# Supplementary Readings Annotated List

## **Feature stories**

Myalgic Encephalomyelitis. Unknown Cause. No Cure. New Hope. By Lily Williams. 2018

Feature story about a child with ME. An excellent overview article.

ASBMB Today, 2018 (American Society for Biochemistry and Molecular Biology)

<a href="http://www.asbmb.org/asbmbtoday/201803/Feature/ME/">http://www.asbmb.org/asbmbtoday/201803/Feature/ME/</a>

# Information for patients

**#MEAction (2018)** 

This page contains information on diagnosis and management of ME, including an 11-minute video and a one-page handout.

https://www.meaction.net/patients/

### Recent research

## Perceptions of chronic fatigue syndrome in the emergency department

Findings from a novel online questionnaire of people with chronic fatigue syndrome (CFS) suggest the majority of these patients do not receive proper care, say researchers. https://www.sciencedaily.com/releases/2019/01/190110171052.htm

Science Daily (2019)

**Journal Reference**: Christian Timbol, James Baraniuk. **Chronic fatigue syndrome in the emergency department**. *Open Access Emergency Medicine*, 2019; Volume 11: 15

DOI: <u>10.2147/OAEM.S176843</u>

# School Nurses Can Improve the Lives of Students With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

The debilitating effects of ME/CFS in the pediatric population can affect all aspects of academic, social, emotional, and physical development. ME/CFS has been diagnosed in children younger than 10 years. Therefore, the school nurse is likely to encounter one or more students in the various stages of this disease, putting the school nurse in a position to ameliorate the impact of this potentially devastating chronic condition.

<u>Friedman</u>, et al., National Association of School Nurses: NASN School Nurse (2018) https://doi.org/10.1177/1942602X18795299 (abstract is free; full article is behind a paywall)

#### The Real Story About Chronic Fatigue Syndrome

Research shows that the condition, once ridiculed as imaginary, is a true physiological disease. Here's what to look for, and how PTs are helping those who have it.

Eric Reis, American Physical Therapy Association: PT in Motion (2017) http://www.apta.org/PTinMotion/2017/9/Feature/ChronicFatigue/

Cardiopulmonary Exercise Test Methodology for Assessing Exertion Intolerance in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

The 2-day CPET methodology is outlined, and the utility of the procedure is discussed for assessment of functional capacity and exertion intolerance in ME/CFS. Basic concepts of CPET are summarized, and special considerations for performing CPET on ME/CFS patients are detailed to ensure a valid outcome. Stevens et al. Front. Pediatr. (2018)

https://www.frontiersin.org/articles/10.3389/fped.2018.00242/full

## Community Symposium on the Molecular Basis of ME/CFS 2018

The Second Annual Community Symposium on the Molecular Basis of ME/CFS, sponsored by Open Medicine Foundation, took place on September 29, 2018 at Stanford University. 19 videos present highlights of research, Q&A, and remarks.

https://www.youtube.com/playlist?list=PLI4AfLZNZEQPxjqF4ojAO3wdCFMeriNBK

Summary of the symposium: <a href="https://www.omf.ngo/second-annual-community-symposium-summary/">https://www.omf.ngo/second-annual-community-symposium-summary/</a>

## **Clinical guidance**

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: What Every Family Physician Needs to Know, What every family physician (or PCP) needs to know about ME/CFS.

Dimmock et al. Family Doctor • A Journal of the New York State Academy of Family Physicians, Winter 2018, p. 23

http://www.nysafp.org/NYSAFP/media/PDFs/Family%20Doctor/Family-Physician-Winter-2018WEB.pdf

# "Primers" for Clinicians

## **Adult primer**

**ME/CFS:** A Primer for Clinical Practitioners

Monograph: pathophysiology, symptoms & diagnosis, management & treatment, helpful tools for clinicians.

Friedberg, et al., International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis IACFS/ME, 2014

http://iacfsme.org/ME-CFS-Primer-Education/News/News-Related-Docs/2014/ME-CFS-Primer-for-Clinical-Practitioners-(2014-rev.aspx

## **Pediatric primer**

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer (2017)

Overview of pediatric ME/CFS with sections about how the disease impacts education and social development of children.

P.C. Rowe et al., Front. Pediatr., (2017)

https://doi.org/10.3389/fped.2017.00121

#### "ME-ICC"

#### Myalgic encephalomyelitis: International Consensus Criteria

Diagnostic criteria reflect the complex symptomatology. Clinical and research application guidelines promote optimal recognition of ME by primary physicians and other healthcare providers, improve the consistency of diagnoses in adult and paediatric patients internationally and facilitate clearer identification of patients for research studies.

B.M. Carruthers, et al., Journal of Internal Medicine (2011) https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x

## "Canadian Consensus Criteria (CCC)"

Myalgic Encephalomelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols – A Consensus Document

A systematic clinical working case definition that encourages a diagnosis based on characteristic patterns of symptom clusters, which reflect specific areas of pathogenesis. Diagnostic and treatment protocols, and a short overview of research are given to facilitate a comprehensive and integrated approach to this illness.

B.M. Carruthers, et al., Journal of Chronic Fatigue Syndrome 11(1):7-115, 2003 Download this document

http://www.mefmaction.com/images/stories/Medical/ME-CFS-Consensus-Document.pdf