

These are symptoms of little known conditions which fall under the “umbrella” term, CNDS (Chronic Neuro-endocrine-immune Dysfunction Syndrome, the term the DHHS prefers). They include Fibromyalgia Syndrome (FMS), Gulf War Syndrome (GWS), Multiple Chemical Sensitivity Syndrome (MCS), Myalgic Encephalomyelitis (ME, the term used in most of the world) / Chronic Fatigue Syndrome (CFS, the term used in the United States), Post-Polio Syndrome and related conditions. Also included is Chronic Myofascial Pain (CMP), which has similar symptoms although the cause of CMP is thought to be different. These conditions are characterized by generalized pain or aching in the connective tissues, poor sleep quality, and numerous other symptoms. They are referred to as syndromes because the symptoms occur in combination. People often liken them to having a very bad case of the flu or having been run over by a truck.

The estimated prevalence of these CNDS conditions is:

- FMS - 2,950 per 100,000
- MCS - 1,510 per 100,000
- ME/CFS - 183 per 100,000
- One in three Gulf War vets has chronic health problems

This totals over 12,000,000 Americans and is seen in both women and men of all age groups, including young children.

Although CNDS can be severe, and often disabling, conditions that affect vast numbers of people, they are often overlooked or given limited attention in facilities that train medical professionals. Because of this, many people with CNDS conditions find themselves inappropriately referred for psychiatric evaluation. These syndromes are also frequently misdiagnosed because their symptoms mimic those of other serious conditions, such as rheumatoid arthritis, lupus, or other auto-immune diseases (i.e., the body’s tissue is attacked by the body’s own defense system, which mistakes it for foreign material). CNDS conditions are not considered to be inflammatory or auto-immune disorders, since no permanent damage is done to the body. Auto-immune disorders, however, can co-exist with CNDS conditions. These syndromes are also considered non-progressive, although symptoms may worsen after onset if appropriate

treatment is not undertaken. Before a diagnosis of one of these CNDS conditions can be made, other illnesses, such as those mentioned above, should be considered by your physician.

Although Fibromyalgia Syndrome is the only one of these syndromes with a diagnostic test at this time, an alert, competent and supportive medical professional who is familiar with CNDS conditions can, along with taking a careful and comprehensive history, make an educated diagnosis. For Fibromyalgia Syndrome, your doctor can conduct a simple “tender point” exam. If 11 of 18 specific tender points on the body hurt when pressed, and aching or pain has persisted for more than three months, the diagnosis is confirmed.

The cause of these syndromes is not known. There is some evidence that the predisposition is hereditary. CNDS conditions appear to be triggered in susceptible individuals by flu-like illnesses, abuse (emotional or physical), chemical exposure, trauma (such as an auto accident or childbirth), or other stressors to the body. It is important to note that these are not psychological disorders. Studies have demonstrated that people with CNDS conditions are no more likely to have psychological problems than others with chronic pain or fatigue.

Severity of symptoms varies from person to person, as does response to treatment. These symptoms, which can fluctuate from day to day, include, but are not limited to:

- Pain (often debilitating)
- Widespread body aches
- Non-restorative sleep
- Fatigue (sometimes severe)
- Lack of energy
- Depression
- Anxiety
- Numbness or tingling in the arms or legs
- Migraine headaches
- Tension headaches
- Irritable bowel
- Irritable bladder
- Cold intolerance
- Restless legs
- Cognitive problems
- Irritability
- Vision problems

- Sinus problems
- Allergies
- Dryness of the eyes or mouth
- Tinnitus (ringing in the ears)
- Fluctuating hearing loss
- Heightened sensitivities (to food, meds, light, chemicals, odors, etc.)

The Chronic Myofascial Pain (CMP) Connection: This condition, in which pain may be extreme, can develop in muscles that are overstressed, overused or injured, and is characterized by localized “trigger points”, which are different from the “tender points” of Fibromyalgia Syndrome. People with CNDS conditions may also develop Chronic Myofascial Pain. CMP pain from trigger points, which refer pain to other locations, is mechanical in nature. Generalized aching of CNDS conditions is biochemical and systemic in nature. Many patients meet the criteria for both, in which case it is important that both be treated appropriately. CMP is treatable by strategies including trigger point injections, massage therapy, daily stretching, and the elimination of stressors. Proper identification and treatment of CMP is of great benefit in reducing many symptoms incorrectly attributed to CNDS conditions. A physician knowledgeable about trigger and tender points will be able to distinguish between them reliably. A physical medicine doctor or licensed massage therapist familiar with Travell and Simons Trigger Point Manuals is the most competent healthcare professional to help relieve or eliminate trigger points.

With proper treatment, many people with CNDS conditions can learn to manage their symptoms, thereby lessening their pain and fatigue.

The first symptom generally treated is the problem of insufficient deep, quality sleep. When quality sleep is achieved, the pain level often decreases, since tissue healing takes place during deep restorative sleep. Certain medications and treatments have been found to be effective in improving the quality of sleep. Other medications and treatments have been found helpful in treating the depression and anxiety which often occur as a result of CNDS conditions. People with these syndromes frequently have unusual reactions to medications. Often, finding the right medication is a process of trial and error, which can be time-consuming and frustrating. However, it is very important that you and your healthcare team

actively work together in finding the right medications, treatments or combinations of both.

Experts agree that stretching and gentle aerobic exercise are essential for many CNDS conditions. However, some experts caution against implementing an exercise program for those with ME/CFS. Walking, pool therapy and stationary exercise equipment are most suitable for people with most CNDS conditions. The optimum time of day for exercise is approximately five hours before bedtime. If this is not feasible, any time of day may be beneficial. For all CNDS conditions, stretching can and should be done several times a day — simple things like shoulder rotation can be done in almost any setting. It is important that stretching be a part of the every-day activities of people with CNDS conditions, since the muscles have been contracted. They can be relaxed with the help of a trained physical therapist familiar with these syndromes. Additionally, muscle tone suffers as a result of inactivity or improper body mechanics. Muscle-strengthening exercises can be performed to rebuild atrophied muscles after they have been relaxed. It is important to note that some traditional repetitive regimens not be performed, since these can exacerbate pain. Those people who cannot tolerate aerobic exercise may respond better to a program of simple basic stretches. Many people with severe pain have found water therapy in a heated pool provides some relief. Most importantly, people with CNDS conditions need to listen to their bodies and not push too hard. A general rule of thumb is, “always stop exercising while you still could do a little more”. The old adage “no pain, no gain” does NOT apply here.

Also helpful for some people with CNDS conditions are massage done by a person familiar with the conditions, warm and soothing baths, relaxation techniques, stress reduction, proper body mechanics and posture, acupuncture, chiropractic, meditation, biofeedback, reduction or elimination of toxic exposures and a healthy diet. It is important to find the treatment, or combination of treatments, that is most effective for each person, since none are effective for all people with CNDS conditions.

It is also important to avoid stressful situations, since stress intensifies symptoms. This may require lifestyle changes. The symptoms wax and wane, and many people with CNDS conditions find it difficult to slow down and be gentle with themselves when they are feeling better.

People with CNDS conditions who are Type A personalities may mistakenly believe that they can push through the pain and fatigue, which can lead to a “flare” — a worsening of symptoms.

Helpful resources include books, videos, newsletters, and local and Internet support groups. Support groups are especially useful for people with CNDS conditions, since their condition is often invisible to their families, significant others, friends and co-workers to whom they “look normal”. In order to better cope with these sometimes debilitating conditions, people need all the help and support they can get from others who understand what they are experiencing. Learning more about these conditions will enable you to be your own best champion.

#### **Persevere - there is much research being done**

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**The Chronic Syndrome Support Association, Inc.**, partnered with **The Fibromyalgia Community**, is a 501(c)3 non-profit corporation. It was founded in order to educate the general population and healthcare professionals who lack current knowledge of the research being done, and potential research that needs to be done, on these serious, yet invisible, conditions. It is our goal to promote awareness of these conditions, and in the process we hope to contribute to the growing body of knowledge about them.

If you believe you may have one of these conditions, seek the assistance of a supportive healthcare professional who is familiar with these chronic illnesses and their treatments.

We hope this pamphlet has provided a measure of education for you.

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## DO YOU SUFFER FROM PERSISTENT

PAIN?

ACHING?

fatigue?