

Survey Treatments: POSITIVE RESULTS 2007-11

Participants: 53

(Those marked with an asterisk denote special cautions from the feedback of participants. These cautions can be found towards the end of this survey and also under the 'Treatments with Negative Comments' section. The numbers in red brackets show how many people out of the 53 participants have been helped by that drug/supplement etc. Not all the 53 participants have tried all these listed treatments.) If a treatment has no indication as to if it's available on the NHS or privately, that is because the patient didn't tell us how they obtained it.*

Disclaimer: whilst we hope that the following information will be helpful, the Grace Charity for M.E. doesn't accept responsibility for any treatments, therapies etc. found in this survey because the feedback has been anecdotal.

Acidophillus (probiotic) (1 person or 1.9% of participants) *Mostly private purchase but can be prescribed on the NHS.* Helped with digestion and immune system.

Acupressure (similar to acupuncture but using pressure points and not needles) (1 person or 1.9% of participants) Not specific in how it helped this person.

Acupuncture (ancient Chinese treatment restoring energies, using needles to stimulate energy) (5 people or 9.4% of participants) *Mainly private treatment although can be prescribed on the NHS, especially for pain symptoms.* Gave a patient more energy and helped her sleep better. Eased a patient's pain and helped her breathing. Helped digestive problems and pain.

Adrenal glandulars (contains the hormone cortisone) (1 person or 1.9% of participants) Not specific in how it helped this person.

Alexander technique (posture control) (1 person or 1.9% of participants) Not specific in how it helped this person.

Almotriptan (Axert) (5HT1 agonist: these drugs narrow dilated blood vessels) (1 person or 1.9% of participants) Helped with migraines.

***Alpha-interferon injections** (antiviral drug) (1 person or 1.9% of participants) *Initially prescribed on the NHS but now might be difficult to obtain.* Helped a sufferer make a full recovery from being paralysed and bedridden. It helped this suffer twice in her life, each time bringing her back to a full recovery. Cured post-exertional malaise.

Amino Acids

***L-Carnitine** (amino acid supplement) (5 people or 9.4% of participants) *Privately purchased.* Helped improve muscle strength and energy of mitochondria. Helped improve sleep, energy levels and stamina. Helped a patient to walk further with stronger leg muscles.

L-Glutamine (amino acid supplement) (1 person or 1.9% of participants) Helped to clear brain fog.

Phenylalanine (essential amino acid) (1 person or 1.9% of participants) Not specific in how it helped this person.

Taurine (amino acid) (1 person or 1.9% of participants) Not specific in how it helped this person.

***Antibiotics** (e.g. for Lyme Disease or arthritis associated with M.E.)

Doxycycline

(1 person or 1.9% of participants) *Antibiotics prescribed for these conditions were given privately by Dr. A. Wright in Bolton.* Not specific in how it helped this patient.

Anticonvulsant drugs, e.g. (see also medicines under Painkillers heading).

*Clonazepam (anticonvulsant drug) (1 person or 1.9% of participants) Not specific in how it helped this person.

*Gabapentin (anticonvulsant drug, also used for neuropathic pain) (5 people or 9.4% of participants) *NHS and private treatment.* Gave a patient more energy and helped her to sleep. Helped with nerve pain. Given to help OI (Orthostatic Intolerance), migraine, vertigo, falls.

Pregabalin (anticonvulsant drug and treatment for neuropathic pain) (1 person or 1.9% of participants) *Available on NHS.* Helped with nerve pain.

Tegretol (anticonvulsant drug) (1 person or 1.9% of participants) Not specific in how it helped this person.

*Topamax (anticonvulsant drug) (1 person or 1.9% of participants) Helped a patient to sleep better.

Antidepressants

*Amitriptyline (antidepressant) (6 people or 11.3 % of participants) *NHS and private treatment.* Used mainly in small doses for sleep, not in usual higher doses for depression. Helped a sufferer have a better sleeping pattern with refreshing sleep. Helped decrease night waking times. Helped someone to sleep and relax. 'Righted awful sleeping pattern of only 2-3 hours to 7-8 hours. Went into stage 4 sleep.'

Dosulipen (antidepressant) (1 person or 1.9% of participants) Helped with sleep. *NHS prescription.*

*Cymbalta (antidepressant) (2 people or 3.8% of participants) for fibromyalgia and M.E. Helped with pain.

Prozac (antidepressant) (1 person or 1.9% of participants) Helped a sufferer to not get too despondent.

Anti-histamines (e.g. Ranitidine, Desloratadine) (3 people or 5.7% of participants) *Private and NHS treatment.* Improved a patient's sleep. Desloratadine helped with allergies. One patient (who said that his health improved after taking Ranitidine), said that his M.E. started after an untreated bout of shingles.

Promethazine (an antihistamine and anti-sickness drug) (1 person or 1.9% of participants) Not specific how it helped this person.

***Aromatherapy** (3 people or 5.7% of participants) General gradual improvement

Autogenic Training (relaxation and meditative technique) (1 person or 1.9% of participants) Not specific in how it helped this person.

Audio CDs/Books (for insomnia) (2 people or 3.8% of participants) Helped with insomnia.

Bach flower remedies (1 person or 1.9% of participants) Invaluable for emotions, said a sufferer.

Biocare B6 (supplement) (1 person or 1.9% of participants) Helped clear brain fog.

Bisoprolol (beta blocker) (1 person or 1.9% of participants) Not specific how it helped this person.

Calcium (1 person or 1.9% of participants) Not specific how it helped this person.

Caprellic Acid (from coconuts) (1 person or 1.9% of participants) Not specific how it helped this person.

***CBT** (Cognitive Behavioural Therapy) (4 people or 7.5% of participants) Has made life as normal as possible. Helped a sufferer think differently about her illness. Helped her to deal with the impact of enormous change. Helped a sufferer manage her energy. *(N.B. The Grace Charity for M.E. does not recommend CBT. See reasons below.)*

Christian perspective (1 person or 1.9% of participants) Not specific how it helped this person.

Christian counselling (2 people or 3.8% of participants) Has made a patient more positive and stopped her depression. A great source of strength.

Christian healing (1 person or 1.9% of participants) Not specific how it helped this person.

Chromium (supplement) (1 person or 1.9% of participants) Not specific how it helped this person.

***Co-Enzyme Q10 (supplement)** (7 people or 13.2% of participants) *Private and NHS treatment.* Made patient more resilient to relapses. Helped to improve muscle strength and energy for mitochondria. Helped improve sleep and energy levels.

***D-Ribose (supplement)** (5 people or 9.4% of participants) *Private treatment.* Helped improve muscle strength and muscle energy (mitochondria). Helped improve sleep, energy levels, muscle aches and stamina.

DHEA (hormonal treatment to supplement the adrenal gland) (1 person or 1.9% of participants) Restored a worn-out adrenal gland.

Diet (9 people or 17%) Not always specific: some are an anti-candida diet, yeast and sugar free. Others tried elimination diet. They had more energy, reduced pains and it helped the immune system. One had better success with organic and non-refined foods. One mentioned that protein food at breakfast, lunch and dinner helped to stop her blood sugar dropping so much. Fresh vegetable juice (made from a juicer) helped one person's digestion and bloated feeling. Beetroot juice and carrot juice helped one person's immunity, especially if she had a cold.

Domperidone (anti-sickness drug) (1 person or 1.9% of participants) *NHS prescription.* Controls nausea so patient can eat in mornings.

Enada (N.A.D.H.) (supplement) (2 people or 3.8% of participants) *Private treatment.* Regulated energy levels.

EPD (Enzyme Potentiated Desensitisation) (treatment for allergies) (1 person or 1.9% of participants) Strengthened body.

Essential Fatty Acids

***VegEPA (supplement, includes Essential Fatty Acid)** (5 people or 9.4% of participants) *Private purchase although Evening primrose Oil (similar) can be prescribed on the NHS.* Made patient more resilient to relapses. Helped with long term repair. Improved sleep and energy levels. Made person feel less awful. Helped with brain fog.

Evening Primrose Oil (supplement, Essential Fatty Acid) (3 people or 5.7% of participants) Stopped burning limbs and twitching. One person found the organic form of EPO helped her more.

MorEpa fish Oils (supplement, Essential Fatty Acid) (2 people or 3.8% of participants) *NHS and private treatment.* Improved sleep, mood and mental function. Helped clear brain fog.

Faith Healing (1 person or 1.9% of participants) Not specific how it helped this person.

***Fungilin (anti-fungal drugs) (1 person or 1.9% of participants)** Not specific how it helped this person.

Gastric acid blockers (1 person or 1.9% of participants) Helped gastric pain.

Gatorade drink (A drink made from sodium, potassium and sugar in electrolytic balance) (1 person or 1.9% of participants) Helped with OI (Orthostatic Intolerance), helped vertigo, increasing blood volume.

***Graded Exercise (2 people or 3.8% of participants)** *Prescribed privately and on NHS.* Has made life as normal as possible. Taught a person to manage their illness and limits. *(N.B. The Grace Charity for M.E. does **not** promote Graded Exercise. See reasons below.)*

Green Barley Grass (1 person or 1.9% of participants) *Private prescription.* Helped a patient's symptoms generally.

Herbal Remedies (general comment) (4 people or 7.5% of participants) Helped with pain relief and with balancing hormones. Also with sleep. Gave some respite for a short time only. Helped with digestive problems and pain.

Herb: Ginkgo Bilboa Helped as a fast 'pick-up' for tired brain.

Herb: Organic Ashwagandha powdered root Brilliant tonic for whole body.

Herb: Wild Yam Root Not specific how it helped this patient.

Herb: Red Clover Flowers Not specific how it helped this patient.

Herbal migraine capsules (New Chapter brand): Have helped a sufferer's headaches.

Herbal Teas (2 people or 3.8% of participants) Helped one sufferer to get rid of food intolerances.

Homeopathy (3 people or 5.7% of participants) *Private homeopathic treatment from German homeopathic company Staufen-Pharma.* In particular, homeopathic injections made from Herpes Virus Type 6 cured a patient within 8 weeks of having severe M.E. for over four years. Helped with persistent sore throats.

Humira (antirheumatic drug) (1 person or 1.9% of participants) *Private treatment. Is very expensive.* Helped correct immune dysfunction of a sufferer after these immune problems showed up in specific private tests. Helped with persistent sore throats and swollen glands.

***Imigran (drug for migraine) (1 person or 1.9% of participants)** An M.E. patient has a GP who has given this drug to M.E. sufferers. Usually this drug is prescribed for migraines but it has been administered to M.E. sufferers if they have 'crashed' (i.e. exacerbation of brain and muscle symptoms). The idea behind prescribing it has been to increase blood flow to the brain for the M.E. sufferer even if they're not in pain. There are no known benefits or side-effects from the person giving us this information. *Please contact the Grace Charity for M.E. if you have tried Imigran, especially if you've received either positive or negative benefits from it.*

Kelp tablets (extract of seaweed) (1 person or 1.9% of participants) Not specific how it helped this person.

Kinesiology (a blend of chiropractic and Chinese medicine) (1 person or 1.9% of participants) Not specific how it helped this person.

Life Style Counsel (? I think that this person may have meant Lifestyle Counselling) (1 person or 1.9% of participants) Not specific how it helped this person.

Linseeds (1 person or 1.9% of participants) Not specific how it helped this person.

***Magnesium** (mainly injections) (8 or 15.1% of participants) *Private and NHS treatment.* Made patient more resilient to relapses. Helped improve muscle strength and muscle energy. Helped sleep and energy levels. Helped in early stages to prevent rate of deterioration.

Marma Therapy (a blend of massage, aromatherapy, herbs, oils and yoga) (1 person or 1.9% of participants) Not specific how it helped this person.

***Massage for lymphatic drainage** (4 people or 7.5% of participants) Not specific how it helped these people.

Meditation (1 person or 1.9% of participants) Not specific how it helped this person.

Melatonin (hormonal supplement often used for inducing sleep) (1 person or 1.9% of participants) Not specific how it helped this person.

***Mestinon** (a drug usually given to those suffering from Myasthenia Gravis to improve muscle strength) (1 person or 1.9% of participants) Greatly improved muscle endurance.

***Mickel Therapy**(Mind/body reprogramming) (2 people or 3.8% of participants) Helped in various ways, e.g. with energy, attention to one's feelings.

***Midodrine** (It treats low blood pressure. It is a 'named patient' drug, signed for by a consultant.) (2 people or 3.8% of participants) Treatment for POTS (Postural Orthostatic Tachycardia Syndrome). Helped by being able to be upright in walking and sitting. Boosted energy.

***Miguard** (painkiller) (1 person or 1.9% of participants) Not specific how it helped this person.

Navoban (a 5HT-3/serotonin antagonist drug often used as an anti-sickness drug) (1 person or 1.9% of participants) Boosted energies considerably.

Neutralising Vaccines (for food and chemical sensitivities) (1 person or 1.9% of participants) *Private and NHS treatment from Breakspear Hospital.* Helped to save a woman's life when her weight dropped below a critical level. Helped her to eat normally again, although still with a restricted diet.

***Nimodipine (a calcium channel blocker)** (1 person or 1.9% of participants) Has taken a patient from being housebound to being 50% well.

Nutrients (via I.V.) (1 person or 1.9% of participants) Not specific how it helped this person.

Nystan (anti-fungal drug) (1 person or 1.9% of participants) Not specific how it helped this person.

Omega 3 (supplement) (4 people or 7.5% of participants) *Private treatment.* Relieved some symptoms.

Osteopathy (5 people or 9.4% of participants) *Private treatment.* General gradual improvement. Helps Central Nervous System.

***Ozone Therapy (oxygenates body tissue)** (1 person or 1.9% of participants) *Private treatment.* Repaired impaired blood cells and toxicity.

***Pacing (8 people or 15.1% of participants)** *Self-management.* Enabled patient to work part-time. Improved sleep. ‘The most effective of all treatments for a sufferer,’ said one patient. Helped a sufferer remain stable. Helped manage energy levels through activity and rest.

N.B. This type of pacing is common sense rest and activity and is not the same type of therapy as the PACE trials from Prof. White et al. The PACE trials are more akin to graded exercise, the results of which could worsen true neurological M.E.

Painkillers (see also Anticonvulsant drugs)

Balacet (for fibromyalgia pain) (painkiller) (1 person or 1.9% of participants) Helped with fibromyalgia.

***Celebrex (painkiller, NSAID [Non-Steroidal Anti-Inflammatory Drug])** (1 person or 1.9% of participants) Not specific how it helped this person.

Co-codamol (painkiller) (2 people or 3.8% of participants) *NHS prescription.* Helped manage pain. Helped someone to sleep and relax.

***Fentanyl Patches (opioid painkiller)** (1 person or 1.9% of participants) Helped spinal and limb pain.

Magnetic Jewellery (1 person or 1.9% of participants) Helped with some pains.

Naltrexone, low-dose (LDN) (painkiller; opioid receptor antagonist. It boosts endorphin levels to support the immune system.) (1 person or 1.9% of participants) ‘Takes the edge’ off someone’s M.E. It helps her to get out of bed to watch TV and have a bath.

***Oxycodone (opioid painkiller)** (1 person or 1.9% of participants) Helped limb and spinal pain.

Solpadol (painkiller) (1 person or 1.9% of participants) *Private treatment.* Lessened pain.

*Ultram/Tramadol (for fibromyalgia pain) (opioid painkiller) (1 person or 1.9% of participants) Not specific how it helped this patient.

Prayer (5 people or 9.4% of participants) People have mentioned being strengthened, receiving a sense of God's peace and strength. One person said that many M.E. symptoms disappeared.

Primdirective (powdered organic whole foods and probiotics) (1 person or 1.9% of participants) Not specific how it helped this person.

Provigil (a drug for narcolepsy, a condition when someone falls asleep automatically several times a day) (1 person or 1.9% of participants) *NHS prescription.* Reduced daytime sleepiness.

Relaxation (4 people or 7.5% of participants) CDs helped one person as long as she didn't play them for more than twenty minutes once a day. She reports that they helped her adrenals and thyroid function and helped her get well enough to go out shopping after being bedbound for several years.

Reflexology (6 people or 11.3% of participants) General gradual improvement. Increased energy levels and caused relaxation. Helped circulation and clearing of brain fog.

Rest (3 people or 5.7% of participants) Helps more than anything with mobility.

Saline infusions with Meyers Cocktail (1 person or 1.9% of participants) *Private treatment.* It improved and stabilised a patient's low blood pressure.

Sea Plasma (supplement) (1 person or 1.9% of participants) Helped to clear brain fog.

Serotonin (in the supplement 5HTTP) (2 people or 3.8% of participants) *Prescribed privately but can probably be prescribed on NHS.* Lifts mood and self-esteem.

Shaman Healing (A form of healing which originated from Mongolia. Helps you to be in touch with the spiritual world.) (1 person or 1.9% of participants) Not specific how it helped this person.

Shiatsu (Japanese massage which uses acupressure) (1 person or 1.9% of participants) Gave more energy and reduced pains.

***Sleeping Pills** (2 people or 3.8% of participants) *Private and NHS treatment.* Improved sleep. Taken in reduced doses.

Sound therapy (1 person or 1.9% of participants) Helped a sufferer with depression.

Thyroxine (drug for thyroid) (1 person or 1.9% of participants) *NHS treatment.*
Corrected hypothyroidism.

Vascular Support Stockings (2 people or 3.8% of participants) Not specific how it helped these people.

Visualisation (A process of meditation when you visualise yourself being better.)
(1 person or 1.9% of participants) Not specific how it helped this person.

Vitamins & Minerals (general) (4 people or 7.5% of participants) Not specific how it helped these people.

Vitamin B Complex (Vitamins) (2 people or 3.8% of participants) Not specific how it helped these people.

Vitamin B12 injections (Vitamin) (5 people or 9.4% of participants) *NHS and private treatment. Can be obtained on the NHS even if blood levels don't show a lack of Vit. B12.* Made a patient more resilient to relapses. Helped increase energy levels. Helped with sensory overload, confusion and cognitive symptoms.

Vitamin C (5 people or 9.4% of participants) General gradual improvement.

Vitamin D (1 person or 1.9% of participants) Not specific how it helped this person.

Water Therapy (for fibromyalgia) (1 person or 1.9% of participants) Loosened tight spots but unhelpful with pain.

Zinc (as a supplement) (1 person or 1.9% of participants) Helped relieve some symptoms.

Cautionary Notes:

THE FOLLOWING THREE TREATMENTS HAD THE MOST NEGATIVE EFFECTS IN OUR SURVEY (see 'Treatments with negative comments' page)

* **Amitriptyline:** Some participants who used amitriptyline complained that this drug gave considerable side-effects, including temporary paralysis, sore throat, nightmares, weight gain and an increase of M.E. symptoms generally.

* **CBT:** Some participants complained that CBT was a waste of time, degrading, and more dangerously, administered by therapists who did not understand M.E. or seem to want to understand M.E. Some reported relapses in their health from CBT.

* **Graded Exercise:** Some participants complained that Graded Exercise was a waste of time, had 'adverse' effects on their health and gave permanent damage, leaving them worse off than before.

The Grace Charity for M.E. does not recommend Graded Exercise or Cognitive Behavioural Therapy to M.E. sufferers (see our document 'Saying No Can Be Positive').

TOP FIVE TREATMENTS WHICH HAVE HELPED (last updated 14/9/2011)

- 1) Various alterations to diet*
- 2) Magnesium * (see warning below), pacing (this is sensible pacing and **nothing** to do with Prof. Peter White's PACE trials).
- 3) Co-Enzyme Q10 *
- 4) Reflexology, Amitriptyline * (used mainly for sleep improvement, not for depression. See cautionary note above.)
- 5) Prayer, osteopathy, acupuncture, D-ribose *, Gabapentin*, Vitamin B12 injections, Vitamin C*, Veg EPA*, L-Carnitine*

Caution: Although magnesium is often helpful to M.E. sufferers, it can cause severe diarrhoea if taken in excessive amounts. One patient source quotes that magnesium in excess of 200mgs daily can cause severe diarrhoea and heart arrhythmia.

Caution: As a general rule, M.E. sufferers tend to need a smaller dose of medicine compared to a non-M.E. sufferer, as M.E. patients can be drug sensitive.

WHERE YOU MIGHT BE ABLE TO GET SOME OF THE ABOVE SUPPLEMENTS/ETC.

Some health food shops might be able to supply some of the treatments mentioned above; alternatively, M.E. sufferers have found some success with the following companies:

- 1) NUTRICENTRE at: www.nutricentre.com This is a company based in London. Their phone number is : 020 8752 8450
M.E. sufferers used to get a discount from them but we're unsure if this is still the case. Why not ask them and let us know?!
- 2) SAFE REMEDIES at: www.saferemedies.com This company is based in Berwick-upon-Tweed, Northumberland. Their phone number is: 01289 332888
- 3) THE VEGEPA FOR M.E. SCHEME. This wonderful idea has been set up so that the income goes towards biomedical M.E. research. VegEPA supplements

can be ordered from www.thevegepaformescheme.com at a good price, generally, compared to elsewhere. You can also buy other Essential Fatty Acid products from here.

- 4) SUPPORT M.E. can sell the supplement Enada (NADH) at a reduced price, generally, compared to places elsewhere. www.supportme.co.uk

ADDITIONAL PATIENTS SINCE THE ABOVE 53 PARTICIPANTS, FROM SEPTEMBER 2011

(In time, the below results will be added to the percentage figures above.)

. **Patient No. 54, male.** Helped by **T3 and T4 (thyroid hormones)** for hypothermia. Also helped by Zomig for migraines. Both prescribed by GP.

. **Patient No.55, female.** Helped by Dr. Myhill's regime: **vitamins and multi-vitamins, Co-Enzyme Q10, magnesium, fish oil, D-ribose.** She took these after 6 months of having M.E. and was back to almost normal function but relapsed when doctors told her to stop taking Myhill's suggestions, as there was no scientific proof.

. **Patient No.56, male.** Had has 'chronic fatigue' and fibromyalgia for over 30 years. Has found **Co-Enzyme Q10, vitamin injections and magnesium** helpful. Also, **Shark Liver Oil** with at least 25% AKG (Alkyglycerol), 10-20mg per day. "Very expensive at that dose but an excellent supplement." **Pregabalin** helped better than buprenorphine patches (all painkiller drugs).

. **Patient No. 57, female.** GP prescribed **Vitamin B12 injections**, after blood test revealed patient was low in this vitamin. Patient says she was really 'helped' by the injections. (Didn't specify.) She has had long-term M.E. Injections were given once every two months.

.**Patient No. 58, male.** A holiday in Austria helped him after having M.E. for 30 years. He's unsure as to why it helped but feels that it might have been the altitude there.

.**Patient No. 59, male.** **Acupan (Nefopam hydrochloride)**, painkiller, helped with energy. **Magnesium supplements** helped him relax at night; **Clonazepam (Klonopin)** helped his bruxism (grinding teeth). **CoQ10** helped with energy; **Vit.C** helped; **Vit.B Complex** helped adrenals and relaxation; **probiotics** useful.

.**Patient No.60, female.** **Resting; pacing** has helped her the most; **massage, reflexology** for blood circulation; **sunshine and hot showers** for blood circulation; **eating steak.**

.Patient No.61, female. Intravenous Vitamin C infusions once a week; **Vitamin B injections; avoidance of allergic foods** e.g. wheat, gluten, yeast, alcohol, sugar; getting a lot of **rest**; never pushing my physical limits when tired; allowing a **recovery time** after overdoing it; keeping a food, illness, wellness diary to help track precipitous events and their causes.

. Patient No.61, male. Had great success with one 5ml injection **antibody, called subcuvia (contains immunoglobulin)**. Injections every 2 weeks.

. Patient No. 62, female. She made massive progress from the **GAPS diet** (a very restricted diet based on organic food). The GAPS diet is said to regulate the pituitary gland.