



Solve M.E.

LOVING SOMEONE WITH ME/CFS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a serious, poorly understood and often disabling disease. ME/CFS affects the immunological, neurological, cognitive, autonomic, and energy production systems of the body. It is not psychiatric in nature and it is not the same as “chronic fatigue.”

ME/CFS follows an unpredictable cycle of waxing and waning along with significant worsening after physical or mental exertion – a cardinal symptom of the illness called post-exertional malaise. Routine medical tests often yield normal results and there is no specific diagnostic test available to clinicians as yet. However, ME/CFS can be diagnosed by a physician who is knowledgeable about the disease. Treatment is symptom-based and individualized since severity of disease and responses to medications vary from person to person. Although many patients improve to some degree 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.

ME/CFS is considered to be an “invisible” illness. With the exception of the most severely affected, there are few outward signs that an individual with the disease is actually ill. Patients who “don’t look sick” can be burdened with additional challenges due to stigma or disbelief. It’s vitally important for people with ME/CFS to have the support of family and friends as they face the daily challenges of living with this complex and debilitating disease.

IMPACT OF ME/CFS ON RELATIONSHIPS

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. They may become more dependent, more preoccupied with personal needs and less able to meet the needs of others. Due to lack of understanding, they 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, support, and acknowledgement that they are, in fact, quite ill even though they may not look sick.

People with ME/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. Abandonment issues are also common. Feeling inadequate, unlovable or unworthy, people with ME/CFS may be afraid of losing friends, partners and families.

Although the primary effects of ME/CFS are experienced by the patients themselves, the illness impacts everyone around them. The disease presents new challenges to relationships and may worsen existing relationship problems. Sudden changes in health and activity levels can make people with ME/CFS seem unreliable to those who do not understand. Due to the unpredictability of the disease, it is difficult for patients to make plans, and those that do make plans often have to cancel at the last moment. Because overexertion leads to relapses, previously enjoyed activities must often be altered or given up. All of these issues may cause friends and family to perceive them as “acting differently” and can often upset the balance in relationships and place tremendous strain on partners and friends. Others may feel neglected when former caregivers now need more help than they can give.

HOW YOU CAN HELP

Although you can't take the pain and suffering away from your loved one, there are things you can do to help ease their burden and improve the quality of their life.

- Educate yourself. Read the Patient Resource pages available on our website. Stay current on research by signing up for free SMCI email updates at <https://solvecfs.org/get-involved-2-2/newsletters/>. (You can customize your subscription to receive as many or few e-mails as you like.) Follow us on Facebook by “liking” our page at <https://www.facebook.com/SolveMECFSInitiative/>.
- Validate and acknowledge the seriousness of the disease. Healthy people do experience pain, exhaustion, and other symptoms from time to time, although not as frequently and definitely not as severely as people with ME/CFS. Statements such as “I get tired too” may cause your loved one 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” or “You’re handling this so well, but I know it gets you down sometimes.”
- Listen to your loved one. Be as patient, caring and supportive as possible. Keep the lines of communication open and be willing to truly listen. Avoid making well-intentioned comments that may be perceived as insensitive and hurtful, potentially damaging closeness and trust. Try not to get angry or let ME/CFS-related issues control your discussions. For example, 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.
- Be helpful when possible. Offer to help in specific ways – running errands, managing finances, helping to fill out disability forms, tracking health insurance claims. Attend medical appointments to show your support, take notes, offer your observations and verify medical reports if necessary.
- Create a “new” normal. Modify goals, plans and expectations as necessary. Avoid comparisons with the way things used to be. As the disease varies in severity from person to person, avoid comparisons with other patients as well. Respect your loved one’s individual need to prioritize, rest, and discontinue any activity at the first hint of overexertion. The patient will often need to change plans at the last minute or decline to do certain things which may worsen symptoms or cause a relapse.
- Enjoy one another. Find activities that you can do together and modify them as necessary to accommodate your loved one’s needs. Just be sure to keep plans and expectations flexible in order to accommodate the unpredictable symptom changes that are inevitable when living with ME/CFS.

TAKE CARE OF YOURSELF

Again, while the primary effects of ME/CFS are experienced by the patients, the illness impacts everyone around them. If you are a primary caregiver, the impact on your own life will be even more significant. However, as everyone knows, you must take care of yourself first or you will have nothing left to give others.

- Acknowledge the impact on your own life. As a caregiver, you will find yourself going through the five stages of grief: Denial; Anger; Bargaining; Depression; and Acceptance. Because you’re caring for someone with a chronic illness, don’t be surprised to find yourself going back and forth on the grief scale.
- Take care of yourself. Take time for yourself whenever you can to rest and recharge. Be sure to eat well, exercise and get plenty of sleep. Consider joining a support group for caregivers or seeing a private counselor for your own mental well-being.
- Create a “new” normal for yourself. Modify your own goals, plans and expectations as possible. Ask for a flexible work schedule if needed. Revise your budgetary goals if your loved one is no longer able to contribute financially.
- Get outside help. Reach out to friends and family for help when possible. Check with social services to see if your loved one qualifies for home health services or other assistance. Check with your doctor, insurance agent, community leader or clergy to see if they know of other resources that might be available.
- Don’t deprive yourself. Don’t stop doing activities that are important to you just because your loved one is unable to participate. If you need to spend more time at home, find new activities that you might enjoy. Take up gardening or baking, learn to play an instrument or speak a new language, try your hand at sewing or woodworking, take an online class. Maybe you’ll discover a new passion that you wouldn’t have even dreamed of before.

Remember, this illness may seem illogical to someone who doesn’t understand it. In fact, more than one scientific researcher has said that ME/CFS is probably “one of the last major diseases” we know so little about. If you love someone with ME/CFS, just be

sure to reassure them of your unwavering love and support.

Further Reading:

Living With Someone Who Has Fibromyalgia or ME/CFS. Adrienne Dellwo. 2018

<https://www.verywellhealth.com/tips-for-living-with-someone-who-has-fibromyalgia-715871>

For Caregivers. American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society

Caregiving.com "Caring for You as You Care for Your Family"

Family Caregiver Alliance. National Center on Caregiving

<https://www.caregiver.org/>

SUPPORT GROUPS FOR CAREGIVERS:

- #MEAction Caregivers Support Group

<https://www.facebook.com/groups/1939159456384009/>

- Family, Friends and Allies for ME

<https://www.facebook.com/groups/583507755345267>

- CFS Caregivers

<http://cfscare.com/>

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