Sutter Health

Referral Guidelines

CHRONIC FATIGUE SYNDROME

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I. Introduction

Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), is a debilitating and complex illness that does not improve with rest and can worsen after physical or mental activity. People with CFS are not able to function the same way they did before the onset of the illness, changing the ability to perform activities of daily living and take part in family and social life. Diagnosing CFS is very challenging and the cause of CFS still remains unknown. A 2015 report published by the Institute of Medicine (IOM) identified that CFS affects 836,000 to 2.5 million Americans and that an estimated 84 to 91% of people with CFS have not yet been diagnosed.

II. CFS Criteria

The Centers for Disease Control and Prevention (CDC) identified CFS as requiring the following three symptoms:

1. **Inability to participate in routine activities that were possible before becoming ill** (e.g., work, school, social life, personal life) that:
    - Lasts for more than 6 months
    - Is accompanied by fatigue that is: often serious, is not the result of ongoing activities, is not from more than usual effort and is not made better by rest.
2. **Post-exertional malaise** (PEM) – the worsening of symptoms after physical, mental or emotional effort that would have not triggered a problem before the illness.
3. **Unrefreshing sleep** – not feeling better after a full night of sleep (e.g. feeling just as tired upon waking up as before going to bed).

In addition, at least one of the following symptoms is also required:

- **Impaired memory or ability to concentrate**. People with CFS may experience trouble remembering, learning new things, concentrating or making decisions.
- **Orthostatic intolerance** (symptoms that occur when standing upright). People with CFS may experience being lightheaded or dizziness when standing upright and may even faint.

Note: Many patients with CFS also report other symptoms, including (but not limited to) the following:

- Aching joints and muscles
- Nausea
- Sore Throat
- Headache

III. Risk Factors for CFS

- While people of all ages can experience CFS, it more often begins in younger and middle-aged adults than in children or older adults.
- Diagnosis of CFS occurs more often in women than in men.

IV. Diagnosis of CFS

CFS is difficult to diagnose and can be complicated by many factors, including (but not limited to) the following:

- No lab test or biomarker for CFS.
- Symptoms of CFS are common to other illnesses.
- CFS has a pattern of remission and relapse making it unpredictable.

The diagnosis of CFS is generally made after a patient's healthcare provider will:

- Inquire on medical history of the patient and their family.
- Conduct a thorough physical and mental status examination.
- Lab tests are ordered, which can include:
    - Complete blood count with a differential count;
    - Erythrocyte sedimentation rate;
    - Chemistry screen;
    - Thyroid stimulating hormone level;
    - Creatine kinase (if muscle pain or weakness is present);
    - Other tests when clinically indicated

Note: While Magnetic Resonance Imaging (MRI) and Single-Photon Emission Computed Tomography (SPECT) scan abnormalities have been more frequently found in patients with CFS, these findings are of unknown significance and do not affect diagnosis or management.

V. Treatment of CFS and Referrals

Because there is not a known cure or approved treatment for patients with CFS, treatment should be supportive and focused on managing and treating common symptoms and comorbid conditions.

Treatment approach to management of common symptoms can include the following:

- **Post-exertional Malaise**
    - Can be addressed by activity management, also referred to as pacing.
    - Referrals to occupational therapy, rehabilitation specialists or exercise physiologists who understand CFS may be appropriate for patients experiencing difficulty in performing activities of daily living.
- **Sleep Disorders**
    - Discussing sleep hygiene measures with patients with insomnia.
    - Pharmacologic therapies, such as over the counter products, or tricyclic agents.
    - If patients still feel unrefreshed after medications assist in getting a full night of sleep, a referral to a sleep specialist may be appropriate.
- **Pain**
    - Tension headaches, myalgias, and skin sensitivity are common with CFS and can be managed symptomatically with a nonsteroidal anti-inflammatory drug (NSAID) or acetaminophen.
    - Other methods for pain management can include heat, gentle massage, and acupuncture.
    - If pharmacologic therapy and other pain management methods do not provide enough relief, a referral to a pain management specialist may be appropriate.
- **Depression and Anxiety**
    - Depression screening
    - Patients diagnosed with either depression or anxiety should be offered appropriate pharmacologic therapy and/or psychotherapy.
- **Cognitive Difficulties**
    - Patients with substantial cognitive problems should be referred for neurocognitive evaluation.

- **Dizziness and Lightheadedness (Orthostatic Intolerance)**
    - For patients with CFS who do not have heart or blood vessel disease, healthcare providers may recommend that patient increase daily fluid and salt intake and use support stockings.
    - Treatment recommendations may include a specialist referral, depending on symptom severity.

Note: All patients with symptoms suggestive of CFS should have a thorough history, physical evaluation and laboratory testing completed prior to referral for specialty consultation.

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