

Exercising with Fibromyalgia and Chronic Fatigue Syndrome

Regular activity at the appropriate intensity can help those suffering from these conditions.

By Matthew D. Hansen, DPT, MPT, BSPTS

Fibromyalgia (FM) and chronic fatigue syndrome (CFS), sometimes referred to as myalgic encephalomyelitis, are silent enemies that steal hours of productive, pain-free activity from their sufferers. Because neither condition can yet be established through definitive lab tests, and because their symptoms often mimic many other health conditions, the often long diagnostic process can be frustrating to patients. Unfortunately, anxiety is frequently amplified by family and friends telling patients that their pain and exhaustion is “all in their head.”

Many experts agree that the symptoms of FM and CFS are so similar that the two appear to be part of the same disorder. This belief is supported further by the observation that as many as 70 percent of people with either diagnosis also meet the criteria for the other.^{1,2} Interestingly, whether someone is diagnosed with FM or CFS might depend on the specialty of the doctor making the diagnosis. Rheumatologists tend to diagnose FM more, while immunologists are more likely to diagnose someone with CFS.

Despite a likely biophysiological link between the two diseases, there is enough variation when it comes to the effect of activity on their symptoms that it's important to delineate their similarities and differences before discussing exercise.

Similar Conditions, but *Not* the Same

Those suffering from FM or CFS frequently experience debilitating fatigue, weakness and muscle pain; flu-like symptoms; sleep disorders; and cognitive-emotional challenges (e.g., forget-

fulness, confusion, irritability/anxiety and/or depression). Men or women may be affected by either condition at any age; however, both pathologies typically affect the middle-aged and occur much more often in women than in men (two to four times more often in the case of CFS and as much as 10 times more often for FM).

Despite FM and CFS sharing common symptoms, more “pure” cases of each do occur. Patients with a clear diagnosis of FM typically experience more pain than those with CFS, possibly related to elevated levels of substance P (the neurotransmitter responsible for transmitting pain signals), and they demonstrate tenderness or pain in at least 11 of 18 distinct locations on their body referred to as “tender points.” Though a definite trigger has not been identified, it appears that FM develops in more people following a traumatic event, whereas CFS seems to develop more often following a viral infection (e.g., influenza, Epstein-Barr or herpesvirus 6).

Patients with a clear case of CFS do not demonstrate increased levels of substance P, nor do they have multiple tender points, but they do often exhibit an increase in RNase L, an antiviral enzyme found in cells. They also often have an inflammatory response to their condition, which may include swollen joints and glands or a fever — a phenomenon that isn't observed in pure cases of FM. Though fatigue and nonrestorative sleep are symptoms of both FM and CFS, post-exertional malaise, or an intensifying of symptoms between 12 hours and 48 hours following exertion, is a greater risk

with CFS, whereas stiffness and immobility following inactivity is more universal in those with FM. Both of these observations come into play when discussing specific indications for exercise.

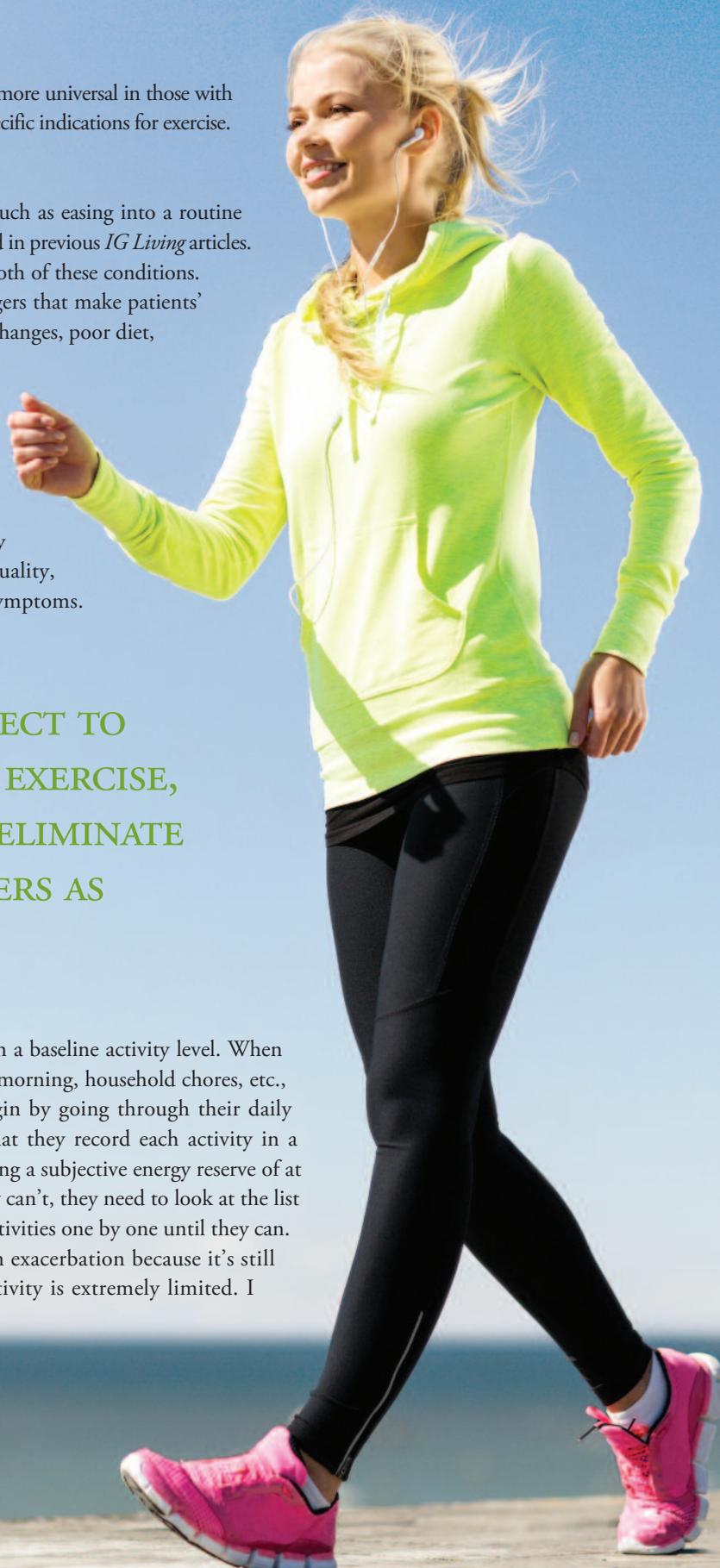
Exercising with Fatigue

Many of the principles regarding exercise with FM or CFS such as easing into a routine and pacing activity are important practices that have been discussed in previous *IG Living* articles. Yet, there are a number of concepts that are specific to one or both of these conditions.

One of the first and most important steps is to identify triggers that make patients' symptoms worse. These could be stress, poor sleep, hormonal changes, poor diet, environmental pollution (e.g., air, noise or bright lights), cold or humid weather (especially with FM), recurrent infections (especially with CFS) and/or too much or too little physical activity. Before patients can expect to experience the benefits of exercise, they need to identify and eliminate or at least avoid triggers as much as possible. Many patients have stopped exercising after beginning a gentle routine because they believed that it was too much activity for them, when in actuality, one of the other triggers (not exercise) was worsening their symptoms.

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Once triggers have been identified, patients need to establish a baseline activity level. When doing so, all physical activity, including getting dressed in the morning, household chores, etc., should be considered exercise. I recommend that patients begin by going through their daily routine without performing any additional exercise, and that they record each activity in a notebook. If they can make it through the day while maintaining a subjective energy reserve of at least six out of 10, then that is their baseline for activity. If they can't, they need to look at the list in their notebook and begin either eliminating or modifying activities one by one until they can. Patients shouldn't worry if they are currently experiencing an exacerbation because it's still important to establish a baseline of activity, even if that activity is extremely limited. I



actually suggest that patients establish at least two baselines: one when they are feeling their “typical selves” and one when they are experiencing an exacerbation. I say “at least,” because baselines for FM and CFS are frequently changing with uncontrollable, yet regular triggers like a woman’s menstrual cycle.

After having established a new baseline, patients can begin to increase their activity level by beginning a mild-to-moderate exercise routine (introducing one new exercise at a time), or by increasing their daily steps walked or daily activity level. These activities should be added to their notebook until they reach a point that they are unable to maintain their energy reserve at a level of at least six out of 10 by the next morning. I argue that no activity should cause a patient to dip below an energy level of four out of 10; however, when introducing activities, it is possible that levels may temporarily dip below a level of six out of 10. The important thing is that the level comes back up by the next day and that a bout of extended post-exertional fatigue is not initiated.

AVOIDANCE OF ACTIVITY AND EXERCISE ALTOGETHER LEADS TO AEROBIC AND MUSCULAR DECONDITIONING THAT WILL, IN TURN, INSTIGATE A CYCLE OF WORSENING SYMPTOMS AND SECONDARY HEALTH COMPLICATIONS.

The Centers for Disease Control and Prevention recommends that any exercise be followed by a rest period at a ratio of one to three.³ For example, if someone walks for five minutes, they should rest afterward for at least 15 minutes before continuing activity. Exercise can also be divided into multiple sessions throughout the day, with longer periods of rest interspersed between, to help control symptoms. If symptoms get worse or if increased pain or fatigue persists for more than several hours with a routine, patients should return to their last manageable level of activity until symptoms subside and then begin to build activity again, even more slowly than before.

Exercising with Pain

Too much activity can lead not only to increased fatigue, but also to added muscle and joint pain. Conversely, and especially in the case of FM, not enough activity can cause the body to become sore and stiff. Avoidance of activity and exercise altogether leads to aerobic and muscular deconditioning that will, in turn, instigate a cycle of worsening symptoms and secondary health complications.

For those patients who experience pain that interferes with their day-to-day function, it may be beneficial to establish a baseline pain level similar to the baseline activity level mentioned previously. The same traditional zero to 10 scale may be used in most cases, with a zero representing no pain and a 10 being the worst pain imaginable. Activity should typically be limited to a level that does not increase pain past a five or a six out of 10, or which at least does not increase the baseline level by more than one or two points.

Anxiety or depression, factors that often influence pain perception, may make patients with FM or CFS poor self-evaluators. It’s important to note that pain is subjective, and patients should not be labeled as malingerers (i.e., exaggerators or fakers) or as babies or wimps because they aren’t able to “take it.” Such labeling is one of patients’ greatest fears and something that most certainly adds to any already existing anxiety, especially when it comes from those who should be part of their support network. That being said, if patients are reporting that their pain is an eight out of 10 as they calmly sit in front of you, it’s probably fair to say that either psychological factors are interfering with their report or those patients at least don’t have a good comprehension of the pain scale. If this is the case, there are several nonsubjective scales, including the FLACC (face, legs, activity, cry, consolability) scale, that can be appropriately administered by a family caregiver or medical professional to more accurately assess pain.

If patients have established energy and/or pain baselines from their daily activity, and they are asking how they can now increase their physical activity, light stretching and range-of-motion or isometric exercises are a good place to start. Exercise programs designed to improve aerobic capacity are not typically prescribed immediately upon initiating a new program, but if patients feel they are ready, light walking, wading in a pool or recumbent biking are the recommended activities.

Special Considerations for Exercising with FM

The National Institutes of Health states that regular exercise is one of the most effective treatments for fibromyalgia.⁴ This includes strengthening and (particularly) aerobic exercise as central components of the long-term program to help improve pain and overall well-being.⁵ More frequent, less vigorous activity is



also important. I prescribe five minutes of gentle activity (e.g., walking or moderate stretching) after every 20 minutes to 30 minutes of being sedentary.

The utilization of correct body mechanics and maintaining proper posture help to avoid prolonged stress to tender points and are other ways to significantly control pain. Though special bracing or Kinesio Taping techniques may help to provide some temporary relief by improving posture, a customized stretching and strengthening program can provide more lasting relief if adhered to. Many patients report that moist heat or massage to increase blood flow before exercise, and cold applied to joints to reduce inflammation after activity, are also successful strategies.

Special Considerations for Exercising with CFS

Several writers have suggested that patients with CFS should frequently monitor their heart rates to keep them below the anaerobic threshold (AT). AT, represented by a heart rate that is approximately 60 percent of maximum heart rate,⁶ is the level of exercise intensity at which the body stops using oxygen to metabolize carbohydrates, fats and proteins as its main source of energy and turns to anaerobic (i.e., oxygen-free) energy systems instead. Anaerobic metabolism produces waste byproducts (e.g., lactic acid) in the muscles and bloodstream faster than they can be carried away, and the body is unable to sustain activity much longer once it reaches this point. Rapid fatigue, prolonged malaise and delayed onset muscle soreness occur as side effects.

Patients with CFS may need to find their AT symptomatically and try to stay below the heart rate at that level rather than using the 60 percent of maximal heart rate rule of thumb. Some will

discover that they can exceed their threshold quite easily with everyday activities so that tasks need to be paced better than they have been and, in some cases, stopped in mid-activity until heart rate can be controlled.

Improvement Is Possible

Despite these recommendations, as well as eating right and getting plenty of rest, exercise may still seem frightening to someone with FM or CFS. If more support is needed, cognitive behavioral therapy may be beneficial by teaching patients how to recognize and control their symptoms through behavioral strategies such as meditation and guided imagery.

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As always, patients should celebrate what they are currently able to accomplish, however small it might seem, and not dwell on what they aren't able to tolerate. That doesn't mean that someone living with FM or CFS must be content with their plight, but they should be satisfied knowing that though it may come slowly, improvement can occur. ■

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