LIVING WITH ME/CFS

The degree to which your life will be impacted by ME/CFS depends on a number of things, including the severity of your disease. If you are mildly affected, you may be able to continue with work, school and social activity as long as you manage your symptoms and carefully plan your activity level to avoid triggering post-exertional malaise. If you are moderately ill, you might need to modify work, school, and other activities while at the same time treating and managing your symptoms. Patients who fall into the moderate-to-severe range are generally unable to work and may be housebound or bedbound from time to time, while the most severely ill require help with even the most basic personal care.

WORKING WITH A DOCTOR

Finding a doctor who is knowledgeable about ME/CFS is challenging. Until recently, “chronic fatigue syndrome” has been considered a diagnosis of exclusion, meaning that any number of unidentified conditions resulting in fatigue have been placed in the same broad category. This practice has led to a one-size-fits-all approach to medical care that is inappropriate and potentially harmful for people living with ME/CFS. To this day, far too many physicians remain unaware of the scope and true impact of the disease.

Fortunately, educational resources for medical practitioners have improved significantly in recent years due to ongoing scientific discovery and a widely publicized report by the Institute of Medicine which clearly defined ME/CFS as a distinct disease. Primary care physicians and other medical professionals now have access to updated information offered by the Centers for Disease Control and other providers of continuing medical education.

There are a number of ME/CFS specialists who see patients in the United States, however, many have long waiting lists and may be located far from where you live. As a result, most patients do their best to establish a good working relationship with a primary care physician and one or more specialists when needed to manage specific issues.

Whether you meet with a specialist, find a new primary care doctor, or choose to work with your current physician, the following tips may be of help:

1. Before your visit, think about your most problematic symptoms and write them down, along with any questions you might have for the doctor. It is far too easy to forget what you’re doing once you’ve arrived at your appointment.

2. When describing your symptoms, give examples. Although it’s common for people to tell the doctor that they’re “tired all the time,” few will explain that they need to lay down for thirty minutes after taking a shower or feel the need to sit down when standing in line. By being specific, you can help the physician narrow down the possible causes of your symptoms and identify potential strategies for minimizing their impact.

3. Take notes during the appointment, or if possible, have someone come with you to help. With cognitive impairment, it is common for patients to misunderstand or simply forget the recommendations that have been made.

4. Be an active participant in your medical care. Ask questions when you don’t understand what has been said. Be sure you understand the purpose and side effects of any prescriptions or supplements that have been recommended.
5. ME/CFS is a complex and challenging disease that is not well understood. If you are seeing someone who doesn't know much about the disease, consider printing and sharing the first page of the CDC’s “Information for Healthcare Providers” on ME/CFS (see link below). The page offers a concise summary of the disease, mentions a new Continuing Medical Education course, and includes links to important new information for medical providers. Another helpful page to bring to your physician is entitled “Treating the Most Disruptive Symptoms First and Preventing Worsening of Symptoms.” This page highlights the need to avoid PEM and provides other important information and resources as well. Although it may be frustrating to have to “educate” your doctor, do try to be respectful when sharing information. “I brought this just in case you haven’t seen the latest information from the CDC about the ME/CFS.”

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 on-line 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. 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.

Living with a chronic illness is challenging can strain relationships. 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.

EMPLOYMENT ACCOMMODATIONS

If you’re fortunate enough to be able to work despite your illness, you may need some type of employment modifications to avoid triggering PEM or worsening your other symptoms. If you work for a company that has 15 employees or more, the Americans with Disability Act (ADA) gives you the right to request “reasonable” accommodations to do your job.

The types of accommodations that may be deemed reasonable for a person with ME/CFS will depend on your job and the severity of your illness. There are a number of possibilities to consider including modification of your workspace and/or lighting, use of stand/lean stools or a wheelchair, arranging to have a flexible schedule and/or the ability to take frequent breaks, using recorded or written instructions rather than verbal direction, and working remotely from home.

In the United States, the ADA is enforced by the Equal Employment Opportunity Commission. The ADA offers a helpful summary regarding your rights as an employee under the Americans with Disability Act at:

https://www.eeoc.gov/facts/ada18.html

DISABILITY INSURANCE

If your illness is moderate to severe, the impact and unpredictably of your symptoms will likely make work impossible. For most people, this can be traumatic on so many levels. There is the obvious distress that comes with your inability to earn an income. There is fear that you will be unable to afford the treatments you need in order to address your symptoms and improve your quality of life. There may be feelings of guilt or shame if you’re unable to contribute financially or need to rely heavily on your family. There may even be feelings that you’ve lost your “sense of self,” particularly if your job was an important part of your life.

If you’re fortunate, you’ll have access to long-term disability insurance through your employer to ease some of your financial
concerns. If not, the Social Security Administration offers two different programs for people who are disabled:

• SSDI (Social Security Disability Insurance) is for people who worked and contributed enough money through payroll deductions and employer contributions to meet a certain standard before becoming ill. In essence, your payroll deductions were used to pay for federally-sponsored Disability Insurance. If you qualify, your benefit is calculated using certain information from your employment history.

• SSA (Supplemental Security Income) is a need-based program designed to help people who do not qualify for SSDI and have no other sources of funds. To receive SSA payments, you must have less than $2,000 in assets ($3,000 for a couple) and a very limited income. With SSA, you will likely qualify for food stamps and some type of federal or state medical insurance (Medicare, Medicaid) depending where you live.

If you're in a position to apply for federal disability benefits, you will need to know more about these two programs. There are a number of links provided at the bottom of this page that may be of help as you navigate your rights along with access to a comprehensive “Disability Handbook” published by the Massachusetts ME/CFS & FM Association.

**Further Reading:**

**WORKING WITH A DOCTOR:**
- ME/CFS Experts in the United States
- CDC's “Information for Healthcare Providers” on ME/CFS
- CDC’s “Treating the Most Disruptive Symptoms First and Preventing Worsening of Symptoms:

**EDUCATING YOUR FRIENDS AND LOVED ONES:**
- What is ME/CFS?
- “Humans of ME/CFS” project
- CDC's Homepage for ME/CFS
- “Unrest” Documentary (As of March 2019, "Unrest" is accessible via Netflix and Amazon.)

**EMPLOYMENT ACCOMMODATIONS**
- U.S. Equal Employment Opportunity Commission
- Rights as an employee under the Americans with Disability Act

**DISABILITY INSURANCE**
- Social Security Association Disability Page
- Disability Handbook by the Massachusetts ME/CFS & FM Association

Disclaimer:
The Solve ME/CFS Initiative Inc. serves as a clearinghouse for information on Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS). Ideas expressed within the Solve ME/CFS Initiative website, print publications or materials, or monthly e-newsletters are strictly those of the authors or quoted individuals. The Solve ME/CFS Initiative assumes no liability for any medical treatment or other activity undertaken by individuals and encourages you to seek advice from a licensed health care professional before beginning any new medication, supplement, treatment, therapy, or exercise regime. The Solve ME/CFS Initiative does not recommend, endorse, make any warranties or representations with regard to any of the materials, products or services provided by companies or organizations referred to in this website, print publications or materials, or e-newsletters.