



CDC ME/CFS SEC Call

"The Management Options (yes there are management options) for People with ME/CFS"

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For closed captioning, please visit:

<https://www.streamtext.net/player?event=4480MECFSStakeholdersEngagementCommunications>



AGENDA

- Welcome and SEC Call Overview
- Updates from CDC
 - Elizabeth Unger, Ph.D., M.D.
Branch Chief, Chronic Viral Diseases Branch
Centers for Disease Control and Prevention
- "The Management Options (yes there are options) for People with ME/CFS"
 - Stephen Gluckman, M.D.
Professor of Medicine, Perelman School of Medicine, University of Pennsylvania,
Philadelphia, PA
- Question and Answer (Q&A)

The findings and conclusions in these presentations are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



Question and Answer (Q&A)

To ask a question within the Zoom webinar platform during the meeting:

- If joining online, please raise your hand virtually
- If joining by phone, please enter *9. When called upon, callers will need to enter *6 to unmute.

Disclosure

These calls are open to the public. Please exercise discretion in sharing personal information, as confidentiality during these calls cannot be guaranteed. This call is being recorded, and the video and transcripts will be posted on the CDC website after the beginning of the year.

If you have additional questions following the call, please email MECFSSEC@cdc.gov.

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Management Options

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ME/CFS

- Is EXHAUSTING for patients and can be challenging for their physicians
- Can be managed successfully by sympathetic and skillful clinicians
- SUCCESSFUL MANAGEMENT IS ACTUALLY VERY REWARDING FOR THE CLINICIAN

Basic Tenets of Management

- Educating patients about the disease
- Making it clear that the patient has come to a health care worker who completely believes the validity of their symptoms
- Managing specific symptoms

EDUCATION

For Patients and Health Care Providers

Fatigue

- Chronic fatigue syndrome is not the same as chronic fatigue
 - Chronic fatigue
 - 25-30% of patients seeing a primary care provider report fatigue at some time
 - Point prevalence about 5%
 - CFS
 - Estimated prevalence in USA: 1-2.5 million

Institute of Medicine Review

(National Academy of Medicine)

- In February 2015 the Institute of Medicine released a comprehensive review of the topic.
 - The original document was over 300 pages of research and commentary
 - The panel consisted of eminent scientists, lawyers, academics and laypersons
 - The document was heavily referenced
 - Many outside reviewers of the draft
 - Over 1000 public comments

IOM Report Conclusions

- “ME/CFS is a serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients. In its most severe form, this disease can consume the lives of those whom it afflicts. It is “real”. It is not appropriate to dismiss these patients.”
- Clearly stressing the legitimacy of the disease
 - “Sufficient evidence that ME/CFS is a disease with a physiologic basis and is not a psychological problem”
 - “It should be taken seriously”

New Diagnostic Criteria

- Three of the following
 - Fatigue
 - A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion and is not substantially alleviated by rest.
 - Post-exertional malaise
 - Physical, psychological, or emotional
 - Unrefreshing sleep
- PLUS
- One of the two following
 - Cognitive impairment (“brain fog”)
 - Orthostatic intolerance

Other Common Symptoms

- Lightheadedness or dizziness
- Palpitations
- Blurred vision
- Pain in joints/muscles
- “Flu-like” symptoms
- Tender lymph nodes
- Chronic sore throat
- Night sweats
- Light sensitivity
- Multiple allergies and sensitivities

Other Things to Consider

- Often present or related
 - Fibromyalgia
 - Postural Orthostatic Tachycardia Syndrome (POTS)
 - Chronic Fatigue Immune Dysfunction Syndrome (CFIDS)

ME/CFS: Case Definition

BUT

- It is important to not get overly “hung up” on the case definition when managing a patient
 - This is an epidemiology/research tool, not a clinical tool.
 - You can (and should) be able to diagnose ME/CFS even if the definition is not completely met.

ME/CFS

- Complicated and controversial **BUT**
 - It is not a new phenomenon
 - It is a “real” illness
 - We know a great deal about it
- A health care provider cannot effectively manage patients with ME/CFS if he or she has doubt about the validity of the patient’s symptoms!

Chronic Fatigue Syndrome Historical Perspective

- It is not a new disease
- It is a newly (relatively) named disease

ME/CFS: Historical Perspective

- 1770 Febricula
- 1871 Da Costa's (effort) syndrome
- 1880s Neurasthenia
 - Sir William Osler writing in 1895 “in all forms there is a striking lack of accordance between the symptoms of which the patients complain and the objective changes discoverable by the physician”

ME/CFS: Historical Perspective

- 1934 Myalgic encephalitis
- 1930-50s Chronic brucellosis
- 1985 Chronic EBV
- 1980-90s
 - CMV
 - HSV
 - HHV6
 - Yeast
 - Total allergy syndrome
 - Chemical sensitivity syndrome
 - Chronic Lyme disease
- 2000s
 - XMRV
 - Other retroviruses

ME/CFS: Etiology

Considerations

- Infectious Agent?
 - Many viruses and other pathogens have been proposed, but none have been scientifically linked to CFS
- Endocrine-Metabolic?
 - Variable, mild hormonal abnormalities have been reported
- Immune Problem?
 - Some suggestions but causality has not been established
 - Epiphenomena?
 - NOT immunosuppressed
- NB: There may not be a single cause

ME/CFS Etiology

- ME/CFS is a biological illness, not a psychologic disorder
 - Patients are not malingering
 - Patients are not hypochondriacs
 - Patients have multiple pathophysiological changes/abnormalities in
 - Immune system
 - Cellular metabolism
 - Neuroendocrine system
 - Autonomic systems

ME/CFS Is Just Another Disease

- ICD 10 code: R53.82
- NIH lab
- CDC website link
- IOM report
- Disability insurance rarely a problem

ME/CFS

- How can we diagnose something without a diagnostic test?
 - There is a characteristic history
 - There is a characteristic physical examination
 - There are characteristic test results

ME/CFS: Characteristic History

- Pre-CFS history of the patient is NOT one of multiple somatic complaints.
 - They are not hypochondriacs. They have been highly functioning individuals who are “struck down” with the disease

ME/CFS: Characteristic Examination

- Normal examination
 - Including Mini Mental Status Exam (MMSE)

ME/CFS: Characteristic Clinical Features

- Specific points to emphasize
 - Though patients often complain of fever, very few have significantly elevated temperatures
 - “I run low temperatures normally”
 - Joints may ache, but there is no objective evidence of joint disease
 - Though muscles fatigue easily, strength is normal as is EMG and muscle biopsy
 - Lymphadenia is common, lymphadenopathy is rare

ME/CFS: Characteristic Laboratory Results

- Normal
 - CBC
 - Chemistry screen
 - TSH
 - Additional tests I often get:
 - Cortrosyn stimulation
 - Sleep study
 - Other tests: only with clinical indication

ME/CFS: Diagnosis

- DO NOT ROUTINELY DO:
 - Serology for
 - CMV
 - EBV
 - Toxoplasmosis
 - Lyme disease
 - ANA
 - Expensive neuroimaging
 - Tilt table testing

ME/CFS: Diagnosis

- If the patient has a typical story, negative physical examination, and negative screening tests we can make the diagnosis.

ME/CFS

Concepts To Remember For Successful Management By Health Care Provider

- Patients with ME/CFS are partially or completely disabled.
- Their outward healthy appearance belies an internal sense of ill health.
- It is common for friends, relatives, employers, and physicians to believe they are malingering or their symptoms are not “real”.
- This results in anger, frustration, and a need to justify their illness
- Support and understanding is a critical part of the good clinical care

ME/CFS: General Steps in Management

1. Give the patient enough time and do a thorough evaluation
2. Reassure the patient that the symptoms are real
3. Discuss problem of patient having to deal with the validity of his/her disease
4. Do not underestimate the benefits of trust, support, and reassurance that you can provide
5. Explain to the patient that this is not a new disease – we know a lot about it
 - Review the history of CFS in detail
6. Avoid the debate over psychogenic vs organic origin

ME/CFS: Specific Steps in Management

1. Tell the patient that there is no cure for ME/CFS, but there are treatments that help
2. “Re-frame” expectations – the patient has a disability and should have appropriate expectations
3. Suggest very gradual graded exercise
 - Inactivity contributes to increased fatigue and depression
4. Suggest Cognitive Behavioral Therapy
5. Treat depression aggressively

ME/CFS: Specific Steps in Management

6. Treat insomnia aggressively (sleep specialist ?)
7. Treat other “treatable” conditions
 - Do not assume that every symptom is ME/CFS related
 - Caution patients about this
8. Pain
 - Duloxetine (Cymbalta[®])
 - 30-60 mg per day
 - Amitriptyline (Elavil[®])
 - 12.5-50 mg per day
 - Pregabalin (Lyrica[®])
 - 150-450 mg per day
 - Topiramate (Topamax[®])
 - 25-200 mg per day
 - Pain management specialist
 - Physical Therapy

ME/CFS: Specific Steps in Management

9. Fatigue

Manage the time each day that can be used effectively

Mindfulness-Based stress reduction

Take more time to complete tasks and take breaks

If able to work, discuss accommodations with employer

Medications

- methylphenidate (Ritalin LA[®])
- modafinil (Provigil[®])
- Armodafinil (Nuvigil[®])

ME/CFS: Specific Steps in Management

10. Orthostatic intolerance and POTS

- Volume expansion; support stockings; increase sodium intake
- Medications
 - clonidine
 - Midodrine
 - Fludrocortisone

11. Cognitive Problems

Establish a routine/schedule

Use organizational aids

Verbal Tagging

Talk aloud when completing a task

Alarms and other reminders

Habit stacking

Smartphone reminders

ME/CFS: Specific Steps in Management

13. See at regular intervals
14. Caution about unproven, dangerous or expensive treatments
15. Offer CDC website
16. Suggest they read IOM (NAS) review. Can be found by searching the web.

ME/CFS: Management

Unproven and Disproved Therapies

- Ampligen
- Essential fatty acids
- Magnesium
- Bovine liver extract
- Acyclovir
- Folic acid
- B12
- Interferon
- Exclusion diets
- IVIG
- Removal of dental fillings
- IL 2
- Cimetidine
- Ranitidine
- Evening primrose
- Many antibiotics
- Corticosteroids

ME/CFS: Management

- Accept the fact that you will not be able to successfully manage all patients with ME/CFS but avoid the temptation to give unnecessary treatments.

Questions and Comments?