

Survey Treatments: POSITIVE RESULTS 2007-19

Participants: 80

*(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/or under the 'Treatments with Negative Comments' section. The numbers in red brackets show how many people out of the 80 participants have been helped by that drug/supplement etc. Not all the 80 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 1.25% of participants) *Mostly private purchase but can be prescribed on the NHS.* Helped with digestion and immune system.

**Acupan** – see under Painkillers heading

**Acupressure** (similar to acupuncture but using pressure points and not needles) (1 person or 1.25% of participants) Not specific in how it helped this person.

**Acupuncture** (ancient Chinese treatment restoring energies, using needles to stimulate energy) (5 people or 6.25% 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) (2 people or 2.5% of participants) Not specific in how it helped this person.

**Alexander technique** (posture control) (1 person or 1.25% of participants) Not specific in how it helped this person.

**Almotriptan (Axert)** (5HT1 agonist: these drugs narrow dilated blood vessels) (1 person or 1.25% of participants) Helped with migraines.

**\*Alpha-interferon injections** (antiviral drug) (1 person or 1.25% 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 sufferer twice in her life, each time bringing her back to a full recovery. Cured post-exertional malaise.

**Amino Acids**

**\*L-Carnitine** (amino acid supplement) (6 people or 7.5% 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. Helped a patient with energy and muscle aches.

L-Glutamine (amino acid supplement) (1 person or 1.25% of participants) Helped to clear brain fog.

Phenylalanine (essential amino acid) (1 person or 1.25% of participants) Not specific in how it helped this person.

Taurine (amino acid) (1 person or 1.25% 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 1.25% 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 1.25% of participants) Not specific in how it helped this person.

\*Gabapentin (anticonvulsant drug, also used for neuropathic pain) (5 people or 6.25% 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) (2 people or 2.5% of participants) *Available on NHS.* Helped with nerve pain. One person said it helped him better than buprenorphine patches.

Tegretol (anticonvulsant drug) (1 person or 1.25% of participants) Not specific in how it helped this person.

\*Topamax (anticonvulsant drug) (1 person or 1.25% of participants) Helped a patient to sleep better.

**Antidepressants**

\*Amitriptyline (antidepressant) (7 people or 8.75 % 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.' One person said it helped her to reverse Sphincter of Oddi Dysfunction (a rare muscle spasm in the digestive system causing liver problems and pancreatitis).

Dosulipen (antidepressant) (1 person or 1.25% of participants) Helped with sleep. *NHS prescription.*

\*Cymbalta (antidepressant) (2 people or 2.5% of participants) for fibromyalgia and M.E. Helped with pain.

Prozac (antidepressant) (1 person or 1.25% of participants) Helped a sufferer to not get too despondent.

**Anti-histamines** (e.g. Ranitidine, Desloratadine) (3 people or 3.75% 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 1.25% of participants) Not specific how it helped this person.

Cyclizine (anti-histamine for nausea) (1 person or 1.25% of participants) delivered through IV (intravenous). This when she was hospitalised with her body rejecting everything except this.

\***Aromatherapy** (3 people or 3.75% of participants) General gradual improvement

**Avoidance of allergy foods** e.g. wheat, gluten, yeast, alcohol, sugar (1 person or 1.25% of participants)

**Autogenic Training** (relaxation and meditative technique) (1 person or 1.25% of participants) Not specific in how it helped this person.

**Audio CDs/Books** (for insomnia) (2 people or 2.5% of participants) Helped with insomnia.

**Ayurveda** (Holistic therapy) (1 person or 1.25%) helped one patient the most. It balances PH levels, staying alkaline to avoid infections.

**Bach flower remedies** (1 person or 1.25% of participants) Invaluable for emotions, said a sufferer.

**Bisoprolol** (beta blocker) (1 person or 1.25% of participants) Not specific how it helped this person.

**Blue green algae** (1 person or 1.25% of participants) Helped a severe sufferer

**Bromelain** (food supplement) (1 person or 1.25% of participants) See heading Painkillers

**Calcium** (1 person or 1.25% of participants) Not specific how it helped this person.

**Caprellic Acid** (from coconuts) (1 person or 1.25% of participants) Not specific how it helped this person.

**\*CBT (Cognitive Behavioural Therapy) (4 people or 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 1.25% of participants)** Not specific how it helped this person.

**Christian counselling (2 people or 2.5% of participants)** Has made a patient more positive and stopped her depression. A great source of strength.

**Christian healing (1 person or 1.25% of participants)** Not specific how it helped this person.

**Chromium (supplement) (1 person or 1.25% of participants)** Not specific how it helped this person.

**Clonazepam (Klonopin) (1 person or 1.25% of participants)** Helped his grinding teeth (bruxism)

**\*Co-Enzyme Q10 (supplement) (11 people or 13.75% 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. Helped one back to almost normal function (along with other supplements) but relapsed when stopped taking it; one sufferer said it helped with his energy.

**Collodial silver spray for colds and sinus infections (1 person or 1.25% of participants)**

**\*D-Ribose (supplement) (7 people or 8.75% of participants)** *Private treatment.* Helped improve muscle strength and muscle energy (mitochondria). Helped improve sleep, energy levels, muscle aches and stamina. One man said that it helped his muscles after exercise. A female sufferer mentioned that she got back to near normal with D-Ribose and other supplements but relapsed when she stopped taking it.

**DHEA (hormonal treatment to supplement the adrenal gland) (1 person or 1.25% of participants)** Restored a worn-out adrenal gland.

**Diary (1 person or 1.25% of participants)** helped to track food/illness/wellness periods of time and their causes.

**Diet (12 people or 15%)** 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. One sufferer said that a gluten free diet helped with digestive problems. Another said that the Paleo diet helped for a

while but became tiring to prepare (the Paleo diet encourages vegetables, fruit, meat, roots, nuts etc. and excludes sugar, salt, dairy and wheat). The GAPS Diet (a very restricted diet based on organic food) helped to regulate a sufferer's pituitary gland.

**Domperidone (anti-sickness drug) (1 person or 1.25% of participants) NHS prescription.** Controls nausea so patient can eat in mornings.

**Duloxetine** see heading Painkillers

**Enada (N.A.D.H.) (supplement) (2 people or 2.5% of participants) Private treatment.** Regulated energy levels.

**EPD (Enzyme Potentiated Desensitisation) (treatment for allergies) (1 person or 1.25% of participants)** Strengthened body.

### **Essential Fatty Acids**

**\*VegEPA (supplement, includes Essential Fatty Acid) (5 people or 6.25% 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 3.75% 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 2.5% of participants) NHS and private treatment.** Improved sleep, mood and mental function. Helped clear brain fog.

**General fish oils (2 people or 2.5% of participants)** Helped a person back (with other supplements) to almost normal function but relapsed when stopped taking it. Helped to clear a sufferer's foggy, forgetful brain.

**Faith Healing (1 person or 1.25% of participants)** Not specific how it helped this person.

**Flax seed (2 people or 2.5%)** The first person mentioned organic cold milled from Higher Nature for irritable bowel; the second person wrote that the capsules of flaxseed oil helped her eye muscle strength for M.E. and fibromyalgia.

**Fluid (IV) (1 person or 1.25%)** for dehydration

**\*Fungilin (anti-fungal drugs) (1 person or 1.25% of participants)** Not specific how it helped this person.

**Gastric acid blockers (1 person or 1.25% of participants)** Helped gastric pain.

**Gatorade drink** (A drink made from sodium, potassium and sugar in electrolytic balance) (1 person or 1.25% of participants) Helped with OI (Orthostatic Intolerance), helped vertigo, increasing blood volume.

**\*Graded Exercise** (2 people or 2.5% 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 1.25% of participants) *Private prescription.* Helped a patient's symptoms generally.

**Herbal Remedies (general comment)** (4 people or 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.

Further details:

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 2.5% of participants) Helped one sufferer to get rid of food intolerances.

**Holiday** (1 person or 2.5% of participants) A holiday in Austria helped one sufferer after having M.E. for 30 years. He's unsure why but thinks it may have been the altitude.

**Homeopathy** (3 people or 3.75% of participants) *One person mentioned private homoeopathic treatment from German homoeopathic 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 1.25% 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 1.25% 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.*

**Immunoglobulin antibody (subcutia)** (1 person or 1.25% of participants) One man had great success with one 5ml injection every 2 weeks for 3 months. This patient had a confirmation from a SPECT scan that he had brain defects. *Private treatment.*

**Kelp tablets** (extract of seaweed) (1 person or 1.25% of participants) Not specific how it helped this person.

**Kinesiology** (a blend of chiropractic and Chinese medicine) (1 person or 1.25% of participants) Not specific how it helped this person.

**LDN (Low-Dose Naltrexone)** (immune modulation drug) (2 people or 2.5% of participants) One said that it helped to decrease her fever and flu-like symptoms; the other said that it improved her mobility and made her feel less awful.

**Life Style Counsel** (? I think that this person may have meant Lifestyle Counselling) (1 person or 1.25% of participants) Not specific how it helped this person.

**Lighting Process** (1 person or 1.25% of participants) Worked well for one year but stopped working and patient became worse

**Linseeds** (1 person or 1.25% of participants) Not specific how it helped this person.

**\*Magnesium** (mainly injections but also supplements, including magnesium malate) (13 or 16.25% 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. A sufferer said that it helped get her back to almost near function along with other supplements but she relapsed when she stopped taking it; another said it helped him to relax at night. One person took Lamberts magasorb magnesium 150mg, 4 times per day – it helped her greatly with anxiety and digestion. One said that magnesium malate helped M.E. symptoms generally.

**Marma Therapy** (a blend of massage, aromatherapy, herbs, oils and yoga) (1 person or 1.25% of participants) Not specific how it helped this person.

**\*Massage for lymphatic drainage** (5 people or 6.25% of participants) Not specific how it helped these people. One patient said it helped her blood circulation.

**Meditation** (5 people or 6.25% of participants) One person said that a meditative CD (restorative yoga nidra) helped to calm her down when overwhelmed with muscle pain.

**Melatonin** (hormonal supplement often used for inducing sleep) (2 people or 2.5% of participants) One said it helped her insomnia.

**\*Mestinon** (a drug usually given to those suffering from Myasthenia Gravis to improve muscle strength) (1 person or 1.25% of participants) Greatly improved muscle endurance.

**\*Mickel Therapy**(Mind/body reprogramming) (2 people or 2.5% 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 2.5% 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 1.25% of participants) Not specific how it helped this person.

**Milk Thistle Complex** from Biocare (1 person or 1.25% of participants) Helped a person with digestive issues.

**Navoban** (a 5HT-3/serotonin antagonist drug often used as an anti-sickness drug) (1 person or 1.25% of participants) Boosted energies considerably.

**Neutralising Vaccines** (for food and chemical sensitivities) (1 person or 1.25% 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 1.25% of participants) Has taken a patient from being housebound to being 50% well.

**Norwegian Krill Oil** (1 person or 1.25% of participants) helped a person in many ways as an all rounder. It is similar to cod liver oil but stringer and cleaner.

**Nutrients** (via I.V.) (1 person or 1.25% of participants) Not specific how it helped this person.

**Nystan** (anti-fungal drug) (1 person or 1.25% of participants) Not specific how it helped this person.

**Omega 3** (supplement) (4 people or 5% of participants) *Private treatment.* Relieved some symptoms.

**Osteopathy** (5 people or 6.25% of participants ) *Private treatment.* General gradual improvement. Helps Central Nervous System.

**Oxybutynin Hydrochloride** (1 person or 1.25% of participants) helped a severe sufferer with her sweating and over-heating. She obtained it from her NHS GP.

**Ozone Therapy** (oxygenates body tissue) (1 person or 1.25% of participants) *Private treatment.* Repaired impaired blood cells and toxicity.



**\*Pacing (9 people or 11.25% 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)

**Acupan (Nefopam hydrochloride – painkiller) (1 person or 1.25%)** Helped with energy.

**Bromelain (food supplement) (1 person or 1.25%)** for neuropathic pain, 2gms maximum. It is an enzyme derived from pineapples.

**Balacet (for fibromyalgia pain) (painkiller) (1 person or 1.25% of participants)** Helped with fibromyalgia.

**\*Celebrex (painkiller, NSAID [Non-Steroidal Anti-Inflammatory Drug]) (1 person or 1.25% of participants)** Not specific how it helped this person.

**Celecoxib (1 person or 1.25% of participants)** helped one woman’s painful legs, *prescribed by NHS.*

**Co-codamol (painkiller) (2 people or 2.5% of participants)** *NHS prescription.* Helped manage pain. Helped someone to sleep and relax.

**Duloxetine (1 person or 1.25% of participants)** helped one person’s pain

**\*Fentanyl Patches (opioid painkiller) (1 person or 1.25% of participants)** Helped spinal and limb pain.

**Magnetic Jewellery (1 person or 1.25% 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 1.25% 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 1.25% of participants)** Helped limb and spinal pain.

**\*Pregabalin (painkiller) (1 person or 1.25% of participants)** Helped their pain but it added weight gain.

**Solpadol (painkiller)** (1 person or 1.25% of participants) *Private treatment*. Lessened pain.

**Sumatriptan (painkiller)** (1 person or 1.25% of participants) Although not strictly classed as a painkiller this drug has helped with migraines.

\***Ultram/Tramadol** (for fibromyalgia pain) (opioid painkiller) (2 people 2.5% of participants) Not specific how it helped one patient. The other said that it initially worked really well but wore off.

**Phytoestrogen** (1 person or 1.25% of participants) stopped a woman's hot flushes with M.E. and the menopause.

**Prayer** (5 people or 6.25% 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.

**Pregabalin** see heading Painkillers

**Primirective** (powdered organic whole foods and probiotics) (1 person or 1.25% of participants) Not specific how it helped this person.

**Probiotics** (1 person or 1.25% of participants) The person said they were helpful.

**Provigil** (a drug for narcolepsy, a condition when someone falls asleep automatically several times a day) (1 person or 1.25% of participants) *NHS prescription*.  
Reduced daytime sleepiness.

**Relaxation** (4 people or 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** (7 people or 8.75% of participants) General gradual improvement. Increased energy levels and caused relaxation. Helped blood circulation of two people and clearing of brain fog for one person.

**Rest** (5 people or 6.25% of participants) Helps more than anything with mobility for one person. Another said that rest helps her the most, never pushing her physical limitations when tired and allowing a recovery time if she has overdone things.

**Sage tea** (1 person or 1.25% of participants) helped clear her sinuses and also helped her hot flushes.

**Saline infusions with Meyers Cocktail** (1 person or 1.25% of participants) *Private treatment*. It improved and stabilised a patient's low blood pressure.

**Sea Plasma (supplement)** (1 person or 1.25% of participants) Helped to clear brain fog.

**Serotonin** (in the supplement 5HTTP) (2 people or 2.5% of participants) *Prescribed privately but can probably be prescribed on NHS.* Lifts mood and self-esteem.

**Serrapeptase** (an enzyme) (1 person or 1.25% of participants) This lady with M.E. said that the enzyme helped heal her shingles.

**Shaman Healing** (A form of healing which originated from Mongolia. Helps you to be in touch with the spiritual world.) (1 person or 1.25% of participants) Not specific how it helped this person.

**Shark liver oil** (with at least 25% AKG, Alkyglycerol, 10-20mg per day) (1 person or 1.25% of participants) The male participant commented 'very expensive at that dose but an excellent supplement'.

**Shiatsu** (Japanese massage which uses acupressure) (1 person or 1.25% of participants) Gave more energy and reduced pains.

**\*Sleeping Pills** (2 people or 2.5% of participants) *Private and NHS treatment.* Improved sleep. Taken in reduced doses.

**Sodium Bicarbonate** (1 person or 1.25% of participants) Helped a sufferer for noise sensitivity

**Sound therapy** (1 person or 1.25% of participants) Helped a sufferer with depression.

**Spatone** (1 person or 1.25% of participants) Helped a severe sufferer; was tolerated more than prescribed iron tablets

**Steroids** (1 person or 1.25% of participants) Helped a severe sufferer with noise sensitivity

**Steak (eating it)** (1 person or 1.25% of participants) Helped a sufferer with her blood circulation

**Sunshine** (1 person or 1.25% of participants) Helped a sufferer with her blood circulation

**Sumatriptan** see heading Painkillers

**TENS machine** (1 person or 1.25% of participants) helped with back pain

**Tramadol** see heading Painkillers

**Thyroxine** (drug for thyroid) **and T3 and T4** (1 person or 1.25% of participants) *NHS treatment.* Corrected hypothyroidism and hypothermia.

**Valaciclovir** (anti-viral drug) (1 person or 1.25% of participants) This drug really helped a sufferer after one year of taking it but he relapsed very badly when stopping it.

**Vascular Support Stockings** (3 people or 2.5% of participants) Not specific how it helped two of these people. One person said that Pneumapress stockings/socks, Saphena Grip helped her painful legs.

**Visualisation** (A process of meditation when you visualise yourself being better.) (1 person or 1.25% of participants) Not specific how it helped this person.

**Vitamins & Minerals** (general) (6 people or 7.5% of participants) Not specific how it helped some of these people. One person said that they helped her back to almost normal function (along with other supplements) but she relapsed after stopping them.

**Vitamin B Complex** (Vitamins) (3 people or 3.75% of participants) Not specific how it helped most of these people. One person said that it helped her adrenals and relaxation.

**Vitamin B6** (2 people or 2.5% of participants) Helped a severe sufferer with noise sensitivity. One sufferer mentioned Biocare brand as a supplement and it helped to clear their brain fog.

**Vitamin B12** (8 people or 10% of participants) (mainly injections but also spray) *NHS and private treatment. Can be obtained on the NHS even if blood levels don't show a lack of Vit. B12.* Injections made a patient more resilient to relapses. Injections helped increase energy levels and helped with sensory overload, confusion and cognitive symptoms. One lady said that the injections really helped her, with injections once every two months.

**Vitamin C** (8 people or 10% of participants) General gradual improvement. 1 participant had the intravenous Vitamin C infusions once a week. Another got it from Biocare and had them at high doses e.g. 1 gram 4-5 times a day; it improved her overall feeling of health.

**Vitamin D** (2 people or 2.5% of participants) Not specific how it helped this person. One person said that Vit.D3 helps her beat winter blues emotionally and helped her with anxiety and improved immunity to winter colds.

**Water Therapy** (for fibromyalgia) (1 person or 1.25% of participants) Loosened tight spots but unhelpful with pain.

**Zinc** (as a supplement) (1 person or 1.25% of participants) Helped relieve some symptoms.

**Zomig** Helped with migraines *Prescribed by GP*

Please see further information below.

### 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 April 2019)

- 1) Magnesium \*16.25% of participants (see warning below),
- 2) Various alterations to diet\* 15% of participants
- 3) Co-Enzyme Q10 \* 13.75% of participants
- 4) Pacing 11.25% of participants (this is sensible pacing and **nothing** to do with Prof. Peter White's PACE trial).
- 5) Vitamin B12 10% of participants; Vitamin C 10% of participants

**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) SAFE REMEDIES at: [www.saferemedies.com](http://www.saferemedies.com) This company is based in Berwick-upon-Tweed, Northumberland. Their phone number is: 01289 332888 (N.B. The Grace Charity for M.E. doesn't necessarily agree with the philosophy of Safe Remedies company but some of its products may well help.)
- 2) 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.thevegepaformscheme.com](http://www.thevegepaformscheme.com) at a good price, generally, compared to elsewhere. You can also buy other Essential Fatty Acid products from here.
- 3) BODYKIND based in Manchester can be very helpful [www.bodykind.com](http://www.bodykind.com)  
Tel: 0800 043 5566

ADDITIONAL PATIENTS SINCE THE ABOVE 80 PARTICIPANTS, FROM  
MARCH 2019

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

**Coconut Oil** helped a male M.E. sufferer with his stomach pains: he got a 300ml jar for £1.79 from Aldi supermarket.