

Founded by nationally recognized clinical expert and Chief Medical Officer Lucinda Bateman, MD, **Bateman Horne Center** is leading the way in the medical advancement and treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (MECFS) and fibromyalgia (FM). By operating one of the few integrated medical research and clinical care programs in the country, Bateman Horne Center is working to develop standardized diagnostic tests and evidence-based treatments to improve the lives of millions of sufferers.

*“When my sister, Shauna Horne, fell ill she was unable to get a diagnosis or the treatment she needed. I had just finished medical school, but was eventually able to diagnose her with MECFS/FM and offer helpful supportive care. BHC is my way of giving thanks to my sister for helping me understand the tremendous unmet need that exists in this patient community. My commitment to them is to bring excellence in research and care.”*

— **Dr. Lucinda Bateman**



While there is no cure, FM and MECFS patients often tell Dr. Bateman they are much better than they used to be. Though each and every patient is unique, when it comes to practical treatment advice, Dr. Bateman has focused on some common truths evident from treating hundreds of patients that apply to almost all those with MECFS and FM. She uses these treatment approaches in her clinic – a nationally recognized center of excellence for treating MECFS and FM – and routinely teaches other medical professionals this simple plan of chronic management for MECFS/FM patients. Her aim is to provide a practical way to continually address symptoms that appear ordinary on the surface but may actually be aspects of illness physiology. This advice can improve symptoms and daily function, but also returns autonomy and empowerment to the patient until science identifies objective biomarkers and develops treatments more specifically directed at disease mechanisms. Achieving best management of these basic chronic illness manifestations also places this person in the most “research ready” position and gives them a chance to be part of these scientific advances.

This plan of support is best implemented after other causes of chronic fatigue and pain have been evaluated and excluded, such as major organ disease or failure, metastatic cancer, autoimmune disease, primary sleep disorders, severe eating disorders, substance abuse or mental illness. Epidemiology studies have shown that many patients debilitated by chronic fatigue have not consulted with a physician at all and, once properly evaluated, were often found to have other undetected illnesses with known treatments.

The following are not listed in any particular order. Each of them are helpful in managing MECFS/FM patient care. Hopefully they’ll help you identify areas you and your health care team can explore.

### **Build emotional resilience**

From day one of illness onset, it’s bad news. People around an individual struggling with MECFS/FM may not understand the illness, how it feels or what to do about it. There might be a flurry of medical attention at first, but as months go by without the kind of physical improvement people expect, those who once offered support may disappear. The ongoing physical limitations are accompanied by ongoing emotional trials—grief, worry, and discouragement. An acute illness is definitely traumatic, but most can muster a good fight while actively seeking a diagnosis and some type of rescue care. It is the chronic unrelenting nature of the illness that really gets old.

MECFS or FM can be especially punishing compared to other chronic illness. Because the symptoms are difficult to measure or prove clinically, they may be met with doubt or disapproval by those whose support is needed most. Because the illness can follow a relapsing and remitting pattern, in addition to feeling limited most of the time, patients often can't predict when they'll feel better or worse. Because of the characteristic post-exertional relapse of MECFS or pain escalation of FM, an honest effort to function or simply have a little fun is often punished mercilessly by a relapse of pain, fatigue, brain fog, sleep dysregulation or worse.

There are innumerable personal losses in the present and potential losses projected far into the future. Focusing on the loss can lead to a downward spiral that can impact life in very tangible ways. In order to thrive, **anyone living with these illnesses must repeatedly rejuvenate the will to live and to find joy in living, even while chronically ill.** It can be done! No one and no disease can take away the freedom to choose how to respond to a difficult situation.

MECFS/FM patients need support in the form of strong advocates and cheerleaders when the going gets tough. Patients with a good support system in place do better over the long term because having advocates and cheerleaders builds up their emotional resilience and helps them to develop insight. This kind of support also helps them learn how to get out of an emotional slump, calm paralyzing fears, and to get back up and take one step forward. It is important for them to cultivate the resources needed—among family, friends, counselors and medical providers—to stay as positive as possible. Remember that much of what is known about MECFS/FM physiology is centered in the brain, and brain physiology responds strongly to the mind. **Emotional resilience can help lead to physical resilience.**

### **Achieve the most restorative sleep possible**

MECFS/FM patients usually agree the better they sleep, the better they feel and function. The trick is figuring out how to accomplish this, and the solutions definitely vary by patient. Improved sleep immediately helps not only fatigue, but pain as well, and it probably improves cognition, mood, headaches and immune function to some degree.

Natural sleep is always best, but the unfortunate fact is that most MECFS/FM patients struggle with chronically disrupted and unrefreshing sleep that is not easily fixed. There is no doubt that left untreated, even for a few days, sleep disruption worsens most aspects of illness. Unfortunately, there is no perfect remedy for sleep. **Practicing good sleep hygiene—such as consistent bedtimes and reducing caffeine intake—is imperative, but often not enough.** Even the best of medications used for sleep have modest success, and some may even have adverse effects that can actually make sleep less restorative. Sleep medications may change the architecture of sleep, alter daytime cognition or worsen fatigue, so they should be used in the lowest effective doses and, as much as possible, directed at the cause(s) of sleep disturbance.

It may be useful to undergo polysomnography (a sleep study) if single drugs or low doses are ineffective. If medication is necessary, it may be helpful for your health care professional to choose one that also treats other symptoms of the illness. For example, while primarily improving sleep, drugs like gabapentin may reduce pain, amitriptyline may keep IBS or migraines in check, and mirtazapine may relieve depression. Achieving restorative sleep is an ongoing mission, but one well worth the attention.

### **Achieve reasonable pain control**

Unrelenting or severe pain is physically and mentally exhausting; it disrupts sleep, worsens mood and prevents physical activity. These are all important reasons to work on reasonable pain control. It may be impractical to eliminate pain completely, so the goal is to push pain into the background, to feel more in control and less frightened by the pain. This can be done by both reducing the pain and by learning to manage pain psychologically.

The first areas to consider when pain escalates are related to sleep, emotion and physical activity. Remember that restorative sleep improves generalized pain. It is also important to note that emotional distress such as fear, depression, guilt or grief can dramatically escalate pain and reduce pain tolerance. With MECFS/FM in particular, overextending physically, such as attempting vigorous or prolonged exercise, can raise pain levels both immediately and for days afterward. Inactivity, such as staying in bed too long, can also increase stiffness and overall achiness. So when pain increases, first reexamine sleep quality, emotional health and physical activity.

The decision to use pain medications, intermittently or persistently, should be made carefully with a qualified medical professional and adapted to each individual situation. Always be sure that appropriate investigations have been done to understand the cause and/or nature of the pain, so that treatment can be directed and maximally effective. Some focal pain conditions can be treated very effectively with high-tech procedures. Fortunately, there are a growing number of effective pain-modulating drugs for the broad spectrum of conditions that can cause pain. Opioids in particular, used regularly or in high doses, may actually worsen hyperalgesia (pain amplification) of neurologic origin, or become self-limiting due to cognitive side effects. Finding the right medication for your system and specific type of pain is key. The goal is to keep pain in reasonable control with thoughtful prevention and treatment, and to seek more intensive treatment from a specialist when this is difficult to accomplish.

### **Balance physical pacing with physical conditioning**

The most effective intervention for MECFS/FM is learning to control the type, duration and intensity of activity to avoid a “crash” or relapse. This is called pacing, or avoiding the push-crash cycle, and it works. Every patient should become familiar with his or her own threshold of relapse, even when it seems like a moving target, and learn to avoid triggering relapse symptoms by keeping activity within a safe level.

On the opposite end of the spectrum, activity limitation can cause diminished strength of both the skeletal muscles and the heart muscle. Without enough use, these muscles actually atrophy, getting smaller and weaker as time goes on. This global decline in strength and stamina is called physical deconditioning, and unfortunately it is often accompanied by weight gain as well. Being deconditioned can worsen pain, fatigue, balance/stability, orthostatic intolerance and sleep, not to mention self-esteem. A thorny problem, deconditioning is not easily repaired because initial attempts to exercise invariably result in a flare-up or relapse of symptoms.

These factors make both pacing and physical conditioning highly important. The objective is to carefully and regularly engage in a controlled level of physical rehabilitation that won't trigger relapse symptoms. The trick is figuring out how to do it—and especially how to adapt to a changing threshold of relapse. Tolerance for stretching, strengthening and cardiovascular exercise varies widely among patients with MECFS/FM. Those with FM-only may find graded exercise the key to improved function. Those with severe MECFS may end up tolerating only stretching, isometrics and walking in the home. It is helpful to start with these guidelines: short duration (<five minutes), low intensity (not strenuous), adequate rest/recovery periods (even a day or more) and utilization of a position (reclining or in water) that won't worsen orthostatic intolerance if that's an issue. Adhere to the general guideline that exercise efforts should cause no illness escalation the following day after a good night of sleep. The process of learning to effectively pace activity while still minimizing deconditioning can be a frustrating challenge, but it is an effective and self-empowering tool when it can be accomplished.

### **Identify and treat comorbid conditions**

There are a number of medical conditions, often subtle in presentation, that frequently overlap or occur in combination (are comorbid) with MECFS/FM. These conditions have well known diagnostic and treatment plans that a medical professional can follow whether familiar with MECFS/FM or not. Since each untreated condition may worsen MECFS/FM symptoms, any improvement in symptoms of comorbid conditions is progress in reducing the symptom burden of MECFS/FM.

Here are some of the more common comorbid conditions present in people with MECFS/FM:

- Sleep disorders (such as obstructive or central sleep apnea; restless legs syndrome, periodic limb movement or myoclonus; excessive sleepiness)
- Allergies, chronic sinusitis and reactive airway disease (asthma)
- Irritable bowel syndrome (IBS), reflux and heartburn (GERD), lactose intolerance, celiac disease
- Focal pain conditions such as osteoarthritis, cervical or lumbar disc disease
- Primary or secondary mental health conditions (such as attention deficit disorders, depression, anxiety)
- Metabolic syndrome (primary or secondary) and type II diabetes
- Hormone imbalances or dysregulation (such as menopause, low testosterone, hypothyroidism, polycystic ovarian syndrome)
- Chronic or recurrent infections (such as herpes simplex or shingles outbreaks)
- Vitamin D and vitamin B12 deficiency or “low normal” values

People with MECFS/FM should learn about their own comorbid conditions, and in partnership with a medical professional, see that they get the most effective treatments available.

The relevance of these supportive treatment options depends on the features of each individual’s illness, but each of them benefits MECFS/FM patients by improving functionality and quality of life. With a chronic condition like MECFS/FM, this can go a long way toward helping patients manage their illness while we search for targeted interventions and ultimately a cure.



#### **Our Vision:**

**A world where patients with MECFS and Fibromyalgia are readily diagnosed, effectively treated, and widely met with empathy and understanding.**

#### **Our Mission:**

**Empowering Patients, Advancing Research, and Improving Clinical Care for all those impacted by MECFS and Fibromyalgia**