

Myalgic Encephalomyelitis (or Chronic Fatigue Syndrome or ME/CFS) is a challenging disease for everyone involved.

Caring for someone with ME requires adaptability, steadfast patience and commitment over many years, if not a lifetime. #MEAAction has crowdsourced this advice from caregivers who care for both adults and children to better equip you.

“It’s about being truly present with their reality — to face it squarely in the face as stark and dark as that can be. If we can’t do that, we can’t really give them the support they need.”

—Mother of a young adult with ME

Take care of yourself

Get plenty of sleep, eat well, exercise and spend time doing activities that make you happy apart from your caregiver role. Try to have moments of joy each day in which you are not thinking about the disease.

Consider seeking professional help to better learn how to deal with the anger, frustration, sadness and fear that may arise.

Protect your patient

ME is a stigmatized disease that can generate disbelief and mistreatment from the medical community, and even from family members and friends resulting in harm to the person.

The carer needs to be aware that these views are prevalent so they can protect the person with ME, and also validate the person’s experience.

Educate yourself

ME is a difficult disease to navigate since most doctors are not educated about it. People with ME will likely visit countless doctors and experiment with off-label treatments, finding it difficult to understand what is helping. Keep a detailed record of the person’s medical history. Save copies of records from every doctor visit, procedure and lab test.

The person’s condition can fluctuate hour-to-hour, day-to-day or week-to-week. Caregivers may find themselves growing frustrated by the unpredictable nature of ME.

The defining symptom of ME is post-exertional malaise meaning the person “crashes” after mental or physical exertion, bringing on an exacerbation of symptoms. The person may not recover for days or weeks. The caregiver can help the person stay within their “energy envelope” and avoid crashing by encouraging active rest.

Advice from caregivers

Try to stay calm. The person with ME may get angry or frustrated and aim it at you. Escalation causes more stress for the person, which contributes to crashes. Strong emotions can accompany any chronic illness and are important to address.

Respect their independence. Respect the desires of the person with ME. If they are an adult, realize that they would be doing things their way if they were independent. Try to enact what they want without judgment.

Their reality is not your reality. They may not tolerate certain sounds, smells or materials that don’t bother you. This may be frustrating as you help them adapt to challenges that you cannot perceive yourself.

Take time for important conversations. You may need to have difficult conversations about identity, value, loss and suicide.