



Chronic Fatigue Syndrome & Fibromyalgia

CFS & fibromyalgia as mitochondrial diseases.

A PATIENT GUIDE

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Chronic Fatigue Syndrome & Fibromyalgia

Chronic fatigue syndrome and fibromyalgia are two complex, and often misdiagnosed diseases. The exact causes are unknown, and no FDA-approved treatment exists. However, there are a variety of integrated approaches – including medication, lifestyle, nutrition, and emotional therapies, that can help improve your symptoms, and your quality of life.

It's worth noting that "CFS" is a debatable name for this disease, as the symptoms extend far beyond "chronic fatigue". In March of 2015, the Institute of Medicine released a report recommending a new name- "Systemic Exertion Intolerance Disease" (SEID) to more accurately classify CFS as a disease, and to eliminate the perceptions. Additionally, their recommendation includes adjusting the diagnostic criteria.

Choosing the Right Physician

Your physician will become your long-term partner in managing your symptoms – finding the right one is critical. While you won't see practitioners with the title "CFS or Fibromyalgia Specialist", these conditions generally fall within the specialty of "rheumatology". However, not all rheumatologists focus on CFS. There are also many other practitioner types who focus on CFS including MDs, DOs, and NDs.

Due to the highly integrated approach, you are also likely to see alternative healthcare practitioners who focus on CFS therapies. Finding a primary care physician, who recognizes and understands the disease, and who is able to help you navigate and coordinate a plan of care utilizing all available options (i.e. a team approach that's centered around YOU), is one of the most critical aspects to achieving your desired outcomes. Ask for referrals from your existing primary care physician, CFS and fibromyalgia support or advocacy groups, or local clinics who may offer referral services.

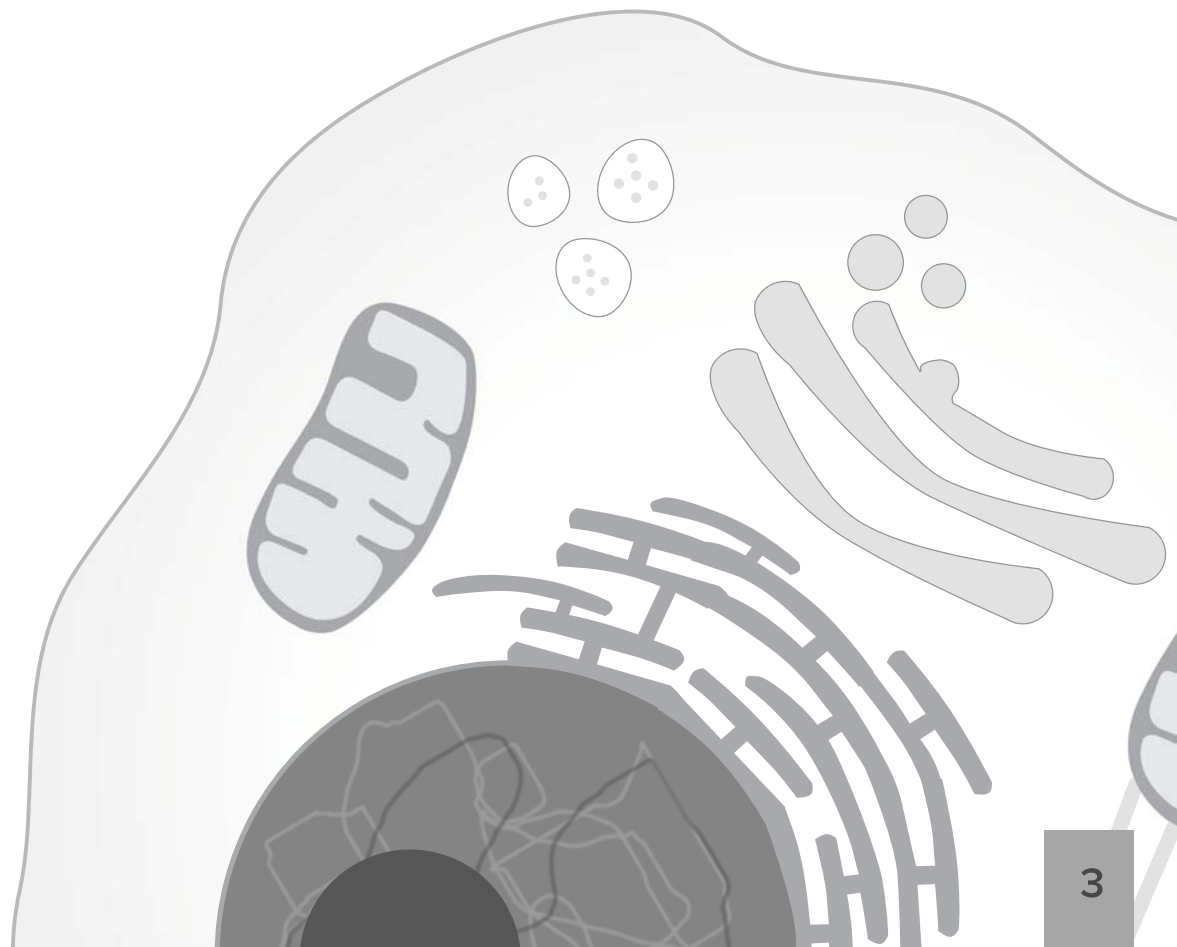
What is Integrative Medicine?

Integrative medicine is an approach that focuses on individualized care, while incorporating lifestyle and nutrition, conventional medicine, and alternative therapies to achieve the best outcomes possible. Chronic conditions and diseases are increasingly being managed using integrative medicine.

Our Body's Cells

Cells are your body's smallest structural and functional unit. Cells form tissues, which form organs, which form entire systems (i.e. cardiovascular, musculoskeletal, digestive, nervous, etc.). Because they are the building blocks for every function of our body, maintaining the performance of cells is a prerequisite for the optimal performance of our tissues, organs and ultimately, every system of our body.

“Organelles” are the components of a cell, each with a very specific function (much like each of the organs of our body). Mitochondria are one type of organelle, and are responsible for the energy production of the cell. Mitochondria (or, singularly - mitochondrion) are the “powerhouses” of every cell in the body. They are responsible for converting fuel, and processing oxygen into energy for the cell. The fuel for our cells is delivered in the form of “adenosine triphosphate”, or ATP for short. ATP is produced through a set of reactions within the mitochondrion known as “The Krebs Cycle” (or “Citric Acid Cycle”). Simply put, it's in the mitochondria that food is converted into stored energy, known as “ATP” - cells utilize this energy to move, divide and ultimately – to survive. Conditions that impair these energy-producing processes are referred to as a “mitochondrial disease,” - and can also broadly be represented as “metabolic disorder.”



Mitochondrial Function

Mitochondria convert the carbohydrates and fats we consume into their cell-ready form. These ATP molecules are constantly being “re-fueled”, allowing the mitochondrion to continue to produce cellular energy. Without cellular energy, our cells would no longer be able to carry out their function, which also means tissues, and organs function less optimally.

Mitochondrial Dysfunction

Today, there are dozens of named conditions that are related to the dysfunction of mitochondria, and it’s a list that continues to grow. These are complex conditions, which are often not easy to diagnosis. The function of the mitochondria naturally declines with age, and ongoing research is being done to determine the effects of the mitochondrial dysfunction and age-related conditions. However, dysfunction can result, or accelerate for unknown reasons.

Because mitochondria are located in nearly every cell of the body, and play a role in nearly every function of our bodies; dysfunction can present itself in many different ways – and vary in every individual. Symptoms can range from mild to complete impairment. Though genetics can be a factor, dysfunction can present itself at any age – not just at birth – and without a hereditary genetic mutation.

The Journey to Diagnosis

Oftentimes patients describe a journey of seeing multiple physicians, several specialists, and various integrative medicine practitioners with some relief using certain therapies, but never any significant or lasting improvement. A journey like this can wear on anyone. Even the most strong-willed and perseverant individuals can feel their psyche fade at times. The complexity and lack of consistent and accurate diagnostic testing methodology also means that misdiagnosis is common.

While the journey is complicated – there is hope! You play a crucial role in diagnosis – be sure to ask questions, continue your self-guided education, find the right physician who is working hand in hand with you, maintain accurate medical history records, journal your symptoms, and adhere to the strategies for care that your physician has recommended.

Complexity of Diagnosis

Due to the complex role of the mitochondria, and the great degree of variation on how symptoms present themselves across individuals, diagnosis of any mitochondrial condition is typically a long, inconsistent process, even when seeing an experienced practitioner.

Diagnosing Subclinical Mitochondrial Disorder

Mitochondropathy, or rather pathology of mitochondria, is often diagnosed by muscle biopsy. However, this is an invasive test and may miss poor functioning mitochondria that do not yet reach the level of frank disease states. This functional condition is often referred to as “subclinical mitochondrial disorder” and can masquerade as a number of other difficult or even debilitating conditions. People suffering from subclinical mitochondropathy may receive a diagnosis of fibromyalgia, chronic fatigue syndrome, chronic Lyme disease, adrenal fatigue, or multiple chemical sensitivities. Peripheral neuropathy that is not responding to treatment or brain fog may be symptoms attributable to subclinical mitochondropathy.

Diagnostic Criteria of Fibromyalgia and CFS

Ultimately, a diagnosis of CFS is one of exclusion, meaning that it is made only after all other conditions have been ruled out, you've experienced 6 consecutive months of severe fatigue, which includes a presentation of 4 out of 8 symptoms including post-exertional malaise (exhaustion) that lasts 24+ hours, unrefreshing sleep, pain, short term memory loss or concentration issues, joint pain without swelling, tender lymph nodes, headaches of a new pattern, recurring sore throat. Fibromyalgia will follow similar criteria, however, if pain is the primary symptom, with "tender points," the diagnosis will likely be fibromyalgia.

My strength did not come from lifting weights. My strength came from lifting myself up when I was knocked down.

- Bob Moore

Coping & Communication Strategies

As if the long diagnosis and chronic symptoms weren't enough, chances are you have friends and family members who are worried about you, but who may have a hard time relating to your symptoms. Even the most supportive friends and family members will wax and wane throughout the journey. There will be times where you are accused of exaggerating symptoms, or those who will interpret it as "lacking motivation", being "lazy" or suggest that it's perhaps depression. You will be offered a variety of "fixes" by well-intentioned people.

At times, you will likely feel ignored more than listened to by practitioners, colleagues, family, and friends. The feelings of isolation require significant coping skills, and if left unaddressed, can lead to depression and anxiety. Group support and therapy groups can be helpful in developing coping skills as long as the individuals within the group do not develop codependent relationships with one another or the group itself.

Some prefer to work one-on-one with a therapist or coach to manage these stressors. Both groups and individual counseling can help you effectively communicate both the technical, medical components of testing and symptom relief as well as communicating one's feelings.

The important thing to remember is that you are not alone. It is estimated that up to 2.5 million Americans currently have CFS, many of whom have not yet been formally diagnosed.¹ Educating friends and family, and gaining them as patient advocates is an important step to improving your quality of life.

*“ You have to be at your strongest
when you're feeling at your weakest. ”*
-UNKNOWN

¹Clayton, EW. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: an IOM report on redefining an illness. JAMA 2015; 313(11): 1101-1102.

CFS & Fibromyalgia Treatment

There is currently no FDA-approved treatment for CFS or fibromyalgia; instead, a comprehensive plan of care will often consist of medication, lifestyle and nutritional recommendations to help manage your fatigue, aid in gaining restorative sleep, restore your digestive health, reduce pain, and reduce “brain fog”.

Micronutrients to Support Mitochondrial Function

Fortunately for all the bad that can come along with subclinical mitochondriopathy, there is also hope. Mitochondria provide much needed energy to the cell using fatty acids as fuels. One naturally-occurring constituent that helps shuttle fatty acids through the outmost mitochondrial membrane is carnitine.

Acetyl L-carnitine appears to be the most bioavailable version of carnitine. Once inside the mitochondria the fatty acid must be broken down by several enzymes. Each enzyme requires a cofactor which is a mineral and a coenzyme which is a vitamin or vitamin-like substance. B-vitamins, vitamin C, magnesium, coenzyme Q10 (CoQ10) and **alpha lipoic acid (ALA)** are involved in these steps. The consequence of burning fatty acids as fuel is the same as burning any fuel. There is exhaust.

Mitochondrial exhaust comes in the form of oxidative stress and the formation of free radicals. Gone unquenched this can cause a myriad of problems. In fact, some integrative medicine clinicians believe that oxidative stress is a root cause of many diseases. Luckily, the body has a system to support this. **Glutathione**, known as the master antioxidant guides the scavenging of these free radicals. Some specialized forms of glutathione can be absorbed and used orally. Also, **N-acetyl cysteine (NAC)** is a precursor to glutathione and is available in supplemental form.

Myths about Mitochondrial Disease, CFS and Fibromyalgia

MYTH There is a standard test for diagnosing mitochondrial conditions.

Because of the complex nature of the mitochondria, diagnosis is often challenging, and specific to the individual. This often results in a lengthy diagnosis, and in some cases, a diagnosis is achieved only when all other options have been ruled out.

MYTH Mitochondrial conditions are always genetic and are therefore present at birth.

There is still much to be known about the role of the mitochondria in chronic disease. Though there are complex hereditary patterns of mitochondrial DNA mutation that can certainly impact one's mitochondrial health, mitochondrial conditions can present themselves at any age. There are also preliminary studies that suggest that the function of the mitochondria can be impacted by the consequence of other conditions, or even viruses. Much advancement is to be done in determining the root cause of these mutations.

MYTH Vaccinations can cause or worsen mitochondrial conditions.

There are no studies that indicate vaccinations worsen, or cause, mitochondrial conditions. More research is needed to determine if there are rare cases.

MYTH CFS only affects women.

While CFS does primarily impact women, 20% of diagnosed cases are found in men and still the majority of cases remain undiagnosed, leaving much to be learned about the true breakdown of CFS patients.

MYTH CFS & fibromyalgia just mean you're tired all the time.

Fatigue is just one symptom of CFS and fibromyalgia. Pain, not being able to achieve restorative sleep, brain fog, digestive distress are all symptoms. This is not an exclusive listing. Individual experiences vary, including the severity of each symptom.



Learn More

The resources below provide more information and support on CFS & Fibromyalgia as well as information on how to find support groups within your community. These resources are not an alternative for professional medical advice. Always consult with your physician regarding your plan of care.

National Fibromyalgia Association
www.fmaware.org

International Association of CFS/ME (IACFS)
www.iacfsme.org

Solve ME/CFS Initiative
www.solvecfs.org

National Fibromyalgia Association
www.fmaware.org

Centers for Disease Control
www.cdc.gov

Talk with your practitioner about how to develop a quality of life care plan that's right for you.