

Treatments With **Negative Comments** and/or **Side Effects**

Participants: 80

(Numbers in brackets denote the number of participants who've made comments about negative side-effects. Not all of these treatments have been tried by all the 80 participants.

Some of these treatments have positively helped M.E. sufferers, despite side-effects.

Please refer to 'Treatments Which have Helped.'

Disclaimer: Although the Grace Charity for M.E. hopes that the following information is helpful, we don't take responsibility for any treatments, therapies etc. found in this survey because it is taken from anecdotal feedback.

Alpha-interferon injections (1 person or 1.25% of participants) (antiviral drug)

Can cause high fever and body aches which abate within 12 hours of each injection.

Amino Acids:

Carnitine (1 person or 1.25% of participants) (amino acid supplement) Mild nausea and slight headache which soon wore off.

Anticonvulsant drugs: (see also Painkillers heading)

Clonazepam (1 person or 1.25% of participants) (anticonvulsant) Caused sleep disorder.

Topamax (1 person or 1.25% of participants) (anticonvulsant) Caused severe weight loss.

Gabapentin (2 people or 2.5% of participants) (anticonvulsant used as a painkiller) Caused dizziness until the patient got used to it. The other sufferer reported nausea and fatigue.

Antidepressants:

Antidepressants generally (1 person or 1.25% of participants) Made a patient's M.E. much worse.

Amitriptyline (6 people or 7.5% of participants) (antidepressant) Caused burning pain, paralysis, Peripheral Neuropathy (this was on 25 – 50 mgs for 3-4 months). Sleep disorder. Terrible sore throat. Nightmares. Huge weight gain. Loads of side-effects. Just one pill (normal dose for a non-M.E. sufferer) made a sufferer extremely ill and unable to move for 48 hours, worsening M.E. symptoms for one month. A male sufferer said that it gave him horrible sedation on the smallest dose.

Cymbalta/Doloxetine (2 people or 2.5% of participants) (antidepressant) Caused extreme nausea for one patient. A second sufferer said it caused nausea and fatigue.

Nortriptyline (1 person or 1.25% of participants) A male sufferer said that it gave him horrible sedation on the smallest dose.

Prozac (1 person or 1.25% of participants) Drove a sufferer to exhaustion

Seroxat (1 person or 1.25% of participants) (antidepressant) Not specific in how it affected this person.

SSRI drugs (generally) (1 person or 1.25% of participants) (antidepressants) Not specific in how it affected this person.

Antibiotics (high dose) (1 person or 1.25% of participants) 'Completely wiped out' a patient, with the bugs still present after the high dose.

Aromatherapy (1 person or 1.25% of participants) (herbal massage oils) If too intense can worsen symptoms.

Buspirone (1 person or 1.25% of participants) (anti-anxiety drug) Not specific in how it affected this person.

CBT (4 people or 5% of participants) (Cognitive Behavioural Therapy) Caused relapse. Of no benefit after 2 courses. Another sufferer said he had no benefit.

Clonazepam (Klonopin) (1 person or 1.25% of participants) (tranquiliser) depressed a sufferer and may have suppressed his respiration.

Co Q 10 (1 person or 1.25% of participants) (enzyme supplement) Mild nausea and slight headache which soon wore off.

Counsellors (inexperienced) (1 person or 1.25% of participants) Not specific in how it affected this person.

Diet (3 people or 3.75% of participants) Wheat, dairy produce and sugar made one sufferer worse. Another said that although the Paleo diet helped for a while it became tiring to prepare.

A vegan diet made one sufferer worse.

D- Ribrose (1 person or 1.25% of participants) (supplement) Mild nausea and slight headache which soon wore off.

Dopamine Agonists (1 person or 1.25% of participants) e.g. pramipexole and rotigotine patches caused nausea, stuffy nose and fatigue

E.C.T. (1 person or 1.25% of participants) (electroconvulsive therapy) Not specific in how it affected this person.

Essential Fatty Acids:

Veg EPA (1 person or 1.25% of participants) (supplement) Mild nausea and headache which soon wore off.

Evening Primrose Oil (1 person or 1.25% of participants) Gave him nasty headaches.

Exercise (1 person or 1.25% of participants) (general exercise) One sufferer writes that exercise has been most detrimental to her condition, provoking many relapses and making her bedbound.

Fungilin (1 person or 1.25% of participants) (antifungal drug) Not specific in how it affected this person.

Graded Exercise (6 people or 7.5% of participants) Caused relapse. Of no benefit after two courses. Worsened illness significantly. 'Worse thing an M.E. sufferer can do.' 'For the first month it was terribly difficult and made me feel worse.' Had adverse effects on health. One sufferer reports that she was a mild M.E. patient but after graded exercise she became wheelchair bound.

High Dose Vitamin C (1 person or 1.25% of participants) Not specific in how it affected this person.

Hydrotherapy (1 person or 1.25% of participants) One sufferer said it almost killed her by making her hypoglycaemic, at the point of collapse and taking days to recover. She says that sufferers should only do vertical hydrotherapy but she was made to lie on her back and walk up and down the pool.

Hydrocortisone (1 person or 1.25% of participants) (steroidal treatment) Worsened a sufferer's sleep

Imigran (1 person or 1.25% of participants) (drug for migraine) Caused extreme tiredness.

Ivabradine (1 person or 1.25% of participants) (drug for POTS) This M.E. patient also had POTS and said that the Ivabradine aggravated her M.E. symptoms.

Lightning Process (1 person or 1.25% of participants) After initial improvement, there was deterioration

Lithium (1 person or 1.25% of participants) (drug for manic depression) Was given to a patient before an M.E. diagnosis. Made her blind and caused severe weight loss.

Magnesium (1 person or 1.25% of participants) (mostly by injections) Mild nausea and slight headache which soon wore off.

Massage (1 person or 1.25% of participants) Intense massage can make things worse and, if too heavy, a massage can exacerbate leg pain.

Mestinon (1 person or 1.25% of participants) (drug used to improve muscle strength especially for Myasthenia Gravis) Side effects reported of severe cardiac problems, necessitating complete bed rest.

Mickel Therapy (1 person or 1.25% of participants) (Mind/body reprogramming) Sufferer thought she was cured from M.E. as she suddenly felt better but the M.E. returned as she upped her activity levels.

Midodrine (1 person or 1.25% of participants. It is a named patient drug, signed for by a consultant.) (Treats low blood pressure. Useful with POTS,

increase in heart rate due to an upright position) Reports of overly excited autonomic nervous system, e.g. supine hypertension (high blood pressure when lying down.)

Miguard (1 person or 1.25% of participants) (5HT receptor agonist, used as a painkiller for migraine) Caused extreme tiredness.

Nimodipine (1 person or 1.25% of participants) (calcium channel blocker, acting on arterial wall muscles preventing constriction. Used in M.E. to increase cellular mitochondrial energy, increase blood flow to the brain and repair neurochemical transmission) A patient comments that on the 4th day of taking this, she had slight nausea and smelly perspiration but these left within 24 hours and didn't return.

Ozone Therapy (1 person or 1.25% of participants) (oxygenates body tissue) Tiring due to treatment of detoxing.

Pacing, (over zealous) (2 people or 2.5% of participants) Lack of social life. A hospital pacing programme pushed a sufferer 'over the top', making her worse.

Painkillers: (see also Anticonvulsant drug heading)

Buprenorphine patches (1 person or 1.25% of participants) (painkiller patches used for fibromyalgia) Patient said it was a difficult drug to live with.

Celebrex (1 person or 1.25% of participants) (painkiller) Caused fluid retention and oedema.

Tramadol (1 person or 1.25% of participants)(opioid painkiller) Caused dizziness and sleep disorder.

Oxycodone (1 person or 1.25% of participants) (opioid painkiller) Gave nausea and dizziness.

Fentanyl (1 person or 1.25% of participants) (opioid painkiller) Occasionally produced a localised rash from the patches.

Pregabalin (1 person or 1.25% of participants) put on weight from it

Propranolol (1 person or 1.25% of participants)(anti-anxiety drug) Slowed down heart rate too much.

Psychotic Drugs (generally) (3 people or 3.75% of participants) Comments such as 'appalling' reactions.

Septrin (1 person or 1.25% of participants)(antibiotic) Not specific how it affected this person.

Steroids (2 people or 2.5% of participants) High dose steroids were detrimental to one sufferer's health. They weakened her immune system causing her to contract many viruses. Another had very bad side-effects from steroidal eardrops which increased her M.E. pain, inflammation and gave eczema.

Stress (1 person or 1.25% of participants) made the symptoms of M.E. worse for one sufferer

Temazepam (1 person or 1.25% of participants)(sleeping pill) Caused severe head pains on sitting up and standing, stomach pains, suppressed breathing, dizziness, nausea

Thyroid hormones (1 person or 1.25% of participants) e.g. T4, armour thyroid and T3 made a sufferer feel worse with diarrhoea and fatigue.

Vitamin D (1 person or 1.25% of participants) Made a sufferer feel sick.

TOP FIVE TREATMENTS WITH NEGATIVE COMMENTS AND/OR SIDE-EFFECTS

(UPDATED April 2019)

- 1) Graded Exercise
- 2) Amitriptyline
- 3) CBT
- 4&5) Psychotic Drugs had same amount of negative feedback as Diet

