanding as you can be.
- Attend medical appointments to show support, take notes, offer your observations and verify reports if necessary.
- Offer to help in specific ways - running errands, managing finances, helping to fill out disability forms, tracking health insurance claims.
- Enjoy activities together, modifying them as necessary, and talk about fun times you've enjoyed together. Keep plans and expectations flexible to accommodate unpredictable symptom changes.
- Avoid comparisons with the way things used to be and with other patients. Create a "new" normal, modifying goals and plans as necessary.
- Keep lines of communication open. Be willing to listen, but let the person know when you are overloaded and need a break. Don't let ME/CFS-related anger control your discussions. Memory impairment may cause patients to interrupt ("If I don't say it right now, I'll forget"). If interruptions are frequent or distracting, suggest that they jot down notes during the conversation.
- Avoid making well-intentioned comments that may be perceived as insensitive and hurtful, potentially damaging closeness and trust.
- Healthy people do experience some ME/CFS symptoms from time to time, although not as frequently or severely as people with ME/CFS. Statements such as, "I get tired too," may cause patients to feel that they and their illness are not being taken seriously. Instead try to word your comments constructively such as "I wish I could make it better for you." And "You're handling this illness so well, but I know it gets you down sometimes."
- ME/CFS patients need empathy and validation but may reject well-intended but unwanted advice or attempts at "fixing." Often he or she just wants you to listen. Reassure the ME/CFS patient of your love, caring and support.

Remember: This illness isn't logical. Respect their need to prioritize, to rest, to discontinue any activity at the first hint of fatigue. The patient may need to change plans at the last minute or decline to do certain things which may produce fatigue or relapse.