

# Tick-borne Infections

## Lyme Disease



### **What are tick-borne infections?**

Tick-borne infections are viruses, bacteria or parasites that people catch from tick bites. In the U.S., these include anaplasmosis,

babesiosis, ehrlichiosis, Lyme disease, Powassan, Rocky Mountain spotted fever, other forms of rickettsiosis, STARI, tickborne relapsing fever and tularemia. They vary in severity, symptoms and signs, and a person infected with one of these often has other tick-borne infections. Of these, Lyme disease is the most common. It is growing in prevalence and spreading into new areas.

Most of these infections are cured when treated aggressively soon after the tick bite. When left untreated or if the patient has other complications, the infection can become chronic, go into "late stage," or a post-treatment syndrome might develop. At that point, it becomes a neuro-endocrine-immune disease. This often happens because many doctors are not aware of the testing controversies, that the rash does not occur in all patients or that the diseases have spread into areas of the country where they used to not occur.

People with Lyme disease are often misdiagnosed with another neuro-endocrine-immune disease. Untreated Lyme can develop into one of the other neuro-endocrine-immune diseases, arthritis or neurological problems and numbness.

### **What should I do?**

Doctors who have become very experienced in treating these infections are often referred to as "Lyme-literate" doctors. They know what antibiotics to use and for how long. If the disease has progressed past the beginning stage, the doctor may add supplements or drug treatments similar to what is used in fibromyalgia or ME/CFS to address the pain and immune system abnormalities.

# Gulf War Illnesses

### **What are Gulf War illnesses?**

Gulf War illnesses (GWI) are a group of diseases that at least 25% of veterans who served in Southwest Asia from 1990-1991 have developed. Irritable bowel syndrome, fibromyalgia, ME/CFS and some infections are included in GWI. These veterans also have developed "undiagnosed illnesses," which could include any combination of the following symptoms: headaches, cardiac problems, weight loss, unexplained rashes, muscle and joint pain, menstruation abnormalities, respiratory problems, neurological problems, sleep disturbances, other gastrointestinal problems and more.

Some recent Iraq and Afghanistan war veterans have developed similar symptoms, but from a different group of exposures. Gulf War illnesses and the associated symptoms are different from psychiatric disorders, such as post-traumatic stress disorder, which is caused by psychological trauma.

### **What causes it?**

The prominent theory now is that some exposures taxed the immune system of those with a susceptibility causing them to develop the illnesses, sometimes years after their service. Infections, vaccines, chemical exposures and many other possibilities have been considered, but none have been proven.

Research shows GWI patients have dysfunctions in their immune, endocrine and neurological systems. Like ME/CFS, some biological abnormalities are more evident when the GWI patient exercises.

### **What should I do?**

See the other neuro-endocrine-immune diseases listed in this brochure for suggestions for those diseases. Symptom management is currently the only treatment option. GWI veterans should seek advice from their state Veterans Affairs Office.

The information in this brochure was reviewed and approved by Andreas Kogelnick, MD, PhD, infectious disease specialist and director of the Open Medicine Institute, doing CDC-funded research into ME/CFS and providing clinical care to neuro-endocrine-immune disease patients for over a decade; and David Hatfield, PhD, a professor who served on the 2013 Congressionally Directed Medical Research Program for Gulf War illnesses.

# I Have What?

A guide for people recently diagnosed with a neuro-endocrine-immune disease.

**Fibromyalgia**  
**Myalgic Encephalomyelitis**  
**Chronic Fatigue Syndrome**  
**Tick-borne Infections**  
**Gulf War Illnesses**

If you have been diagnosed with one of these chronic, multi-systemic illnesses, know you are not alone in your journey.



Your life has changed, but you can still have a life full of purpose, joy and hope.

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### **What kind of doctor should I see?**

Neuro-endocrine-immune illnesses are also called “complex chronic illnesses,” “chronic multi-systemic illnesses” or other terms. Because they include dysfunctions in the neurological, immunological, endocrine and other body systems, no one medical specialty has embraced these diseases. Patients often end up seeing quite a few different specialists for optimum care. Experts who focus on just these diseases tend to have long waiting lists.

### **Can I have more than one of these diseases?**

Yes. Often, a person will come down with more than one of these diseases at once or develop another one of these diseases years after they first became sick. Because the symptoms are very similar, some are diagnosed with one of the diseases then find out they actually have another one of these diseases.

### **What’s going on in my body?**

While each of these diseases may have differences in triggers or primary symptoms, they all include dysfunctions in the autonomic nervous system. This is the control center for body functions that don’t require conscious thought, such as blood pressure, digestion, heart rate, pain response, the immune system and endocrine system. Your nervous system automatically controls these, but in these diseases, it is not functioning correctly to keep your body systems balanced.

### **Where can I find support?**

Having understanding and supportive family and friends will be very helpful. You should include them as you learn about your disease. If you need to file for disability benefits, you should consult with an attorney early in the process. Facebook groups and online message boards can provide encouragement from other patients and prevent isolation.

Our website offers information on low-cost medications, local support groups and more. Join our social media pages or sign up to receive our newsletter to keep up to date on research and advocacy news.



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# Fibromyalgia

### **What is fibromyalgia?**

The word means fibrous tissue and muscle pain. Most scientists agree that this type of pain, with tender points next to joints, comes from a nerve and chemical overreaction, not tissue damage in the area where the pain is felt. Most patients also experience many other symptoms, including sleep disruptions, fatigue, morning stiffness and a lack of mental alertness, called “fibro fog.”

### **What causes it?**

While the cause is not known, triggers include operations, accidents, stress and others. Based on research, a common theory is that the trigger and a genetic susceptibility contribute to developing the disease. It can occur in anyone, including men and children; although it occurs at a higher rate in women as do most immune system diseases.

### **How do I manage the pain?**

Some people find that drugs for fibromyalgia pain or other pain drugs help. Others do not find relief from these drugs or cannot tolerate the side effects. Some drugs that might help with the pain include low dose Naltrexone, muscle relaxers or antidepressants. All drug therapies should be started in low doses, and strong opioids should be avoided.

Other therapies include massages, acupuncture, meditation, mild physical therapy or exercise and stretching. Reducing stress and other nervous system stimulations will be helpful. Caffeine and stimulant drugs should be avoided. Your doctor may recommend supplements, such as vitamin D, magnesium or a good multi-vitamin.

### **What about the other symptoms?**

If your fatigue is severely debilitating, you should ask your doctor if you also have one of the other diseases in this brochure. Notebooks, putting things in the same place and other strategies can help reduce your frustration from the thinking problems. Sleep treatment will include good “sleep hygiene” practices and possibly sleep medicines according to your particular needs. Anxiety can be reduced with drugs and by limiting nervous system stimulations.

# Myalgic Encephalomyelitis Chronic Fatigue Syndrome



### **What is ME/CFS?**

“Myalgic encephalomyelitis,” the European term for the disease, means muscle pain and brain or spinal cord inflammation. There are many other names for the disease.

The distinctive feature is an increase of symptoms after mental or physical activity. This is called “post-exertional malaise” or “post-exertional neuro-immune exhaustion” and can come any time after the activity, even 24 or 48 hours afterward. It may last days or weeks. Over 60 symptoms are reported with this disease, but the most debilitating are extreme fatigue, like your body is fighting an infection, and an inability to process information and forgetfulness.

### **What causes it?**

While the cause is not known, triggers include infections, stress or other illnesses. A common theory is that the trigger and a genetic susceptibility contribute to developing the disease. It can occur in anyone, including men and children; although it occurs at a higher rate in women. Exertion beyond the person’s capacity at the time, which varies, causes a chain reaction of dysfunctions that increase symptoms. Many ME/CFS patients have orthostatic intolerance, where blood pressure drops from standing or sitting.

### **How do I manage the symptoms?**

Although there is no FDA-approved drug for the disease, some doctors use drugs or supplements to lessen symptoms, improve immune system function, regulate blood pressure and fight reactivated infections.

Pacing, which is small and low levels of mental or physical activity mixed with reclining rest periods throughout the day, is the most important management strategy. Don’t push, even if that means you stop after only a few minutes of activity.

Good nutrition and fluids are also helpful.