



# FAQs: Frequently Asked Questions from ME Essential Magazine Summer 2019

You can use the following list to find answers from Dr Charles Shepherd and our other experts on various topics given in ME Essential – the ME Association’s members magazine. If you don’t have the back-copy of the magazine, please contact head office.

## **5-HTP supplements (Winter 2019)**

Acne treatment and ME, including Roaccutane (Autumn 2011)

Activity management - gym based programme (Autumn 2009)

Acyclovir and oral herpes (Summer 2012)

Addison’s disease (Winter 2009)

Adrenal gland function – short synacthen test (Autumn 2012)

Aids and adaptations (Autumn 2012)

## **ALCOHOL**

- Alcohol intolerance (October 2007)
- Alcohol intolerance - what is the cause? (Spring 2012, p15)

Allergies (Autumn 2014)

Allodynia (Summer 2015)

Amantadine (Summer 2016)

## **AMITRIPTYLINE**

- Amitriptyline (Summer 2010)
- Amitriptyline for headaches (Spring 2011)
- Amitriptyline for pain and sleep (Spring 2016)

Ampligen – and FDA decision to not approve use in USA (Summer 2013)

ANA (anti-nuclear antibody) test and ME/CFS (Winter 2017)

## **ANAEMIA**

- Anaemia (Summer 2018)
- Anaemia – iron deficiency (Autumn 2009)

Animal testing (Winter 2009)

Antibiotics – are they safe for people with ME/CFS? (April 2008)

Antibiotics – MEA website info (Autumn 2018)

Antidepressants – withdrawal symptoms (Spring 2014)

Antidepressants – safe in ME/CFS? (Summer 2015)

Anxiety and panic attacks – are they part of ME/CFS? (Autumn 2018)

## **APPETITE**

- Appetite – change in (Summer 2012)
- Appetite – loss of (Summer 2016)

APPG on ME – information to give to MPs (February 2013)

Asthma and ME/CFS overlap (Winter 2016)

Autism (Winter 2013)

Balance problems (Spring 2016)

Beetroot juice – can it boost energy levels? (Summer 2016)

## **BENEFITS**

- Carer's credits (Autumn 2011)
- ESA appeals (Winter 2010 and Autumn 2011)
- ESA – is the situation getting any better? (Spring 2015)
- ESA – preparation for medical assessment (Autumn 2016)
- Fit notes – what is a fit note (Summer 2014)
- Industrial Injury Benefit (Winter 2010, p13)
- Maximus taking over the DWP contract from Atos (Summer 2015)
- Medical Assessments: at home (Spring 2005)
- Medical Assessments: permission to record (Summer 2012, p19 and Autumn 2018)
- PIP: Can I still work and claim PIP? (Winter 2019)
- PIP Tribunal advice (Autumn 2015) advice
- PIP Appeal (Summer 2018)
- Sickness certificates from a GP (Spring 2011)

- Supportive medical evidence – what can the doctor do? (Autumn 2013)
- Test results – is it worth including them on an ESA application? (Summer 2014)
- Tribunal – attending one (Summer 2012, p14)
- Tribunal for PIP (Autumn 2015)

Beta blockers (April 2007)

## **BIOBANK**

- Donations of blood samples (Spring 2011)
- Immune system research at (Autumn 2017)

Blepharospasm – eyelid twitching (Summer 2013)

## **BLOOD**

- Blood donation and ME/CFS - can I give blood? (April 2008)
- Blood pressure – high/hypertension (Winter 2013)
- CRP and ESR (Winter 2015)

Blue Badge problems (April 2008)

Blue Badge refusals (Spring 2012, p15)

Body piercing - hazards of (Winter 2010, p12)

Book list (Autumn 2011)

Burrswood Hospital – What happens there? (Winter 2014, p8)

Burrswood Hospital – in patient care (Spring 2016)

Caffeine – how much is safe? (Spring 2014)

Care homes for people with severe ME/CFS (Spring 2019)

Caring for son with severe ME/CFS (Autumn 2017)

Carer's credits (Autumn 2011)

Cavity wall insulation (Winter 2012)

Changing a GP (Summer 2010, p8)

Chocolate (January 08)

Chronic fatigue (Summer 2019)

### **CLASSIFICATION**

- Classification of ME/CFS (Winter 2012)
- Classification: Illness or Disease? (Summer 2012, p15)
- Classification: Is ME a neurological disease? (Spring 2018)

Clinical trials – how do they work (Summer 2013)

### **COELIAC DISEASE**

- Coeliac disease (April 2006)
- Coeliac disease - home testing kits (January 2008)
- Coeliac disease and wheat intolerance (Winter 2010)
- Coeliac disease/gluten free diet (Summer 2015)

Coenzyme Q10 – Does it work? (Winter 2014)

Coffee drinking – how much is safe? (Spring 2014/p128)

Cognitive dysfunction – severe (Winter 2013)

Cognitive dysfunction – deteriorating (Spring 2014/p128)

Cold fingers and toes (Spring 2010)

Cold sores – treatment (Winter 2016)

Colds and a cough that won't go away (Spring 2016)

### **CONTAGIOUS**

- Can ME/CFS be passed to other family members? (July 2008)

Contraception choices in ME/CFS (Spring 2015)

Coughs and colds in winter – that won't go away (Spring 2016)

Cortisol - investigating low levels (November 2008)

Creatine kinase blood test (Winter 2010, p14)

Creatine supplements (April 2006)

Critical Illness Insurance (Autumn 2009)

CRP blood test (Winter 2015)

Curcumin for fatigue (Summer 2011)

Curcumin and turmeric (Summer 2017)

Cyclophosphamide clinical trial in Norway (Spring 2018)

#### **DENTAL**

- Dental anaesthetics (Spring 2010)
- Dental amalgam filling removal (Autumn 2015)

#### **DEPRESSION**

- Depression (February 2013)
- Depression or low mood? (Autumn 2017)
- Depression and ME/CFS (Spring 2018)

Deterioration in symptoms (Summer 2018)

#### **DIABETES**

- Diabetes (Winter 2013)
- Diabetes type 2 – is it more common in ME/CFS? (Summer 2016)
- Diabetes and ME/CFS (Summer 2018)

Diagnosis - is it correct? (July 2008)

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## **DIET**

- Dietary management of irritable bowel syndrome – Sue Luscombe (Winter 2015)
- Dietitians and nutritionists – what are the differences? (Summer 2017)
- Are very restrictive diets safe? (Autumn 2018)
- Ketogenic diet: Is it worth trying? (Winter 2019)

## **DISABILITY**

- Disability Discrimination Act (April 2007)
- Disability aids and adaptations (Autumn 2012 and Summer 2013)
- Disabled Facilities Grant (Summer 2013)
- Disability leave – what is it? (Autumn 2013)
- Disability rating scale (Autumn 2013)
- Disabled students allowance (Winter 2009)

Dorsal root ganglionitis (Autumn 2012)

## **DRIVING**

- Can I drive with ME/CFS? (February 2009)
- Driving a car with ME/CFS (Autumn 2013)
- DVLA guidance (Autumn 2013)
- Have you been advised to stop driving? ([April 2018 MEA Facebook](#))

## **DRUG AND TESTING NOTES**

- Hydrogen sulphide urine test (August 2009)
- Melatonin (as Circadin) becomes available on NHS prescription (July 2008)
- Valganciclovir - meeting with Roche Pharmaceuticals (November 2008)

## **DRUGS**

- including statins, that can cause muscle problems (November 2008)
- for ME/CFS that can cause weight gain (Spring 2018)
- that may exacerbate ME/CFS (October 2018)

Dry eyes (Autumn 2009) plus MEA website information (October 2018)

Dysphagia (Winter 2016)

Education of health professionals – update on initiatives (Spring 2019)

EPA/Eicosapentaenoic acid (Winter 2014, p9)

## **EMPLOYMENT**

- Employment problems (Autumn 2005)
- Employment: gradual return to work (Winter 2009)
- Employment: ill health retirement criteria (Spring 2011)
- Employment: should I tell my employer that I have ME/CFS (Spring 2011)
- Employment: sickness certificates from a GP (Spring 2011)

Endometriosis (July 2007)

Ehlers-Danlos syndrome (Spring 2011)

Epidemiology - how many people have ME/CFS (Winter 2012)

Epileptic type seizures in ME/CFS (Spring 2012)

ESR blood test (Spring 2010 and Winter 2015)

Examination findings – why don't doctors examine patients anymore? (Autumn 2015)

## **EXERCISE**

Exercise testing – Vo2 max test ((Autumn 2014)

Eyelid twitching - blepharospasm (Summer 2013)

Fainting episodes (Autumn 2017)

Fasciculations (Summer 2015)

Fatigue levels increasing – explanations for (February 2013)

Faecal microbiota transplants (Autumn 2017)

Fertility (February 2009)

Fingerprint loss as a diagnostic marker (Winter 2019)

Fit notes (Summer 2014)

Fingerprint loss as a diagnostic marker (Winter 2019)

## **FUNCTIONAL**

- Functional neurological syndrome (Winter 2015)

Gabapentin for pain (Autumn 2012)

Gabapentin and pregabalin – new prescribing controls (Summer 2019)

Gastric distress/motility problems (Winter 2009)

### **GENERAL PRACTICE**

- GPs – Home Visits (Winter 2014, p9 and Autumn 2016)
- GPs – Unhelpful: what to do? (Jan 2008)
- GPs – Changing to another one (Summer 2010)
- GP – Refusing to make a hospital referral (Spring 2017)
- GP Management – what can a GP do? (Winter 2017)

Gilbert's syndrome (February 2013)

Ginseng (Spring 2016)

Gluten free diet (Summer 2015)

Good days and bad days (Summer 2009)

Gum disease and mouth ulcers (Autumn 2018)

Hair problems (Winter 2012)

### **HEADACHES**

- Headaches (Winter 2009, p15)
- Headaches – getting worse (Spring 2014)
- Headaches - use of amitriptyline (Spring 2011)
- Headaches – use of tinted glasses (February 2013)

Health Care Plan – setting one up (Summer 2017)

Haemochromatosis - misdiagnosis (July 2008)

Heat sensitivity (July 2007)

Heel pain/plantar fasciitis (Spring 2017)

Herpes and acyclovir (Summer 2012, p14)

### **HIV/AIDS**

- HIV/AIDS - as part of the differential diagnosis (Spring 2011)
- HIV testing and ME/CFS (Winter 2017)



Home visits by GPs (Winter 2014, p9 and Autumn 2016)

Hospital services (February 2009)

Housing – rehousing on medical grounds (Autumn 2014)

HRT – what are the alternatives? (Summer 2015)

Hydrotherapy (Spring 2017)

Hyperacusis/sensitivity to loud noise (November 2008 and Autumn 2016)

Hyperbaric oxygen therapy (Spring 2015)

### **HYPERMOBILITY**

– Hypermobility syndromes (Spring 2011; Spring 2012, and Winter 2013)

Hypertension (Winter 2013)

Hypoglycaemia (Autumn 2016)

Hypnosis for sleep disturbance (Summer 2014)

Hypnotherapy (Summer 2012, p15)

Hypothalamic function (Spring 05 and Autumn 2011)

Hypothyroidism (Spring 2014)

Ill health retirement (Spring 2011)

### **IMMUNE SYSTEM**

– Immune system – overactivity (Summer 2012, p15)

– Immune system research at the Biobank (Autumn 2017)

– Immune dysfunction in ME/CFS – tests, treatment (Autumn 2013)

Immunoglobulin treatment for chronic pain (Spring 2011)

Inherited - can ME/CFS be passed on to other family members? (October 07, p13)

Industrial Injury Benefit (Winter 2010, p13)

## **INSURANCE**

- Critical illness cover (Autumn 2009 and Winter 2017)
- Income protection policies and active rehabilitation (Winter 2017)
- Life insurance (Winter 2012 and Winter 2014)
- PHI disputes (April 2008)
- XMRV problems (Summer 2010)

Interstitial cystitis (Spring 2019)

Iron supplements - can they improve fatigue levels? (Spring 2012)

## **IRRITABLE BOWEL**

- Irritable bowel syndrome – dietary management – Sue Luscombe (Winter 2015)
- Irritable bowel syndrome of IBD? (Winter 2016)
- IBS symptoms getting worse (Spring 2019)

Isoprinosine/Imunovir (January 2006)

Itching and fatigue (November 2008)

Itchy skin/eczema (Summer 2018)

Jaundice (February 2013)

Jaw pain (Winter 2017) Joint hypermobility – see hypermobile joints

Joint pains (Autumn 2009)

Joint pain in ME/CFS – could it be RA? (Spring 2017)

Jury service (Summer 2015)

Ketogenic diet: Is it worth trying? (Winter 2019)

Life expectancy (Summer 2016)

Life insurance – why is it difficult to obtain? (Winter 2014)

Lightning Process (Summer 2010)

Liver function tests (July 2006)

Low mood or depression (Autumn 2017)

Lumbar puncture (October 2007)

Lustral/sertraline (Autumn 2012)

### **LYME DISEASE**

- Lyme disease – symptoms and investigation of (Winter 2017)

Lyrica/pregabalin (Spring 2010)

Magnesium (Spring 2010)

Marshall protocol (Summer 2011)

Mast cell disease (Summer 2017)

Maximus – DWP benefit assessments (Summer 2015)

### **M.E.**

- encephalopathy or encephalomyelitis? (Autumn 2018)
- neuroinflammation and encephalomyelitis (Spring 2017)

### **ME ASSOCIATION**

- Paying for MEA literature (Winter 2010, p13)

Medical Research Council – why are they so reluctant to fund biomedical research into ME/CFS? (July 2008)

Medicines and drugs – cautions when buying on-line (Spring 2012)

Melatonin (Spring 2005)

Memory and concentration problems (Summer 2009)

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## **MENOPAUSE**

- Menopause, HRT etc. (January 2008, p13)
- Menopause – vaginal dryness/pain (Spring 2010)
- Menopause – alternatives to HRT (Summer 2015)

Menstrual exacerbation of symptoms (Winter 2013)

Mercury (dental) filling removal (Autumn 2015)

Metabolomics – explanation (Summer 2018)

Methyphenidate/Ritalin (July 2007)

Microbiota – faecal transplants (Autumn 2017)

Mitochondria – what do they do? (Summer 2013)

Mouth ulcers (Summer 2009 and Autumn 2012)

MRI brain scan – adverse effects? (Winter 2016)

MS (multiple sclerosis) or ME/CFS? (Autumn 2015)

MUS = medically unexplained symptoms (Summer 2017)

## **MUSCLE**

- Muscle cramp (Summer 2017)
- Muscle symptoms (Winter 2010 - p11)
- Muscle twitchings (Summer 2015)
- Muscle: creatine kinase blood test (Winter 2010, p14)

Myoclonus (Autumn 2016)

Naltrexone (Autumn 2009 and Winter 2012)

Nausea (Summer 2013)

## **NEUROINFLAMMATION**

- Neuroinflammation – what does it mean (Spring 2017)

Neurologist attitude to ME/CFS (Winter 2015)

Neurological classification – Is ME/CFs a neurological disease (Spring 2018)

Neuropathic pain (Winter 2015)

NHS clinics – self referral (Autumn 2014)

NHS clinics – what happens when you visit one? (Winter 2016)

NHS Continuing Care Plan (Summer 2014)

### **NATIONAL INSTITUTE HEALTH AND CARE EXCELLENCE (NICE)**

- NICE guidelines and doctor's freedom to prescribe (Summer 2010)
- NICE guideline – does my doctor have to follow the recommendations? (Spring 2018)

Night sweats (Spring 2014)

Nimodipine - is this drug a new treatment for ME/CFS? (April 2008)

Nimodipine – why won't my doctor prescribe this drug? (Summer 2013)

Nomenclature: SEID (Autumn 2015)

Nomenclature: ME and CFS – why does MEA also use CFS? (Spring 2016)

Nutritional assessment and support (Summer 2019)

Nutritionists and dietitians – what is the difference? (Summer 2017)

Ovarian cancer - part of the differential diagnosis (Summer 2011)

Overseas medical treatment and problems with entitlement to NHS care (November 2008)

Overweight – can it affect the underlying disease process (Summer 2014)

### **OXYGEN**

- Oxygen – low levels in relation to ME/CFS (Summer 2018)
- Oxygen therapy (Winter 2010, p12)
- Oxygen therapy – oxygen concentrators (Summer 2012)
- Oxygen therapy – hyperbaric oxygen (Spring 2015)

Ovarian cancer, fatigue and IBS (Spring 2014 and Summer 2015)

PACE trial and inclusion of ME sub-group (Summer 2012)

## **PAIN AND PAIN RELIEF**

- Allodynia (Summer 2015)
- Neuropathic pain (Winter 2015)
- See also: Gabapentin, Immunoglobulin, Pregabalin/Lyrica and TENS machine

Safety of over-the counter preparations (Spring 2012)

Palpitations (Summer 2010)

Paraesthesiae (Autumn 2016)

PHI/Permanent Health Insurance payment disputes (April 2008)

Plantar fasciitis (Spring 2017)

Pleconaril (Autumn 2005)

Polymyalgia (Summer 2018)

## **POST-MORTEM RESEARCH**

- Dorsal root ganglionitis (Autumn 2012)
- Post-mortem research - what to do if you want to leave your body to ME research (November 2008 and Spring 2010)
- Still being able to donate other body parts (Spring 2011)
- How much tissue is required (February 2013)

## **POST-VIRAL FATIGUE SYNDROME (PVFS)**

- Post-viral fatigue syndrome - what is it (Spring 2011)
- PVFS – preventing it turning into ME/CFS (June 2017)

Pneumococcal vaccine (Summer 2019)

Pregabalin/Lyrica for pain relief (February 2010)

Probiotics (Autumn 2016)

Pruritis (Summer 2018)

Quinolones and fluroquinolones (Autumn 2018)

Rehousing on medical grounds (Autumn 2014)

Relapse after years of good health (Winter 2014)

## **RESEARCH**

- Research - volunteering for (Summer 2009 and Winter 2015)
- Research funding to NHS clinic - UK vs USA (Spring 2012)
- UK ME/CFS Research Collaborative (Summer 2013)

Restless legs syndrome (Spring 2011)

Roaccutane for acne (Autumn 2011)

Ribose - is it an effective supplement? (July 2008)

## **RITUXIMAB**

- Rituximab – clinical trials (Summer 2013)
- Rituximab – obtaining on NHS (Winter 2013 and Summer 2014)
- Rituximab update (Autumn 2015)
- Rituximab – When will a UK trial start? (Winter 2016)
- Rituximab – Update on clinical trials (Spring 2019)

Selenium (Summer 2016)

Sertraline/Lustral (Autumn 2012)

SEID – name change (Autumn 2015)

## **SERVICES CLINICAL**

- Burrswood Hospital – What happens there? (Winter 2014)
- Cuts to NHS services for ME/CFS (Autumn 2011)
- How to try and set an NHS clinic up post NICE (January 2008)
- Long NHS Waiting lists (Winter 2010)
- Refusal to refer (Spring 2012)
- Self-referral to NHS clinics (Autumn 2014)

## **SEVERE ME/CFS**

- Severe ME/CFS – care homes for (Spring 2019)
- Severe ME/CFS – caring for son who has severe ME/CFS (Autumn 2017)
- Severe ME/CFS – Nutritional assessment and support (Summer 2019)

Shingles vaccine (Winter 2013)

Sickness – nausea (Summer 2013)

Skin irritation (Summer 2018)

Skin rashes (Winter 2019)

## **SLEEP**

- Hypnosis for sleep disturbance (Summer 2014)
- Research into sleep disturbance (February 2013)
- Restless legs syndrome (Spring 2011)
- Sleepiness during the day (April 2007)
- Sleep paralysis (Spring 2015)

Sodium oxybate (Summer 2012)

Social care assessments (Spring 2011)

Sodium oxybate for sleep (Summer 2012)

Sore throat remedies (Summer 2014)

SPECT scans (Summer 2010)

Statins and muscle problems (November 2008)

## **STEROIDS**

- Steroids (Summer 2009)
- Steroid treatment – is it safe? (Spring 2015)
- Steroids – high dose as a treatment for ME/CFS? (Autumn 2017)

Stress and ME/CFS (Summer 2017)

Supplements – money down the drain? (Spring 2017)

Sweating – night sweats (Spring 2014)

Swallowing problems (Winter 2016)

Swollen hands and feet (Summer 2017)

Symptom deterioration (Summer 2018)

Synacthen test for adrenal function (Autumn 2012)

## **TEENAGERS**

- consent, confidentiality and child protection issues (Autumn 2018)

Temperomandibular jaw dysfunction and jaw pain (Winter 2017)



TENS machine (Winter 2009, p112)

Test for ME (February 2009)

Throat and voice symptoms (Winter 2010)

### **THYROID**

- Thyroid function and ME (Spring 2009 and Spring 2014)
- Thyroid function tests (Winter 2013 and Winter 2014)
- Thyroid function tests – regular monitoring (Summer 2011)

Tinnitus (Summer 2019)

Tinted glasses for headaches (February 2013)

Tonsils removal (October 07)

Trauma: Can it trigger ME/CFS? (Winter 2019)

Travel sickness (Summer 2006)

### **TREMOR**

- Tremor in the hands (Autumn 2011)
- Tremor in ME/CS (Spring 2018)

Turmeric and curcumin (Summer 2017)

Vaccinations (Autumn 2012)

Valganciclovir (October 2007 and Autumn 2011)

Vegetarians and anaemia (Autumn 2009)

### **VITAMINS**

- Vitamin B12 injections (October 2006, and Winter 2015)
- Vitamin B12 testing (Summer 2011)
- Vitamin C - high dose (Summer 2009)
- Vitamin D deficiency and sunlight (Spring 2014)

VO2 max exercise test (Autumn 2014)

Volunteering for research studies (Winter 2015)

## WEIGHT

- Weight gain and how to lose weight (October 2007)
- Weight gain and underlying disease process (Summer 2014)
- Weight gain and weight loss (Sue Luscombe – Autumn 2015)
- Weight gain caused by drugs (Spring 2018)
- Weight loss (Spring 2015)

Wheat intolerance (Winter 2010)

## XMRV and MLVs

- XMRV - patient selection/criteria for research trials (February 2010)
- XMRV - and insurance (Summer 2010)

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