Index of ME/CFS Published Research

An A-Z index of the most important published research

2nd November 2020
The ME Association
Foreword

Welcome to the ME Association Index of Published ME/CFS Research.

This is an A-Z index of the most important published research studies and selected key documents and articles, listed by subject matter, on myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS). It is correct to 2nd November 2020.

The Index is updated at the end of each month and we publish a weekly update of recent research publications that are also available on the MEA website and social media.

The Index adopts the subject headings used in the MEA Clinical and Research Guide which provides a review of current clinical knowledge and research evidence and is updated annually.

This authoritative and very popular book is written by Dr Charles Shepherd, Hon. Medical Adviser to the ME Association and Dr Abhijit Chaudhuri, consultant neurologist at Queen’s Hospital in Romford.

The 2020 edition is now available to order from the MEA website shop. We are pleased to be able to offer free hard copies to health professionals upon application and it is also available on Kindle.

Please support our vital work

If you would like to support our efforts and ensure we are able to inform, support, campaign, and invest in biomedical research, then please donate today.

Just click the image opposite or click here for one-off donations or to establish a regular payment.

You can even establish your own fundraising event on JustGiving.

Or why not join the ME Association as a member and be part of our growing community?

For a monthly (or annual) subscription you will also receive ME Essential – quite simply the best M.E. magazine!
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The ME Association Index of Published ME/CFS Research

The ME Association
7 Apollo Office Court, Radcliffe Road, Gawcott, Bucks, MK18 4DF ME Connect Helpline: 0344 576 5326 Available every day of the year, during the hours of 10am-12noon, 2pm-4pm and 7pm-9pm. The ME Association is a registered charity number 801279.
Please note: Research published after June 2020 (the date of the last update to
the MEA Clinical and Research Guide or ‘Purple Book’) is highlighted in purple
in the listing below.

1. Nomenclature and definition

Asprusten TT, et al. (2015) Study findings challenge the content validity of the
Canadian Consensus Criteria for adolescent chronic fatigue syndrome. Acta
Paediatrica 104 (5):498-503 Link:

Brurberg et al. (2013) Case definitions for chronic fatigue syndrome/myalgic
encephalomyelitis (CFS/ME): a systematic review. BMJ Open 4 (2). Link:
https://bmjopen.bmj.com/content/4/2/e003973

Syndrome: Clinical work case definition, Diagnostic and Treatment Protocols.
Journal of Chronic Fatigue Syndrome 11(1): 327-338 Link:

Criteria Journal of Internal Medicine 270 (4): 327-338 Link:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3427890/

Clayton EW. (2015) Beyond Myalgic encephalomyelitis/chronic fatigue
syndrome: An IOM report on redefining an illness. JAMA 313 (11): 1101-1102 Link:
https://jamanetwork.com/journals/jama/article-abstract/2118591

Approach to Its Definition and Study. International Chronic Fatigue Syndrome
Study Group. Annals of Internal Medicine 121 (12): 953-959. Link:

Goudsmit EM, Shepard C, et al. (2009) ME: Chronic Fatigue Syndrome or a
distinct clinical entity? Health Psychology Update 18 [1]: 26-33 Link:
http://www.foodsmatter.com/me_and_cfs/cfs_me-causes_general/articles/go
dsmit-me-clinical%20entity-10-12.html

Howard H. (2018) Recent insights into 3 under recognized conditions: Myalgic
encephalomyelitis–chronic fatigue syndrome, fibromyalgia, and environmental
sensitivities–multiple chemical sensitivity. Canadian Family Physician 64 (6): 413-
415. Link: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5999262/

Institute of Medicine (2015) Beyond Myalgic Encephalomyelitis/Chronic Fatigue


2. Epidemiology


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3. Co-morbidity


4. Biomedical Research

4.1 Biobank UK ME/CFS


4.2 Biomarker Landscape Project

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4.3 Cardiac Function


Campen CM and Visser FC (2018) The Abnormal Cardiac Index and Stroke Volume Index Changes During a Normal Tilt Table Test in ME/CFS Patients Compared to Healthy Volunteers, are Not Related to Deconditioning, Journal of Thrombosis and Circulation 107. Link: https://tinyurl.com/y5nb9dyr

Campen CM et al. (2020) 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. Clinical Neurophysiology Practise [Epub ahead or print]. Link: https://www.sciencedirect.com/science/article/pii/S2467981X20300044


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4.4 Exercise physiology/testing


4.5 Gastrointestinal and microbiome


Kenyon J et al. (2019) A Retrospective Outcome Study of 42 Patients with Chronic Fatigue Syndrome, 30 of Whom had Irritable Bowel Syndrome. Half were treated with oral approaches, and half were treated with Faecal Microbiome Transplantation. *Human Microbiome Journal* 13. Link: https://tinyurl.com/y2cqxzgf


### 4.6 Gene expression


4.6.1 Epigenetics


4.7 General reviews


### 4.8 Genetic predisposition


### 4.9 Immunology


Groven N et al. (2020) MCP-1 is Increased in Patients with CFS and FM, whilst several other immune markers are significantly lower than healthy controls. Brain, Behaviour & Immunity- health [Epub ahead of print]. Link: https://www.sciencedirect.com/science/article/pii/S2666354620300326#!


Jonsjo MA et al. (2019) Patients with ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) and chronic pain report similar level of sickness behavior as individuals injected with bacterial endotoxin at peak inflammation. Health [Epub ahead of print]. Link: https://www.sciencedirect.com/science/article/pii/S2666354619300298


4.10 Infection


Asprusten T et al. (2019) EBV-requisitioning physicians’ guess on fatigue state 6 months after acute EBV infection. BMJ Paediatrics Open 3 (1). Link: https://tinyurl.com/y39pwy8r


Coffin JM and Stoye JP. (2009) A New Virus for Old Diseases? *Science* 326(5952): 530. Link: [http://science.sciencemag.org/content/326/5952/530](http://science.sciencemag.org/content/326/5952/530)


4.11 Ion channels


4.12 Metabolomics


4.13 Miscellaneous


Thakur V et al. (2020) Protective Effect of Hemin Against Experimental Chronic Fatigue Syndrome in Mice: Possible Role of Neurotransmitters. Neurotoxic Research [Epub ahead of print]. Link: https://tinyurl.com/y8bloc4g


4.14 Mitochondria and energy production


Bohne V and Bohne O (2019) Suggested Pathology of Systemic Exertion Intolerance Disease: Impairment of the E3 Subunit or Crossover of Swinging Arms of the E2 Subunit of the Pyruvate Dehydrogenase Complex Decreases Regeneration of Cofactor Dihydrolipoic Acid of the E2 Subunit. *Medical Hypothesis* [Epub ahead of print] Link: [https://tinyurl.com/y6fbud4a](https://tinyurl.com/y6fbud4a)


Sweetman E et al. (2020) A SWATH-MS analysis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome peripheral blood mononuclear cell proteomes reveals mitochondrial dysfunction. *Journal of Translational Medicine* 18 (365). Link: [https://tinyurl.com/y7rw58vq](https://tinyurl.com/y7rw58vq)


### 4.15 Muscle


### 4.16 Neurology: Autonomic nervous system (ANS) dysfunction


Lee J et al. (2020) Clinically accessible tools for documenting the impact of orthostatic intolerance on symptoms and function in ME/CFS. Work [Epub ahead of print]. Link: https://content.iospress.com/articles/work/wor203169


4.17 Neurology: Central nervous system and neuroimaging


#### 4.18 Neurology: Hypothalamic and neuroendocrine function


4.19 Neurology: Neuropsychology and cognitive function


4.20 Neurology: Neurotransmitter function


4.21 Pain


4.22 Phenotypes and sub-groups


4.23 Post-Exertional Malaise (PEM)


Holtzman C et al. (2019) Assessment of Post-Exertional Malaise (PEM) in Patients with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS): A Patient-Driven Survey. Diagnostics 9 (1). Link: https://www.mdpi.com/2075-4418/9/1/26


4.24 Post-mortem research


4.25 Sleep disturbance


4.26 Vision

5. Psychiatry and psychology


Thompson et al. (2019) Cognitive factors are associated with disability and pain, but not fatigue among physiotherapy attendees with persistent pain and fatigue. *Physiotherapy* [Epub ahead of print]. Link: https://tinyurl.com/yype9zu8

Van Deuren S et al. (2020) Fatigue-Related Cognitive-Behavioral Factors in Survivors of Childhood Cancer: Comparison with Chronic Fatigue Syndrome and Survivors of Adult-Onset Cancer. *Journal of Adolescent and Young Adult Oncology* [Epub ahead of print]. Link: https://www.liebertpub.com/doi/10.1089/jayao.2020.0094


6. Sociology


### 7. Future research recommendations


Tokunaga K et al. (2020) Inclusion of family members without ME/CFS in research studies promotes discovery of biomarkers specific for ME/CFS. *Work* [Epub ahead of print]. Link: https://content.iospres.com/articles/work/work203177


8. Clinical assessment, symptoms, and diagnosis

8.1 General


8.2 Investigations


8.3 Physical examination


8.4 Symptoms

Pain – see Biomedical Research, 4.21 above.
Post-Exertional Malaise – see Biomedical Research, 4.23 above.
Sleep disturbance – see Biomedical Research, 4.26 above.
Vision – see Biomedical Research, 4.28 above.

9. Management

9.1 Cognitive Behavioural Therapy (CBT)


9.2 Complementary and alternative therapies


### 9.3 Diet and nutrition


9.4 Exercise, Pacing and activity management


Link: https://pubmed.ncbi.nlm.nih.gov/33114704/


Vink M and Vink-Niese A (2020) Graded exercise therapy doesn’t restore the ability to work in ME/CFS. Rethinking of a Cochrane review. Work [Epub ahead of print]. Link: https://content.iospress.com/articles/work/wor203174


9.5 General management


BACME. (2015) British Association for CFS/ME: Therapy and Symptom Management in CFS/ME. Link: [https://www.bacme.info/](https://www.bacme.info/)


Chu L et al. (2020) Environmental accommodations for university students affected by myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Work [Epub ahead of Print]. Link: [https://content.iospress.com/articles/work/wor203176](https://content.iospress.com/articles/work/wor203176)


9.6 PACE Trial, The


Vink M. PACE trial authors continue to ignore their own null effect. Journal of Health Psychology 22 (9): 1134-1140. Link: https://www.ncbi.nlm.nih.gov/pubmed/28805519


9.7 Pharmacological treatment


Bolton MJ et al. (2020) Low-dose naltrexone as a treatment for chronic fatigue syndrome. BMJ Case Reports 13 (1). Link: https://casereports.bmj.com/content/13/1/e232502


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Van Campen LMC and Visser FC (2019) The Effect of Curcumin in Patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis Disparate Responses in Different Disease Severities. Pharmacovigilance and Pharmacoepidemiology 2 (1). Link: https://tinyurl.com/gpvhgd


9.8 Pregnancy


10. Prognosis and quality of life

10.1 Age


10.2 Mortality


### 10.3 Prognosis and recovery


### 10.4 Quality of life


10.5 Severe ME


11. Vaccinations


Hviid A et al. (2020) Association between quadrivalent human papillomavirus vaccination and selected syndromes with autonomic dysfunction in Danish females: population based, self-controlled, case series analysis. *BMJ* 370: m2930. Link: https://www.bmj.com/node/1033205.full


12. Children and adolescents


Ascough C et al. (2020) Interventions to treat pain in paediatric CFS/ME: a systematic review. *BMJ Paediatrics Open* 4 (1). Link: https://bmjpaedsopen.bmj.com/content/4/1/e000617


Collin SM, et al. (2015) Chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME) is different in children compared to in adults: a study of UK and Dutch clinical cohorts. BMJ Open 5(10): e008830. Link: http://bmjopen.bmj.com/content/5/10/e008830


Crawley E and Sterne JAC. (2009) Association between school absence and physical function in paediatric chronic fatigue syndrome/myalgic encephalopathy. Archives of Disease in Childhood 94(10): 752-756. Link: http://adc.bmj.com/content/94/10/752.info


Harland MR et al. (2019) Paediatric chronic fatigue syndrome patients’ and parents’ perceptions of recovery. BMJ Paediatrics Open 3 (1). Link: https://bmjpaedsopen.bmj.com/content/3/1/e000525


Loades ME et al. (2020) How common are depression and anxiety in adolescents with chronic fatigue syndrome (CFS) and how should we screen for these mental health co-morbidities? A clinical cohort study. *European Child and Adolescent Psychiatry* [Epub ahead of print]. Link: https://pubmed.ncbi.nlm.nih.gov/32964335/

Loades ME et al. (2020) Do adolescents with Chronic Fatigue Syndrome (CFS/ME) and co-morbid anxiety and/or depressive symptoms think differently to those who do not have co-morbid psychopathology? *Journal of Affective Disorders* [Epub ahead of print]. Link: https://www.sciencedirect.com/science/article/pii/S0165032719334561

Loades ME et al. (2020) Sleep Problems in Adolescents With CFS: A Case-Control Study Nested Within a Prospective Clinical Cohort. *Clinical Child Psychology and Psychiatry* [Epub ahead of print]. Link: https://tinyurl.com/ybmsmyvd


Loades ME et al. (2019) Obstacles to recruitment in paediatric studies focusing on mental health in a physical health context: the experiences of clinical gatekeepers in an observational cohort study. *BMC Medical Research Methodology* 19: 89. Link:


Neale FK et al. (2019) Illness duration, mood and symptom impact in adolescents with chronic fatigue syndrome/myalgic encephalomyelitis? Archives of Disease in Childhood 105 (9): 911-912. Link: https://adc.bmj.com/content/early/2019/06/13/archdischild-2018-316720.long


Norris T et al. (2017) Natural course of chronic fatigue syndrome/myalgic encephalomyelitis in adolescents. Archive of Diseases in Childhood doi: 10.1136/archdischild-2016-311198. Link: http://adc.bmj.com/content/early/2017/01/19/archdischild-2016-311198


Solomon-Moore E et al. (2019) Physical activity patterns among children and adolescents with mild-to-moderate chronic fatigue syndrome/myalgic encephalomyelitis. BMJ Paediatrics Open 3 (1). Link: https://bmjpaedsopen.bmj.com/content/3/1/e000425


BioPsychoSocial Medicine 7: 5. Link: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3570350/


13. Government Documents

13.1 Disability support


13.2 Economic cost to the UK


13.3 General reports, debates, and statements

All-Party Parliamentary Group on ME. (2020) Inaugural meeting to re-establish APPG led by Carol Monaghan MP with Dr Charles Shepherd and the MEA providing secretariat. Link: https://www.meassociation.org.uk/2020/01/the-all-party-parliamentary-group-on-me-to-re-convene-please-invite-your-mp-to-attend-09-january-2020/


House of Commons (2013) Debate. 11 February col. 517W. Secretary of State re: ME/CFS WHO classification. Link: https://publications.parliament.uk/pa/cm201213/cmhansrd/cm130211/text/130211w0003.htm#13021150000045


14. Healthcare


**The ME Association: Please support our vital work**

We are a national charity working hard to make the UK a better place for people whose lives have been devastated by an often-misunderstood neurological disease.

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