

# <u>Udpluk af Forskningsartikler om PEM hos ME-patienter og skader ved</u> <u>GET (gradueret træningsterapi)</u>

**1. July 2018** <u>- Mark Vink and Alexandra Vink-Niese:</u>

<u>Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe,</u>

**2. Oct. 2019** - C. (Linda) M.C. van Campen, Freek W.A. Verheugt, Peter C. Rowe, Frans C. Visser

<u>Cerebral blood flow is reduced in ME/CFS during head-up tilt testing even in the absence of hypotension or tachycardia: A quantitative, controlled study using Doppler echography</u>

During HUT (head-up tilt test), extracranial Doppler measurements demonstrate that CBF (cerebral blood flow) is reduced in ME/CFS patients with POTS (postural orthostatic tachycardia syndrome), dOH (delayed orthostatic hypotension), and even in those without heart rate (HR) and blood pressure (BP) abnormalities.

**3. June 2019** - Lien K, Johansen B, Veierød MB, Haslestad AS, Bøhn SK, Melsom MN, Kardel KR, Iversen PO.

Abnormal Blood Lactate Accumulation During Repeated Exercise Testing in Myalgic encephalomyelitis/chronic Fatigue Syndrome,

Exercise intolerance, PEM and delayed recovery are prominent symptoms in ME/CFS. Intriguingly, this study indicates that previous exercise increases lactate accumulation in ME/CFS as opposed to the reduction seen in healthy controls, although the mechanism for this has yet to be established

**4. Feb. 2016** - Gina Rutherford , Philip Manning , Julia L Newton

Understanding Muscle Dysfunction in Chronic Fatigue Syndrome,

This narrative review examined the literature for evidence of biochemical dysfunction in CFS/ME at the skeletal muscle level. Results: Studies show evidence for skeletal muscle biochemical abnormality in CFS/ME patients, particularly in relation to bioenergetic dysfunction

# **PEM = Post Exertional Malaise**

**5. Dec. 2011,** J. Mark Vanness, Christopher R. Snell & Staci R. Stevens

#### **Diminished Cardiopulmonary Capacity During Post-Exertional Malaise**,

**Purpose**: To compare results from repeated exercise tests as indicators of post-exertional malaise in CFS.

**Conclusion**: In the absence of a second exercise test, the lack of any significant differences for the first test would appear to suggest no functional impairment in CFS patients. However, the results from the second test indicate the presence of a CFS related post-exertional malaise. It might be concluded then that a single exercise test is insufficient to demonstrate functional impairment in CFS patients. A second test may be necessary to document the atypical recovery response and protracted malaise unique to CFS.

**6. April 2014,** Betsy A Keller, John Luke Pryor & Ludovic Giloteaux

<u>Inability of myalgic encephalomyelitis/chronic fatigue syndrome patients to reproduce VO<sub>2</sub>peak indicates functional impairment,</u>

ME/CFS patients have been reported to fail to reproduce results in a second CPET performed one day after an initial CPET.

Conclusuin: ME/CFS participants were unable to reproduce most physiological measures at both maximal and ventilatory threshold intensities during a CPET performed 24 hours after a prior maximal exercise test. Our work confirms that repeated CPETs warrant consideration as a clinical indicator for diagnosing ME/CFS. Furthermore, if based on only one CPET, functional impairment classification will be mis-identified in many ME/CFS participants.

7. Sept. 2015 - Frank N.M. Twisk, Keith J. Geraghty

<u>Deviant Cellular and Physiological Responses to Exercise in Myalgic Encephalomyelitis and Chronic Fatigue Syndrome</u>,

Post-exertional "malaise" is a hallmark symptom of ME and CFS.

Various abnormalities, including abnormal physiological responses to exertion, can account for post-exertional "malaise"

and "exercise avoidance". Since these abnormalities are not observed in sedentary healthy controls, the abnormalities and

deviant responses cannot be explained by "exercise avoidance" and subsequent deconditioning, nor by psychogenic factors.

#### **8. Jan. 2011** - Tom Kindlon

Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome,

Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) based on increasing activity levels are often recommended for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). However, exercise-related physiological abnormalities have been documented in recent studies and high rates of adverse reactions to exercise have been recorded in a number of patient surveys.

#### 9. Litteraturoversigt over forskning der viser at CBT og GET skader ME-patienter.

#### 10. Jan. 2016 - Frank Twist

#### PACE: CBT and GET are not rehabilitative therapies,

Both CBT and GET have been qualified by the PACE trial investigators as "moderately effective treatments". However, looking at the data of the follow-up study1 and other PACE trial studies, CBT and GET do not qualify as rehabilitative therapies for chronic fatigue syndrome or myalgic encephalomyelitis, as defined by the London criteria.

#### 11. June 2019 - Graham McPhee, Adrian Baldwin, Tom Kindlom, Brian M Huges

Monitoring Treatment Harm in Myalgic encephalomyelitis/chronic Fatigue Syndrome: A Freedom-Of-Information Study of National Health Service Specialist Centres in England,

Graded exercise therapy (GET) can cause harm for some patients with ME, but assessment shows that patients are warned about the potential for harms.

#### **12. 2017 -** S. Eyssens

#### **EMERGE - national veiledning om PEM hvor GET frarådes**

Primer that provides an overview of the core symptom of Post-Exertional Malaise (PEM) in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), as well an analysis of the evidence base for the commonly recommended treatment of Graded Exercise Therapy (GET), and to highlight the risk of harm which GET poses to people with ME/CFS.

#### 13. 2016 – James C Coyne

Professor James C. Coyne, Ph.d, Emeritus Professor of Psychology in Psychiatry og ekstern videnskabelig rådgiver for EU kommissionen. Coyne <u>retter skarp kritik mod påståede resultater i forskningsstudie om adfærdsterapi til ME patienter fra Forskningsklinikken for Funktionelle Lidelser.</u>

### 14. Sept. 2009 - Frank N.M. T and Michael M

<u>CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS</u>

CBT/GET is not only hardly more effective than non-interventions or standard medical care, but many patients report that the therapy had affected them adversely, the majority of them even reporting substantial deterioration.

Eexertion and thus GET most likely have a negative impact on many ME/CFS patients.

## 15. Maj 2018

Indsigelse fra amerikanske Workwell Foundation imod træning til ME patienter,