



## ME/CFS Treatment Advice

### Pearls of Wisdom from an ME/ CFS Physician

By Lucinda Bateman, MD

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A nurse practitioner and fatigue clinic administrator are talking about burnout. The administrator groans, "I am so tired of slow scientific progress and of not being able to help my ME/CFS patients." The nurse practitioner smiles and says, "I hear you, but I don't agree that there is nothing that helps. Again and again, as I've become familiar with ME/CFS patients and their condition, they've told me they are so much better than they used to be!"

This scenario reminds us of what we already know but sometimes forget: **there are many ways to improve the situation of patients with ME/CFS, even if a cure is not yet within our reach.**

True, there is marked heterogeneity (variety and individual differences) within the large group of people meeting the ME/CFS case definition. But when it comes to practical treatment advice, there are definitely some common truths or "pearls of wisdom" that seem to apply to almost everyone. The five "pearls" listed below have been used to teach medical professionals a simple plan of chronic management for ME/CFS patients. The plan provides a practical way to continually address ME/CFS symptoms that on the surface may appear complicated or daunting. This advice can improve daily function, at least until science identifies biomarkers and develops treatments directed at the physiology of the illness.

Obviously 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, 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 sometimes found to have other more treatable illnesses.

The following pearls of wisdom aren't listed in any particular order. Each of them are helpful in managing ME/CFS patient care. Hopefully they'll help you identify areas you and your health care team can explore.

#### Pearl 1: Build emotional resilience

From day one of a ME/CFS diagnosis, it's bad news. People around an individual with ME/CFS may not understand the illness, how it feels or what to do about it. At first a ME/CFS patient might receive attention, 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. 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's living with the "C" in ME/CFS that really gets old.

ME/CFS 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 ME/CFS follows a relapsing and remitting pattern, in addition to feeling limited most of the time, patients can't predict when they'll feel even moderately better or worse. Because of the characteristic post-exertional symptoms of ME/CFS,

an honest effort to function or simply have a little fun is often punished mercilessly by a relapse of pain, fatigue and brain fog. 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 ME/CFS 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.

ME/CFS 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's 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 ME/CFS physiology is centered in the brain, and the brain responds strongly to the mind. Emotional resilience can help lead to physical resilience.

## Pearl 2: Achieve the most restorative sleep possible

ME/CFS 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 ME/CFS patients struggle with chronically disrupted and unrefreshing sleep that's not easily fixed. There is no doubt that left untreated, even for a few days, sleep disruption worsens most aspects of ME/CFS.

Unfortunately there's 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 you may have. For example, while primarily improving sleep, drugs like Lyrica (pregabalin) or Neurontin (gabapentin) may reduce pain, and Elavil (amitriptyline) may keep IBS symptoms in check.

Achieving restorative sleep is an ongoing mission, but one well worth the attention.

## Pearl 3: 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's also important to note that emotional distress such as fear, depression, guilt or grief can dramatically escalate pain and reduce pain tolerance. With ME/CFS 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. 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.

#### Pearl 4: Balance physical pacing with physical conditioning

The most effective intervention for ME/CFS 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's 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 ME/CFS symptoms.

These factors make both pacing and physical conditioning important for people with ME/CFS. 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 ME/CFS. It's 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.

The process of learning to effectively pace activity while still minimizing deconditioning can be a frustrating challenge, but it's an effective and self-empowering tool when it can be accomplished.

#### Pearl 5: 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 ME/CFS. These conditions have well known diagnostic and treatment plans that a medical professional can follow whether familiar with ME/CFS or not. Since each untreated condition may worsen ME/CFS symptoms, any improvement in symptoms of comorbid conditions is progress in reducing the severity of ME/CFS.

Here are some of the more common comorbid conditions present in people with ME/CFS:

- 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 or shingles outbreaks)
- Vitamin D and vitamin B12 deficiency or “low normal” values People with CFS should learn about their own comorbid conditions, and in partnership with a medical professional, see that they get the best supportive treatment available.

### **Wisdom applied**

The relevance of these clinical pearls of wisdom depends on the features of each individual's illness, but each of them benefit CFS patients by improving functionality and quality of life. With a chronic condition like ME/CFS, this can go a long way toward helping patients manage their illness while we search for targeted interventions and ultimately a cure.