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 31st August 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 clinical and research guide which provides a review of current clinical knowledge and research evidence.

This authoritative and popular 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 2020 edition has now been published and is available to order from the website shop. 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.

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

Just click the image opposite or visit our JustGiving page for one-off donations or to establish a regular payment. You can even establish your own fundraising event.

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 in the UK today!


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**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

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


4.4 Exercise physiology/testing


Davenport T et al. (2020) Properties of measurements obtained during cardiopulmonary exercise testing in individuals with myalgic encephalomyelitis/chronic fatigue syndrome. *Work* [Epub ahead of print]. Link: [https://content.iospress.com/articles/work/wor203170](https://content.iospress.com/articles/work/wor203170)


### 4.5 Gastrointestinal and microbiome


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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/y2cqyzzf


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=IwAR2zEL0iL6uAW1y9oXu6fP0k60mBLRL707wLBgFySpaMhYb8Qm8UcZhm5eU


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](https://tinyurl.com/ybl998as)


Maxmen A. (2018) A reboot for chronic fatigue syndrome research. *Nature* 553 (7686): 14-17. Link: [https://www.nature.com/articles/d41586-017-08965-0](https://www.nature.com/articles/d41586-017-08965-0)


4.8 Genetic predisposition


4.9 Immunology


Dibnah B et al. (2019) Investigating the role of TGF-B and fatigue in Chronic Fatigue Syndrome. *Annals of the Rheumatic Diseases* 78 (2). Link: [https://ard.bmj.com/content/78/Suppl_2/1495.2.abstract](https://ard.bmj.com/content/78/Suppl_2/1495.2.abstract)


Hornig M, et al. (2015) Distinct plasma immune signatures in ME/CFS are present early in the course of illness. *Science Advances* 1(1): e1400121. Link: [http://advances.sciencemag.org/content/1/1/e1400121](http://advances.sciencemag.org/content/1/1/e1400121)


Lande A et al. (2020) Human Leukocyte Antigen alleles associated with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). *Scientific Reports* 10: 5267. Link: [https://www.nature.com/articles/s41598-020-62157-x](https://www.nature.com/articles/s41598-020-62157-x)


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


van Kuppeveld FJM and van der Meer JWM. (2012) XMRV and CFS - the sad end of a story. The Lancet 379(9814): e27-e28. Link:
http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60899-4/fulltext


4.11 Ion channels


4.12 Metabolomics


Yamano E, et al. (2016) Index markers of chronic fatigue syndrome with dysfunction of TCA and urea cycles. Science Reports doi: 10.1038/srep4990. Link: https://www.nature.com/articles/srep34990

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


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


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.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)


Malik S et al. (2020) Cognitive–behavioural therapy combined with music therapy for chronic fatigue following Epstein-Barr virus infection in adolescents: a feasibility study. *BMJ Paediatrics Open* 4 (1). Link: [https://bmjpaedsopen.bmj.com/content/4/1/e000620.abstract](https://bmjpaedsopen.bmj.com/content/4/1/e000620.abstract)


9.2 Complementary and alternative therapies


9.3 Diet and nutrition


9.4 Exercise, Pacing and activity management


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


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](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)


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


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


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 comorbid anxiety and/or depressive symptoms think differently to those who do not have comorbid 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


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


### 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/](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](https://publications.parliament.uk/pa/cm201213/cmhansrd/cm130211/text/130211w0003.htm#13021150000045)

**House of Commons (2013).** Written evidence to Health Select Committee from the ME Association. Link: [https://publications.parliament.uk/pa/cm201415/cmselecm/cmhealth/401/401vw11.htm](https://publications.parliament.uk/pa/cm201415/cmselecm/cmhealth/401/401vw11.htm)


14. Healthcare


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