

When Someone You Love has ME/CFS or FM ***Tips for Carepartners***

There are many diseases that can be considered invisible, but there are substantial differences in how individuals are viewed culturally and socially, depending on their diagnoses. Diabetes, lupus, MS, and others can be invisible illnesses, but few would ever question the limitations of someone with one of these diseases. Yet, this happens frequently for the millions diagnosed with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM).

ME/CFS and FM patients often bear the extra burden of family, friends, coworkers, and even healthcare professionals who don't believe they are ill because they don't "look sick" and definitive diagnosis remains elusive. Yet ME/CFS and FM are serious and complex diseases marked by often debilitating symptoms.

Strong support from family and friends is critical for patients as they work to integrate the challenges of ME/CFS and FM into their lives. The keys to helping a person with ME/CFS and FM are compassion, education, and communication.

If you are a caregiver, partner, family member or friend of someone with ME/CFS and FM, our hope is that this information will help you be more effective and compassionate in that role.

LISTEN. Your willingness to listen will help validate and acknowledge the seriousness of the disease. ME/CFS and FM patients need empathy and validation but may reject well-intended but unwanted advice. Instead of trying to relate your own challenges or "fix it", simply show you care with words like "I'm sorry that you're feeling so poorly" or "I wish I could make it better for you."

BE UNDERSTANDING. ME/CFS and FM affect 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.

Reassure the one with ME/CFS and FM of your love and support. Some important changes in dynamics to keep in mind are:

- People with ME/CFS and FM 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. Some loved ones may feel neglected when a person who is ill now needs more help than they can give.

- Abandonment issues are common. Feeling inadequate, people with ME/CFS and FM may be afraid of losing friends, partners and family.
- Due to lack of understanding and acceptance by some professionals, insurers, employers and the public, ME/CFS and FM patients may feel the need to "prove" their illness. Try and understand this is often a request for respect, understanding and support, rather than vying for special treatment or attention.

Keeping these perspectives and challenges in mind may allow you to extend more grace and diffuse painful situations.

BE PRESENT. Living with ME/CFS and FM can be incredibly isolating and lonely. This isolation is magnified because of the essential disease management; the search for things that might help, and the heartache when they don't. The unpredictable crash that disrupts what life remains brings loss, fear, and anxiety. Because of all this, there may be no gift more valuable than your time.

- Attend medical appointments to show support, take notes, offer your observations.
- Offer to help run errands, manage finances, fold laundry, prepare a simple meal, or track health insurance claims.
- Enjoy activities together, modifying them as necessary. Accommodate unpredictable symptom changes. Talk joyfully about fun times enjoyed together.

BE FLEXIBLE. ME/CFS and FM present new challenges to relationships and may worsen existing problems. Sudden changes in health and activity levels can make people with ME/CFS and FM very unpredictable. It is difficult for patients to make advance plans and they often must cancel at the last moment. Because overexertion leads to relapses, previously enjoyed activities must often be altered or given up.

This also places a tremendous strain on partners and friends. Avoid comparisons with the way things used to be and don't compare your loved one to other patients. Create a "new normal," modifying goals and plans as necessary, to fit the unique needs of the one you love.

INVEST IN YOURSELF. Although the primary effects of ME/CFS and FM are experienced by patients, the illness impacts everyone around them. As a care partner, it's important to recognize that ME/CFS and FM present challenges and bring changes to your life as well.

- Educate yourself about ME/CFS and FM. Subscribing to our e-news or following BHC on Facebook or Twitter can help.
- 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 or FM-related anger control your discussions.

Take time for yourself so that you can continue to be there for the long haul for someone who needs and appreciates your love and support.

