



Solve M.E.

Solve M.E. Patient and Caregiver Resource Guide:

Securing a Personal Support System; Loving Someone with ME/CFS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a serious, poorly understood and often disabling disease. 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 illness.**

Securing Your Personal Support System

It is imperative to secure a personal support system to help you through this most difficult, debilitating disease for a multitude of reasons. The ME/CFS diagnosis can be stressful for family and friends, especially if they don’t understand this disease and what your symptoms mean.

Support in the early stages of ME/CFS may feel the same as support you would receive for any other illness. People with ME/CFS often report waning support as the illness drags on. Education with your support system is the key to their continuing support as the illness ebbs and flows, and during long periods of stagnated progress.

The ME/CFS experience can be isolating. Susan Rebecca Culbertson, MSW LISW, shares her advice for those newly diagnosed:

“It is difficult to protect your self confidence and maintain your dignity, if the persons in your life do not understand the current state of your debilitation. It is of crucial importance to educate your support system, when you are able. **Not only do you need to allow others to help you, you need to actually ask for help. Sounds easy. It’s not. Do it anyway. You’ll be glad you did.** It can make a huge difference in your healing, and in your day to day life.

Do the best you can, be honest with your loved ones about your limitations, ask for help when you can and stop worrying about what other people think or say. Above all, **be kind to yourself and skip the feelings of guilt, shame or blame when you're simply unable to do what others would like you to do. It is not your fault.**"

Educating Your Friends and Loved Ones

Despite the fact that ME/CFS can be as disabling as multiple sclerosis, heart disease and other chronic conditions, most of the general public is unaware of the impact it has on lives. On top of that, the misinformation perpetuated for decades about "chronic fatigue syndrome" has led to patients being negatively judged by others. Sadly, this often places additional strain on people who are already struggling to cope with such a complex and debilitating disease.

It is important that the members of your family and closest friends know enough about the disease to have a general understanding of what is happening. Ask them to read about the disease on our website along with some of the stories in our ["Humans of ME/CFS" project](#). Have them check out [the CDC](#) or other online resources. If you're working with a knowledgeable medical professional or are involved with a support group, invite them along to learn about the disease. If you have access to the award-winning 2017 documentary [Unrest](#), consider watching it with them and discussing how the disease impacts you personally. Show them this document. While no one can truly know what you're going through, it's important to have the support and understanding of your friends and loved ones when possible.

Regarding other people in your life, it's up to you to determine what, if anything, you need to share with them. Many patients avoid the "chronic fatigue" label entirely because it comes with so much baggage. Saying that you've been diagnosed with a relatively unknown neuro-immune disease that robs your energy and causes other problems is usually enough.

Understanding the Impact Of ME/CFS on Relationships

If you are a loved one of someone with ME/CFS, it is important to understand the impact that this disease can have on every aspect of 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 Caregivers and Loved Ones 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 Solve ME email updates at <https://solvecfs.org/get-involved-2-2/newsletters/>.
- **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.

Taking Care of Yourself as a Caregiver

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.

PROPOSALS TO PRESERVE HEALTHY & HELPFUL FAMILIES

Any illness of a member of the family has an impact on the entire family. Sometimes an illness can make a family stronger and closer, or it may cause stress and friction, or maybe even both at times.

The difference family support can make for a person dealing with M.E. is immeasurable.

Encourage your ME/CFS family member to share what it’s like for them having an illness that few people understand.

Support during the early stage of this illness may be easier, than during the ongoing lingering stage of ME/CFS. Persons with ME/CFS report waning family support as this illness drags on.

Blended families have layers of stress, even prior to an ME/CFS illness in the family. It is even more important early on to address how each family member is being affected, and what each family member can do to support the family member with ME/CFS.

To onlookers, it is sometimes difficult to know how to react when a family member with ME/CFS doesn't look sick. They were physically active at the family backyard BBQ yesterday, and today they are "lounging" on the couch.

Sourced from Susan Rebecca Culbertson, MSW LISW