Index of ME/CFS Published Research
An A-Z index of the most important published research
Forward

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 31st July 2020.

The Index will be updated at the end of each month and made available in the research section of the ME Association website. Each update will be accompanied by a website blog of that month’s published research abstracts to help keep you informed of the latest research developments.

The Index adopts the subject headings used in the ME Association’s authoritative clinical and research guide which provides a current review of current clinical knowledge and research evidence.

The guide 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 2019 edition is still available via Kindle on Amazon. A 2020 edition will be published once the coronavirus lockdown lifts and head office reopens. We are pleased to be able to offer free hard copies to health professionals upon application.

The ME Association are very grateful to Dr Barbara de Barros, Charlotte Stephens, and Russell Fleming, for producing this Index which is proving a very popular and helpful resource.

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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The ME Association: Please support our vital work

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Do you need to talk?
ME Connect is the telephone helpline service of the ME Association. It provides information and support for people with ME and those who live with or care for them.
ME Connect provides a safe and understanding environment for people with ME so that they know they are being heard and understood.

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Please note: Research published after January 2019 (the date of the last update to the MEA Clinical and Research Guide or ‘Purple Book’) is highlighted in purple in the listing below. We will be publishing a 2020 edition of the Guide later in the year once the coronavirus lockdown lifts and head office reopens.

1. Nomenclature and definition


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](https://bmjopen.bmj.com/content/4/2/e003973)


2. Epidemiology


3. Co-morbidity


4. Biomedical Research

4.1 Biobank UK ME/CFS


4.2 Biomarker Landscape Project


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](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 Pratise* [Epub ahead or print]. Link: [https://www.sciencedirect.com/science/article/pii/S2467981X20300044](https://www.sciencedirect.com/science/article/pii/S2467981X20300044)


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/y2cqzgfc


4.6 Gene expression


**Grabowska A et al.** (2020) Review of the Quality Control Checks Performed by Current Genome-Wide and Targeted-Genome Association Studies on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Frontiers in Pediatrics* 8: 293. Link: [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7304330/?fbclid=IwAR2zEL0iL6uAW1y9oXu6fPoK60mBLRL707wLBgFySpaMhYb8Qm8UcZhm5eU](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7304330/?fbclid=IwAR2zEL0iL6uAW1y9oXu6fPoK60mBLRL707wLBgFySpaMhYb8Qm8UcZhm5eU)


### 4.6.1 Epigenetics


### 4.7 General reviews


**Lubet S and Tuller D** (2020) The Concept of 'Illness Without Disease' Impedes Understanding of Chronic Fatigue Syndrome: A Response to Sharpe and Greco. *Medical Humanities* [Epub ahead of print]. Link: https://tinyurl.com/ybl998as


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)


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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


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](https://content.iospress.com/articles/work/wor203169)

Li H, et al. (2014) Autoimmune Basis for Postural Tachycardia Syndrome. *Journal of the American Heart Association* 3: e000755. Link: [http://jahapublications.org/content/3/1/e000755](http://jahapublications.org/content/3/1/e000755)


### 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)


### 4.24 Post-mortem research


4.25 Sleep disturbance


4.26 Vision


5. Psychiatry and psychology


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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](https://tinyurl.com/yype9zu8)


6. Sociology


Cuesta A et al. (2019) Fibromyalgia, Chronic Fatigue Syndrome, and Multiple Chemical Sensitivity: Illness Experiences. *Clinical Nursing Research* [Epub ahead of print]. Link: [https://tinyurl.com/y68aa9ak](https://tinyurl.com/y68aa9ak)


Murray R et al. (2019) Duvet woman versus action man: the gendered aetiology of Chronic Fatigue Syndrome according to English newspapers. Feminist Media Studies. Link: https://tinyurl.com/yyfayo7v


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.iospress.com/articles/work/wor203177


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)


Baos S, et al. (2018) Investigating the effectiveness and cost-effectiveness of FITNET-NHS (Fatigue In Teenagers on the interNET in the NHS) compared to Activity Management to treat paediatric chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME): protocol for a


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9.2 Complementary and alternative therapies


9.3 Diet and nutrition


9.4 Exercise, Pacing and activity management


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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](https://content.iospress.com/articles/work/ wor203174)


9.5 General management


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


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


Campen CL et al. (2019) Open Trial of Vitamin B12 Nasal Drops in Adults With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Comparison of Responders and Non-Responders. *Frontiers in Pharmacology* [Epub ahead of print]. Link: [https://tinyurl.com/ugd8om5](https://tinyurl.com/ugd8om5)


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


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](https://bmjpaedsopen.bmj.com/content/4/1/e000617)


Brigden A, et al. (2018) Using the internet to cope with chronic fatigue syndrome/myalgic encephalomyelitis in adolescence: a qualitative study. *BMJ Paediatrics Open* 2 (1). Link: [https://bmjpaedsopen.bmj.com/content/2/1/e000299](https://bmjpaedsopen.bmj.com/content/2/1/e000299)


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


Haig-Ferguson A, *et al.* (2009) Memory and attention problems in children with chronic fatigue syndrome or myalgic encephalopathy. *Archives of Disease in Childhood* 94(10): 757-762. Link: [http://adc.bmj.com/content/94/10/757.info](http://adc.bmj.com/content/94/10/757.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](https://bmjpaedsopen.bmj.com/content/3/1/e000525)


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


Neale FK et al. (2019) Illness duration, mood and symptom impact in adolescents with chronic fatigue syndrome/myalgic encephalomyelitis? Archives of Disease in Childhood [Epub ahead of print]. 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


**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/


14. Healthcare


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