



# Caring for People with Myalgic Encephalomyelitis

## Table of Contents:

- 1) [Educate Yourself](#)
- 2) [Take Care of Yourself](#)
- 3) [Family Dynamic](#)
- 4) [Relationship with the Patient](#)
- 5) [Resources](#)
- 6) [Advocate](#)
- 7) [Power of Attorney](#)
- 8) [Get Organized](#)
- 9) [Join the Community](#)
- 10) [Read more](#)

Myalgic Encephalomyelitis (also known as Chronic Fatigue Syndrome or ME/CFS) is a complex, challenging disease for everyone involved - not least the caregiver. Caring for someone with ME will require adaptability, steadfast patience and commitment over many years, if not a lifetime.

#MEAction has crowdsourced this advice from caregivers who care for both adults and children with ME. Gain knowledge, perspective and skills to better equip you to navigate the long, convoluted journey of this disease.

To contribute to this document or provide feedback, email [editor@meaction.net](mailto:editor@meaction.net).



1. **Educate yourself about the disease.** ME is a difficult disease to navigate since the research is still thin, and the medical community often does not understand it nor know how to treat it.

In the US, the caregiver will likely find themselves accompanying the person with ME to countless doctor appointments, and experimenting with off-label medications and supplements while finding it difficult to understand what is helping.

In the UK, patients typically see their GP who will often recommend Graded Exercise Therapy or Cognitive Behavioural Therapy. Patients have reported

being harmed irreparably by undergoing GET, and the treatment should be avoided. [Read more](#).

2. People with ME also find that their condition can fluctuate from hour-to-hour, day-to-day and week-to-week so what they were able to do yesterday or last week may change. Caregivers may find themselves growing frustrated by the changing, unpredictable nature of ME.

The core defining symptom of ME is post-exertional malaise meaning that the person with ME “crashes” or “collapses” after mental or physical exertion, bringing on an exacerbation of the person’s cognitive and physical symptoms. The person may not recover for days or weeks. The caregiver should help their patient to stay within their energy envelope and avoid crashing by supporting the person to actively rest.

Keep in mind that caring for someone with mild or moderate ME will be a very different experience than caring for someone with severe ME, and that the person’s needs may change overtime.

This [primer](#) by the International Association for Chronic Fatigue Syndrome and Myalgic Encephalomyelitis is a good place to begin to understand the full definition of the disease from symptoms to diagnosis. Staying abreast of the latest scientific [research](#) is also important.

Even though there are no FDA-approved treatments available, there are many off-label treatments that patients have found helpful. Learn more about these topics on the #MEAction Patient Resources [page](#).

Unfortunately, it is difficult to find a doctor who understands or treats ME. #MEAction has crowdsourced a global directory of ME doctors on our Resources [page](#).

Other conditions often coexist with ME/CFS, and should be investigated in their own right and treated appropriately. These conditions include fibromyalgia, multiple chemical sensitivity, orthostatic intolerance, irritable bowel syndrome, irritable bladder syndrome, migraine headache, among others. Learn more at the IACFS/ME clinical guidelines, see [sections 4.6 and 5.8](#). For children, see the [Pediatric Primer](#), section 6.

- 3. Take Care of Yourself.** As a caregiver, it is important to take care of yourself even as you dedicate yourself to helping your loved one live with ME. Get plenty of sleep, eat well, exercise and spend time socializing or doing activities that make you happy apart from your caregiver role. Don't neglect your own health. Consider seeking professional help to better learn how to deal with the anger, frustration, sadness and fear that may arise, and how to communicate your feelings and needs with those around you.

Try very hard to have moments each day in which you are not thinking about your caregiving role or the disease, moments of enjoyment, joy, escape. Read a book, have coffee with a friend, take a walk. Don't let the negative overwhelm you. Take time to find peace, happiness and gratitude in the midst of the challenges.

- 4. Your family dynamic may change.** ME can have a devastating toll on the lives of people with ME and their families, including loss of careers, decreased quality of family life, social isolation, and feelings of hopelessness.

Family roles can shift. One parent may find that they have to put a career on-hold indefinitely to take care of a child with ME, and the other parent may suddenly become financially responsible for supporting the entire family. Families may have to take vacation in shifts so that there is always someone at home to take care of the person with ME. The family will find that it continually has to adjust its goals, expectations and perspective as situations change with passing years.

*"Siblings have lost their safety zone too," says one carer of a sick child. "Every time my children get a cold, they think they are developing what my daughter has [who has ME]. And my daughter has asked me so many times if I think the siblings are getting ME like her. The safety zone has been altered."*

- 5. Your relationship with the patient may change.**

Both the caregiver and person with ME will find that their worlds have changed as they learn to live with the ever-shifting reality of ME. For parents of children with ME, as the child develops into adolescence, new situations will continue to arise that will likely frustrate everyone, such as dating, learning to drive and

keeping up with peers.

“Patients, families, caregivers have to do a balancing act between what the new “normal” is (and the changes in relationships) and not losing touch with and hopes for living a productive life,” says a mother of sons with ME.

Here are tips to keep in mind for the caregiver:

- **Stay Calm.** Try to stay calm if the person with ME gets angry or frustrated and aims it at you. Reacting only exacerbates the situation and causes more stress for the patient, which contributes to crashes. Anger and frustration are totally expected when one has such a horrid debilitating disease.
- **No one is to blame.** Avoid blaming the person for their disease. And, don’t blame yourself. Like any disease, ME does not happen because of something you did or failed to do.
- **Don’t psychologize the disease or the person.** Recognize that there is a difference between the disease and the accompanying emotions that can arise from having any chronic illness. The fear, anxiety, anger and depression that may develop from losing function due to the disease are important to address - but they are *not* the symptoms defining the disease. Remember: ME is a multi-system disease that causes dysfunction of the neurological, immune, endocrine and energy metabolism systems.
- **Their reality is not your reality.** They may not be able to tolerate chemical cleaners, perfume or certain sounds that you don’t even notice. You may find this very frustrating as you attempt to help them to adapt to challenges that you cannot perceive yourself.
- **Respect their independence.** Respect the inner life and desires of your person with ME. If they are an adult, realize that they would be doing things differently if they were independent, and not how you do them. Therefore, try to enact what the patient wants without judgment, if at all possible, in order to give them some sense of independence and control over their lives. This can be hard if the person wants things done in ways that take more time, or in ways that are different than how you do things.

“This disease robs patients (and caregivers) of control so it is important to find as

many ways as possible for patients to have control where and when they can. (This also applies to caregivers and families.)” said a mother who has two sons with ME. “It is important to foster independence and provide choices wherever possible.”

The person with ME may make decisions affecting their treatment and care that you don’t agree with; it’s important to respect the decisions they make over their own bodies.

*“My son is older but I did play a strong medical advocate role for the first few years of his disease,” said a mother of a young adult with ME. “Then we reached a point when he didn’t want to keep trying new treatments and I still hoped there’d be something there. We worked through it but it was painful during the process. The key takeaway for carers is to stay centered on the patient’s experience and reality and respect what they need, not what we as carers might hope.”*

- **Not everything is related to ME.** If you are taking care of a child with ME, recognize that they still developing and may be entering a time of puberty, which is especially difficult if your child does not have many interactions with peers to help navigate the confusing changes. Your child may begin to experience fears, pains and anxieties that are related to puberty, and not to ME.
- **Facilitate social experiences** as much as possible for the person with ME either in-person or online. Finding other people with chronic illnesses is also important for sharing relatable experiences.
- **Facilitate moments of pleasure.** For the most severely ill, this may be difficult or impossible, but for those who are moderate, small gestures like offering their favorite foods, or taking a ride to the beach or to the park can improve their lives.
- **Don’t neglect necessary conversations.** In the face of such a difficult disease, you may need to have important and difficult conversations about identity, value, loss and suicide. Two men with ME share their thoughts on suicide and ME in this [testimony](#). Jennie Spotila writes about suicide and chronic illness on her [blog](#).

“To me as a caregiver, it’s about being truly present with the patient’s reality, to face it squarely in the face as stark and dark as that can be,” said a mother of a

young adult with ME. “If we can’t do that, we can’t really give them the support they need.”

6. **Find resources to help you.** Get informed about government services that may help with finances and caregiving. ME is not well understood by the medical establishment and so it may take a fight to get the services you deserve.

In the US, Social Security Disability Insurance (SSDI) is not often available for young people unless a parent is on SSDI, is deceased or receives Social Security Retirement benefits. Supplemental Security Income (SSI) is a different program that more young people would likely qualify for.

Learn more about getting on Social Security Disability Insurance in the US [here](#). Get as much help with anything you can for as much as you can afford. You can't do it all. It's really hard. Find grocery delivery services, meal delivery services.

7. **Advocate for the person with ME.** Validate their experience. ME is a contested, stigmatized disease that can generate disbelief and mistreatment from the medical community and, even, from family members and friends resulting in harm to the patient. The carer needs to be aware that these views are prevalent so that they can protect the person with ME, and also validate the patient's experience. Anger is a natural response to this situation, as is trepidation toward dealing with the medical community.

Learn about the political situation affecting ME so that you can better advocate for people with ME. Sign up for the #MEAction [newsletter](#) to stay up-to-date on government policies affecting ME, and advocacy happening around the world. Learn more about issues by topic on the forums, [Phoenix Rising](#), or at [Science for ME](#).

*“As caregivers, we are interpreting the symptoms of our patient and relaying the message to the doctors,” says a mother of a 12-year-old daughter with ME. “I feel overwhelmed at times that I have misinterpreted my daughter's message and often feel the doctor is second guessing my motive. It becomes a vicious circle.”*

**Trust your own Instincts:** Even as you continually seek the advice of professionals, remember that you live and work with the patient on a daily basis

and that there may be times when the clinical advice is unhelpful, and even damaging.

“Do not give your power away to social workers, nurses, doctors, anybody. You work, live with the person, you do know better and trust has to be earned,” writes the [Stonebird blog](#).

8. **Power of Attorney:** Consider getting a Durable Power of Attorney for Health Care and Health Care Directive, and a regular Power of Attorney so you can talk to doctors, medicare, insurance people and pharmacies if the person with ME is unable to do so for themselves, or would prefer not to. Do this before it becomes too difficult to discuss their desires with them.

9. **Get organized.**

“The person with severe ME is not going to fit into standard procedures and practices, do not expect that it is going to be easy and expect that formal agencies are going to reach out and comprehend,” writes the [Stonebird blog](#).

- Keeping an organized, detailed record of the person’s medical history is crucial. Get copies of the records from every doctor visit, every procedure and every lab test. Make a notebook. It is really hard to rely on getting records later, especially since there are likely to be so many appointments, doctors, procedures and tests.
- Keep an updated list of medications and supplements that the person is taking. Take it to every doctor’s appointment and leave them a copy.
- Document the effects of any new medication, treatment or supplement day-by-day. Track their energy level, number of steps, time spent in or out of bed. Use [these](#) medical templates to help you. Try new medications or supplements one at-a-time so you know which treatment is having an effect. Some medications may take months to make a difference so don’t give up too soon unless there are adverse reactions.
- Take photos often so that you can educate future doctors or caregivers. Share them with the public to spread awareness of ME, if you and the person with ME are comfortable doing so.



- Set up the room so that functions can be operated via remote control, such as lights, fans, heaters, etc.
- Set up a call mechanism - such as a remote doorbell - for the person to call you if needed.
- For people with severe ME, figure out communication tools that require little energy such as creating a list of common communications that the person can point to, or using post-it-notes to attach to something so that the person does not have to talk: green=more, red=remove, purple = needs fixing, etc.

**10. Join the community to find support and hope.**

- [Caregivers Facebook Support Group](#)
- [Parents of Kids & Teens with ME/CFS & Related Illnesses.](#)
- [FFAME \(Friends, Family, and Allies for ME\)](#)

**11. Learn more about caregiving for people with ME:**

- [American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society](#)
- [Caring for people with severe myalgic encephalomyelitis: An interpretative phenomenological analysis of parents' experiences](#)
- [Stone Bird blog](#)
- [Treating CFS & Fibromyalgia: An Integrated Approach](#)