



MEDICALLY UNEXPLAINED SYMPTOMS

A RESOURCE FOR VETERANS, SERVICE MEMBERS, AND THEIR FAMILIES

Medically Unexplained Symptoms is a term used for persistent health symptoms which remain unexplained after a complete medical evaluation. It has been reported that vague or ill-defined health symptoms account for half of all outpatient visits and that one third of these symptoms remain unexplained after a thorough assessment (Jackson, et al., 2005). Although common, symptoms which remain unexplained for long periods of time even after a complete medical evaluation can be confusing and frustrating for both patients and providers. Sometimes there is a consistent clustering of the same or similar symptoms. When this happens, they are referred to as medically unexplained syndromes (MUS). A syndrome is a collection of signs and symptoms known to frequently appear together but without a known cause. Being given the diagnosis of an MUS can be a relief because you have a label– a diagnosis, but the key is how to effectively manage the multiple symptoms. This can be very challenging but will often lead to feeling better and being more in control of your health. This fact sheet gives an overview of three specific MUS's: myalgic encephomyelitis/chronic fatigue syndrome (systematic exertion intolerance disease) (ME/CFS (SEID)), Fibromyalgia, and Irritable Bowel Syndrome and discusses things you can do to minimize the symptoms and improve your quality of life. It is possible that these syndromes can all occur at the same time.

CHRONIC FATIGUE SYNDROME

Chronic Fatigue Syndrome (CFS) is a condition in which people have unexplained severe fatigue of at least 6 months duration, as well as a number of accompanying symptoms like muscle aches, sore throat, poor sleep, or problems with memory and concentration.

One recent study estimates CFS occurs in about 1% of the general population, although some studies estimate up to 3% (for review see, Lim et al., 2020). CFS has also been diagnosed at an increased rate among service men and women (Eisen et al., 2005). A study showed that CFS was more common in Gulf War Veterans than non- Gulf War Veterans (Kang et al., 2009). At this time, the exact cause for this is unknown.

There are no specific blood tests or medical procedures to diagnose CFS. The diagnosis can be given once other diseases, which can also cause fatigue, have been ruled out and the provider has determined that the patient meets the criteria for CFS. Thus CFS is considered a diagnosis of exclusion. There are a number of routine tests including blood work and a complete physical examination by a clinician that can effectively rule out most of the other major causes of fatigue and these must be done and be negative prior to being diagnosed with CFS. The good news is that this does not require years of endless invasive and extensive testing.

Treatment for CFS is based on individualized care plans. Therapies which may help CFS symptoms include:

- a program of graded aerobic exercise which involves slowly increasing physical activity
- psychological therapies specifically designed to help people cope with chronic symptoms, and
- medications to address specific symptoms.

Clinical experience shows that with appropriate symptom management some patients improve. In general, people with CFS experience good and bad periods and symptoms may fluctuate. It is important to know your normal range of symptoms. Clinical experience and research supports a “watchful waiting” approach. If a symptom gets much worse than usual, it is a good idea to discuss it with your doctor. In general, regularly scheduled follow up visits are important to discuss any new approaches to treatment or breakthroughs in the understanding of the syndromes.

For specifics about Chronic Fatigue Syndrome, you can visit the Center for Disease Control website at:

<http://www.cdc.gov/CFS/>





FIBROMYALGIA

Fibromyalgia (FM) is another MUS that is characterized by diffuse pain and/or stiffness, and pain across the body. A diagnosis of FM is based on the patient's subjective symptoms of widespread pain and symptom severity. Pain must be present for greater than three months at the same level of intensity on each side of the body as well as above and below the waist.

FM is a common condition that affects approximately 5% of the general population. It affects women more than men.

A study in Veteran populations showed that FM has been diagnosed more frequently in Gulf War Veterans compared to non-Gulf War Veterans (*Eisen, et al., 2005*). No known cause for FM has been identified.

Treatment focuses on reducing pain. Graded exercise therapy including paced activities like walking or biking is recommended and has been shown to improve the symptoms of FM. Medications are also used to reduce symptoms of FM.

If symptoms get much worse, you should talk about them with your health care provider. Keep in mind that the symptoms of FM may fluctuate with periods of good health followed by periods when symptoms may flare up or worsen.

IRRITABLE BOWEL SYNDROME

Irritable Bowel Syndrome (IBS) is an MUS that interferes with the normal functioning of the large intestine. It is characterized by a group of symptoms, including crampy abdominal pain, bloating, constipation, and diarrhea. IBS is considered a "functional bowel disorder" because it causes problems with the function, not the structure, of the bowel. This means that when samples of the bowel are looked at by colonoscopy or under a microscope they appear normal in patients with IBS, which is very different from patients with inflammatory bowel disease (Crohn's Disease or ulcerative colitis) or cancer, which can look very abnormal. IBS is the most common functional gastrointestinal disorder and occurs worldwide. It can occur in up to 15 percent of the

general US population. IBS is also commonly diagnosed in the Veteran population.

IBS may cause a great deal of discomfort and distress, but it does not permanently harm the intestines and does not lead to intestinal bleeding or to any serious disease such as cancer. To diagnose IBS, the provider will take a thorough history of the symptoms to determine how often and for how long the symptoms have been occurring. The provider will use the history, and in some cases additional testing, to rule out other types of intestinal disorders that would require different treatment.

Most people can control their symptoms with diet, stress management, and medications prescribed by their health care provider.

TREATMENTS FOR MEDICALLY UNEXPLAINED SYNDROMES

The following treatments have been found to be helpful for many people who have medically unexplained symptoms often characterized by chronic pain or persistent fatigue and/or syndromes (CFS, FM, IBS).

As with any new health regimen, you should first contact your health care provider and determine your exercise readiness.

Graded Exercise

A program of graded exercise or activity is a valuable treatment available for someone with CFS or FM to help them improve their physical condition and their quality of life. People with pain and chronic fatigue should not overexert themselves, but should maintain a regular, balanced activity program consisting of short, slow walks at first and then building up to activity of longer duration and eventually greater intensity. The goal is to gradually increase physical activity. Stretching and flexibility are also very important for any exercise program, so be sure to include gradual stretching at the start and finish. Remember, if you feel too tired, or your symptoms get worse, take a day off and then restart your program at a slightly shorter duration or lower intensity and work back up to your planned routine. Keeping an exercise record (date, duration of





exercise, what you did and how you felt) can be helpful in modifying your exercise routine and in seeing how far you've come. Resuming and increasing your physical activity may help alleviate some of your pain and your fatigue and improve your mental function, as well.

Psychological Therapies

Patients living with medically unexplained syndromes can benefit from cognitive-behavioral therapy (CBT) to help cope with and adjust to living with a chronic illness condition. CBT is a psychological therapy that emphasizes the important effect our thoughts have on how we feel and behave. Goals include replacing unhealthy, negative thinking patterns, beliefs and behaviors with healthy, positive ones that promote recovery and well-being. CBT is often recommended in combination with other treatments and is tailored to address a patient's symptoms, success with other treatments, etc.

Once engaged in CBT an individual works with his or her counselor to set personal goals and work on strategies to achieve them. The strategies can include pacing of everyday activity, finding new ways of completing tasks, improvement of sleep, exercise, use of social support, and daily practices such as relaxation. When it becomes challenging to achieve the goals or implement the strategies, the individual and counselor work together to identify any thoughts, beliefs, or behaviors that are barriers to success.

Pharmacological Therapy

Pharmacologic therapy, also called drug therapy, should focus on reducing symptoms or treating an underlying cause of the condition. There are different types of medications which may help a person who has CFS, IBS, and FM. It's important to remember that certain medications may not be appropriate for every patient.

A health care provider will determine which medications may be right, taking into account medical history and current symptoms.

If you feel like your symptoms may improve with the help of medication, speak to your health care provider about which medication may be appropriate, but be smart about your medicines. Make sure you know the following about every medicine you take:

- What is the indication for the medication?
- How and when do you take it?
- Do you take it as needed (for a specific symptom or sign) or on a regular basis?
- What are the intended positive effects of the medicine?
- What are the possible negative effects of the medicine? How often do they happen? What should you do if they happen?
- How long should you keep using the medicine?
- When should you follow up with the provider on the impact of the medicine?

There are currently three medications that are FDA approved to specifically treat pain associated with fibromyalgia. These include Lyrica (pregabalin), Cymbalta (duloxetine), and Savella (milnacipran).

There are several categories of medications often prescribed for IBS including anti-spasmodics, anti-diarrheal, and anti-depressant drugs as well as fiber supplements. There are also some medications approved by the FDA specifically for IBS, but they can only be used in certain subgroups of people. Discuss the possibility of using these with your provider if you are interested.

RESEARCH

Ongoing research is constantly providing new information about the possible causes, diagnosis and management of Medically Unexplained Syndromes. If you have questions about research in these areas, it's important to use your health care provider as a resource.





The internet also can provide a tremendous amount of information, but it's important to understand how the research has been conducted and its relevance to you. For more information about understanding how to interpret current research findings, please see our WRIISC fact sheet that is located on our website fact sheets page.

The following websites provide thorough information about current initiatives investigating MUS's:

- <http://www.cdc.gov/cfs/programs/>
- <http://clinicaltrials.gov/ct2/results?cond=%22Fibromyalgia%22>
- <http://www.clinicaltrials.gov/ct2/results?term=irritable+bowel+syndrome>

COMMON QUESTIONS AND CONCERNS

What is the difference between a syndrome and disease?

A syndrome is a collection of signs and symptoms known to frequently appear together but without a known cause. CFS, FM, and IBS are all syndromes. A disease is a known entity which has a recognized cause and usually a demonstrable cellular, tissue and/or organ abnormality with an identifiable group of signs and symptoms.

The diagnosis of a medically unexplained syndrome (CFS, FM, IBS) is based on a group of persistent and specific troublesome symptoms. Giving a name to a syndrome makes it easier to discuss the condition

and to be able to investigate possible causes, the natural history or course of the syndrome and how to treat it. However, some health care providers may not universally recognize the existence of these syndromes. Unexplained symptoms may be seen in people following deployment, regardless of when or where deployed, but are also found in civilian populations.

It's important to realize that treatment and prognosis for medically unexplained symptoms versus a medically unexplained syndrome (CFS, FM, IBS) is often the same, with the focus on reducing symptoms and improving quality of life.

I've been struggling with unexplained syndromes for many years and I am not sure what to do to get the help I need?

It's important to address your symptoms and concerns with your health care provider. You can also discuss with your VA provider getting a referral to the War Related Illness and Injury Study Center (WRIISC) if your symptoms are persistent after standard work up and your condition remains undiagnosed. The WRIISC provides comprehensive medical evaluations for Veterans with medically unexplained symptoms and focuses on providing a road map to help minimize impairments and improve overall quality of life.

Please visit our website:

<http://www.WarRelatedIllness.va.gov>

or call us at 1-800-248-8005 for more information on how to get a referral.

