

Chronic Fatigue Syndrome (Systemic Exertion Intolerance Disease): More Than Tired

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Dr. Rowland is a graduate of Rush University Medical College in Chicago, Illinois. She completed her residency at Advocate Illinois Masonic Medical Center in Chicago. Dr. Rowland serves as editor-in-chief for the Family Physicians Inquiries Network's Priority Updates from the Research Literature series and is an associate medical editor for the AAFP's FP Essentials. Kate enjoys teaching about topics that aren't always easy to think about, and need research, synthesis, and empathy to understand. She also enjoys teaching about research and evidence-based medicine topics. Kate strives to make her lectures relevant to practice, thought provoking, and informative.



Learning Objectives

1. Use IOM SEID diagnostic criteria to diagnose patients presenting with chronic fatigue.
2. Diagnose patients who do not meet SEID criteria as their symptoms and evaluations dictate.
3. Evaluate patients for comorbidities associated with SEID, at treat accordingly.
4. Develop collaborate treatment plans, emphasizing adherence to prescribed therapies (e.g. cognitive behavioral; graded exercise therapy).



Audience Engagement System

The screenshots illustrate the user flow: Step 1 shows the home screen with navigation icons; Step 2 shows a list of CME activities with a red arrow pointing to the 'CME011 Acute Coronary Syndromes' entry; Step 3 shows the detailed view of this activity, including a red arrow pointing to the 'Unchain My Heart' title.



AES Question



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Chronic fatigue syndrome can be described as:

- A. Feeling tired or run down at least 3 hours a day at least 3 days a week in the previous 3 weeks
- B. Feeling tired because the patient feels "blue" or "down in the dumps"
- C. Feeling tired and having other physical symptoms from multiple body systems
- D. A somatization disorder characterized by feeling tired
- E. Fatigue provoked by an untreated parasitic infection

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Straight from the patient

- "I didn't want to talk about it very much because I had the experience of being dismissed and ridiculed. People don't understand this illness."
- "When my doctor at Johns Hopkins finally said 'You have a real disease' that was an important moment to me"

Laura Hillenbrand <http://well.blogs.nytimes.com/2011/02/04/an-author-escapes-from-chronic-fatigue-syndrome/>

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Definition and Terminology

- Chronic fatigue syndrome
- Myalgic encephalomyelitis
- Chronic fatigue immune dysfunction syndrome
- Systemic exertion intolerance disorder

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Epidemiology

- Thought to affect up to 2 million people
 - Many cases undiagnosed
- Women > men (2:1)
- Average age of onset 33
 - Average age of diagnosis may be older

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2015 IOM Definition of SEID

- Fatigue +
- Post-exertional malaise +
- Unrefreshing sleep +
- At least one of:
 - Cognitive impairment
 - Orthostatic intolerance

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The Fatigue of SEID

- Unexplained fatigue >6 months duration
 - New onset
 - Not due to ongoing exertion
 - Results in a reduction of previous activity
 - Persistent and not relieved by rest
- Fatigue is typically debilitating

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Post-Exertional Malaise

- Prolonged recovery from mental or physical exertion
- Change from baseline ability to tolerate mental or physical stress
- PEM is considered a distinguishing feature of SEID

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Post-Exertional Malaise

- PEM can be assessed with 2-day cardiopulmonary exercise test (CPET)
 - Patient works out on stationary bike to max effort
 - VO₂max and work output measured on consecutive days
 - Patients without SEID should fully recover and have equal performance on subsequent days
 - Patients with SEID may not recover within 24 hours

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Unrefreshing Sleep

- Sleep does not restore energy or a sense of well-being
- 92% of patients with SEID report unrefreshing sleep
 - 16% of controls

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Sleep and SEID

- Other sleep disturbances common, but not required for diagnosis:
 - Problems falling asleep
 - Problems staying asleep
 - Need for daily naps

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Other Components of SEID Diagnosis

- Cognitive impairment
 - "Brain fog" reported by 98% of SEID patients
 - ~50% of controls
 - Difficulty with memory, expression, or concentration
 - Symptoms worsen with prolonged effort
- Orthostatic intolerance
 - Symptoms are worse when in any position other than laying down
 - Orthostatic BP
 - Tilt-table testing

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Systemic Exertion Intolerance Disorder

- Symptoms must be severe
- Patients with psychiatric diagnoses are excluded
- Patients with other medical conditions known to cause chronic fatigue are excluded

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Other Common Symptoms

- Pain
 - Diffuse, no clear patterns
 - Arthralgias
 - Myalgias
- Lymphadenopathy
- GI symptoms
- Pharyngitis

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Etiology

- ?post-viral
- ?autoimmune
- ?psychosomatic
- ?multifactorial

- The XMRV story



Image credit: CDC/Dr. Fred Murphy, J. Nakano

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Making the SEID Diagnosis

- Clinical diagnosis
- DePaul fatigue questionnaire
- CDC Symptom Inventory for CFS

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Differential Diagnosis

- Rheumatologic conditions
 - RA
 - Fibromyalgia
 - Dermatomyositis/polymyositis
 - Lupus
 - Polymyalgia rheumatica
- Neurologic conditions
 - Multiple sclerosis
 - Narcolepsy
 - Dementia

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Differential Diagnosis

- Endocrine conditions
 - Hypothyroidism/hyperthyroidism
 - Adrenal insufficiency
- Hematologic-oncologic conditions
 - Cancer
 - Severe anemia
- Gastroenterologic conditions
 - Celiac disease
 - Parasites

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Differential Diagnosis

- Mental health conditions
 - Major depression
 - Somatization disorders
 - Conversion disorders

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Work Up

- The CDC recommends:
 - CBC with differential
 - Total protein/Albumin/Globulin levels
 - Glucose
 - C-reactive protein
 - Electrolytes/Calcium/Phosphorus
 - Blood urea nitrogen (BUN)/Creatinine
 - ANA and rheumatoid factor
 - ALT/AST/Alkaline phosphatase
 - Thyroid function tests (TSH and Free T4)
 - Urinalysis

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Further Work Up

- Depending on symptoms
 - Sleep study
 - Monospot
 - Anti tissue-transglutaminase/antiendomysial antibodies
 - HIV

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Approach to the Patient with SEID

- Believe the patient
- Believe the diagnosis
- Set goals and standards you are comfortable with
- Accept the possibility of an unsatisfying outcome
 - What will this be like for the patient? For you?

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Treatment

- Set clear treatment goals based on patient's symptoms and patient's goals
- Avoid narcotics
- Avoid hypnotic sleep agents

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Which of the following has been shown to be effective for the treatment of SEID?

- A. SSRIs
- B. Acyclovir
- C. Melatonin
- D. Methylphenidate
- E. None of the above

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Which of the following treatments has been demonstrated to be effective for treatment of CFS?

- A. Replacement of dental amalgam
- B. Tai chi
- C. Cognitive behavioral therapy
- D. Guided imagery
- E. None of the above

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Pharmacotherapy for CFS

- Medications that have been studied and don't work
 - SSRIs
 - Melatonin
 - Antiviral meds
 - Steroids
 - Methylphenidate
- Medications that have been studied and do work
 - Sadly, none!

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Other Therapy Options

- Gabapentin
- Pregabalin
- Tricyclic antidepressants
- Non-hypnotic sleep agents
- Fludrocortisone

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Pharmacotherapy for SEID

- Symptom-directed
 - Sleep
 - Cognition
 - Fatigue



Image credit: wikimedia user ParentingPatch.

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Non-Pharmacologic Therapy

- Cognitive behavioral therapy well studied
 - Form of psychotherapy focused on goals and behaviors
 - Improves symptoms
 - May not improve functional outcomes
 - Unclear whether CBT improves objective ability to do physical activity, although patients report improved subjective ability

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Non-pharmacologic therapy

- Graded exercise therapy (GET)
 - Gradual increase in physical therapy to increase stamina and strength
 - Carefully monitored to not exceed a threshold of exertion
 - Improves symptoms
 - Improves functional outcomes

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Graded exercise therapy

- 2016 Cochrane review
 - 8 RCTs, ~1500 patients
 - Exercise therapy reduced fatigue more than no treatment or non-exercise treatment
 - 2 points on 11 point scale
 - Not better than CBT
 - Did not make SEID symptoms worse

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Pacing

- Patients determine available energy, based on how they feel that day, then divide energy into a list of tasks
- Emphasis on moving deliberately, frequent breaks for rest, changing between activities
- “Pace” the day

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GET and Pacing

- Heart rate monitors may be useful for both GET and pacing
- Emphasis on gentle exertion without over-exertion
- Gradual increase in activity



Image credit:
https://en.wikipedia.org/wiki/Heart_rate#/media/File:Polar_Heart_Rate_Monitor.jpg

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Sleep Disorders

- Sleep hygiene
- Sleep diaries



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Support Groups

- One study found worse outcomes with support group attendance
- CDC still recommends them as “possibly useful”

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Which of the following is not known to be commonly comorbid with SEID?

- A. Alzheimer disease
- B. Irritable bowel disease
- C. Major depression
- D. Celiac disease
- E. A and D

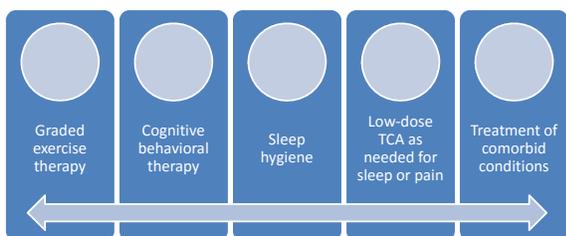
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Comorbid Conditions

- Major depression
- IBS
- Fibromyalgia

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Overview of Treatment of SEID



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The Prognosis of CFS is:

- A. 90% of adults will resume premorbid levels of functioning within 5 years
- B. 50% of adults will resume premorbid levels of functioning within 5 years
- C. 30% of adults will resume premorbid levels of functioning within 5 years
- D. <10% of adults will resume premorbid levels of functioning within 5 years

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Prognosis

- 6% of adults regain premorbid levels of function
 - Up to 50% improve
- 50-80+% of children regain premorbid levels of function

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Diagnoses and Coding

- SEID found under chronic fatigue syndrome NOS: R53.82
- Post-viral fatigue: G93.3
- Weakness: R53.1
- Fatigue: R53.83
 - Malaise
 - Lethargy
 - Exhaustion
 - Lack of energy
 - “Want of vitality”
 - Overworked
 - Overstrained
 - Prostration

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Practice Recommendations

- Include SEID on the differential of patients with unexplained fatigue and other systemic symptoms (SOR C)
- Adopt the 2015 Institute of Medicine recommendations for diagnosis of SEID (SOR B)
- Use a multidisciplinary treatment of SEID, including graded physical therapy, pacing techniques, and psychotherapy for adaption to chronic disease (SOR B)

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Resources

- www.cdc.gov/cfs
- <http://solvecfs.org>
- <http://www.iacfsme.org>

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Questions?

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Billing & Coding

When services performed in conjunction with:

Office Visit 992xx

Additional tests to confirm or monitor:

99490 Chronic Care Management-20 minutes monthly

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Interested in More CME on this topic?
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