M.E. Treatments

No treatments for Myalgic Encephalomyelitis (M.E.) or for the broader category of Chronic Fatigue Syndrome (CFS) have been officially approved thus far in the U.S.

Here is a summary of treatment modalities that have been reported anecdotally or in the medical literature to have positive effects on the illness.

Pathogens:

M.E. patients appear to have a problem with a wide variety of pathogens that normal people’s bodies naturally keep in check. Many of these are usually controlled by the Natural Killer Cells, which (along with other components of the immune system) have been found to be dysfunctional in this disease.

Commonly, M.E. patients show abnormal levels of some or all of the following pathogens: herpes family viruses (e.g. EBV, CMV, HHV-6, HHV-7); enteroviruses; various insect-borne bacteria (e.g. borrelia, bartonella, ehrlichia); systemic parasites (e.g. babesia, toxoplasma gondii); other bacteria (chlamydophila pneumonii, streptococcus, staphylococci, rickettsiae); mycoplasma; coxiella burnetii (Q fever); parvovirus B19; intestinal parasites (e.g. blastocystis, giardia, other amoebas, worms); and fungi (e.g. aspergillus, candida).

These infections are mostly reactivated intracellular ones, meaning that they show up as IgG rather than IgA or IgM on lab tests. Infections can be systemic or settle into specific organs in the body.

While it seems like killing these infections would be a good idea, many M.E. patients (especially those who are severely ill) have a very hard time with this. Like AIDS patients, they often get what is known as an IRIS (Immune Reconstitution Inflammatory Syndrome) response. Because inflammation is particularly problematic in M.E., this sort of “die-off” or “Herxheimer” response can make patients significantly sicker, sometimes permanently so.

Even when pathogen killers are tolerated, they usually work slowly in M.E. patients. Often months are needed before improvements are noted, and patients who discontinue the treatments often relapse.

Ampligen is an experimental intravenous drug that has been used in M.E. on a compassionate care basis off and on since the mid-1990s. It appears to work as an
“immunomodulator,” changing the cytokine balance so that the sufferer’s system can better address infections while simultaneously experiencing less damage from runaway inflammation. Many extremely ill patients report experiencing substantial improvements while on the drug and a few studies have been published demonstrating its effectiveness, but the effects have not been consistent across patients and the drug has yet to be approved. The drug is currently offered on a “cost-recovery” basis to patients (as much as $50,000 a year, only some of which is ever covered by insurance), and only a handful of M.E. specialists offer it. Thus, few M.E. patients have access to it.

A number of doctors specializing in M.E. have experimented with drugs targeting herpes family viruses, since these viruses can cause serious damage when they are not kept in check by the immune system. For instance, CMV attacks the heart; EBV causes non-Hodgkins lymphoma; and HHV-6A (an uncommon virus often found in severely ill ME/CFS sufferers) causes severe neurological damage. “Heavy duty” drugs that have been studied include valgancyclovir, cidafovir, foscarnet and ribavirin; other drugs commonly used for herpes simplex (such as valacyclovir, famcyclovir and acyclovir) also are used.

Many patients do not tolerate antiviral drugs (more because of “die-off” responses than side effects); some do not benefit; and a few report significant improvements. Studies done on valgancyclovir by Dr. Jose Montoya of Stanford University suggest that patients who have been sick for less time may be more likely to show a positive response to the drug.

“Lyme Literate Medical Doctors” (LLMD’s) attempt to treat bacteria, mycoplasma and parasites. Because of the nature of the infections, certain drugs (such as doxycycline, minocycline, azithromycin, clarithromycin, rifaximin and metronidazole) tend to be most commonly prescribed. As with the herpes family viruses, these treatments prompt a range of results: many patients cannot tolerate the drugs, some experience no benefit, and a few get significantly better.

Nystatin is a drug used to target overgrowths of candida in the intestinal tract. Other antifungals such as fluconozole target fungal infections throughout the body. Fungal infections tend to become resistant to these drugs fairly easily, meaning that they can be a recurring problem.

Some doctors use transfer factors, herbs or other supplements to attempt to address pathogens, in addition to or instead of prescription drugs. These also can provoke “die-off” responses.

Research from 2009 reporting an association between M.E. and the retrovirus XMRV led to a few patients experimenting with the antiretroviral drugs raltegravir, zidovudine and
tenofovir, found in laboratories to be effective at controlling the virus. Again, some patients found that an IRIS response kept them from being able to tolerate the drugs (problems with side effects seemed less common); some patients showed no change; and a few patients reported improvements (though without getting close to full recoveries). XMRV has since been generally accepted as not being associated with the disease.

GcMAF, a substance that activates macrophages to kill pathogens, has been tried in M.E. as well as in AIDS and cancer. M.E. patients report the usual mixed results seen with the other pathogen killers.

**Toxins:**

M.E. patients tend to have problems with toxins in general, but especially with inflammatory toxins. Toxins that are particularly inflammatory include ones made by environmental molds and other microorganisms (such as those present in water-damaged buildings and fields treated with the pesticide Roundup); certain metals (such as mercury and aluminum); and naphthalene.

One study reported finding mycotoxins (made by toxic molds) in the urine of 93% of M.E. patients, and many patients trace their start of M.E. to a toxic mold exposure. A leading researcher and physician in the field, Ritchie Shoemaker, reports that most M.E. patients have HLA DR genotypes that he believes are associated with difficulties detoxifying mold and/or Lyme toxin, resulting in innate immune system regulation problems.

Shoemaker’s recommendations include evacuation from moldy buildings, the drug cholestyramine to remove toxins through the intestines, and treatments aimed at restoring neuropeptide regulation of immune function and poor capillary circulation. However, severely affected M.E. patients frequently report not tolerating the cholestyramine and not experiencing much noticeable improvement from moving or the other treatments. It is possible that removal of patients from a moldy environment (or the proper remediation of mold present) may prevent further declines or allow slow long-term improvements, however.

Some patients state that just as some people have a hyper-reactivity to gluten, they have a hyper-reactivity to even tiny amounts of mold toxin. They say that by staying out of moldy buildings and certain outdoor environments (or showering after visiting), and by discarding contaminated belongings, they have experienced dramatic health improvements and become more able to tolerate treatments such as pathogen killers.

The mercury in vaccines, amalgam fillings and seafood is thought by some to possibly be problematic for M.E. sufferers. Many patients report first getting sick, or permanently
getting much worse, after getting a vaccine, but whether this is due to the inflammation from the immune activation, the mercury, the adjuvants, or a contamination with some kind of pathogen is unclear.

Some patients report that their condition became worse after improper removal of amalgam fillings (the protocol recommended for this population is to use a dental dam and other techniques to prevent the inhalation or ingestion of the loosened-up material). A few patients also report doing better after careful removal of root canals.

Naphthalene is a chemical present in some kinds of mothballs. Some doctors report that patients have experienced severe reactions, such as passing out, as a result of tiny exposures.

Most M.E. patients react negatively to a variety of chemicals, such as bleach, tar, gasoline, air “fresheners,” pesticides and perfume. Some display Multiple Chemical Sensitivity (MCS), with even tiny amounts of any kinds of chemicals causing severe reactions.

Techniques for the removal of toxins from the system include nutritional supplements to support natural processes; binding them for removal through the intestines (with cholestyramine or natural substances); and sweating them out (e.g. with regular or far-infrared saunas or at hot springs). Many M.E. patients get very sick when they attempt to detox, and regardless improvements tend to come slowly.

The Gut:

M.E. sufferers generally have a variety of problems with their intestinal tract, including dysbiosis (fewer “good” microorganisms and more “bad” ones than normal people have); intestinal permeability (“leaky gut”); inflammation; and gut problems (such as “Irritable Bowel Syndrome”). With recent medical thought suggesting that a high percentage of immunity stems from the gut, many M.E. doctors have focused their attention on improving its function.

Ideally, probiotics crowd out candida, problematic bacteria and other pathogens in the gut. Supplementing probiotics (with general or specific strains) is a common treatment, with most M.E. patients finding that they need to introduce massive quantities (such as can be obtained only with homemade kefir or yogurt) to get any noticeable results. Transplants of fecal matter from healthy donors (such as newborn babies) also have been proposed in an attempt to introduce a better balance of microorganisms into the intestines.
Avoidance of sugar and other refined carbohydrates is usually counseled, to attempt to keep candida from blossoming. Targeted antibiotics or herbs to address specific pathogenic bacteria or parasites in the intestines are sometimes used.

M.E. sufferers also frequently have high stomach pH and insufficient digestive enzyme production, and thus can benefit from supplements with hydrochloric acid and enzymes.

Leaky gut is a problem in autism as well as M.E., with no particularly effective drugs or supplements yet available to address the problem. A main intervention here is to look at diet, since undigested particles of certain kinds of foods can cause severe inflammation if they penetrate the inner wall of the intestinal tract. Gluten is a main offender, with many people finding that even tiny amounts of wheat are enough to set off a major reaction. Other foods can be problematic as well.

As in autism, the diet that seems most consistently helpful for M.E. patients is the “caveman” one: vegetables, meats, nuts, olive oil and possibly small amounts of certain fruits. Because M.E. sufferers tend to be sensitive to toxins, avoidance of processed and non-organic foods is preferable.

**Nutritional Deficiencies:**

Proper methylation is needed for the utilization of glutathione. If this does not occur, people have problems with a wide variety of systemic processes, including detoxification, energy production and control of pathogens. A number of researchers have suggested that methylation difficulties are present in autism, and Dr. Rich van Konyenburg and other ME/CFS specialists have speculated that this may be the case in M.E. as well.

At the root of the problem may be a difficulty in converting folic acid to an activated form of folate. Supplementing with folic acid (present in the drug leucovorin) or tetrahydrofolate (present in the drug Deplin and supplements containing Metafolin) can overcome this problem. Other nutrients (such as SAM-e, phosphatidyl choline, phosphatidyl serine and high doses of B12) also may be helpful or necessary to address methylation difficulties, some doctors say.

Some people find intravenous or nebulized glutathione to be of help as well.

A number of doctors have focused on the role of the mitochondria in the disease. They suggest that supplementing with nutrients such as magnesium, B vitamins, ribose, acetyl-L-carnitine, NADH (nicotinamide adenine dinucleotide, the active form of niacin), and ubiquinone (a form of Coenzyme Q10) can be particularly helpful in giving patients the “fuel” they need to make more energy. Intravenous “Myers’ Cocktails” consisting of
magnesium, B vitamins and other nutrients can be especially effective, some patients say.

Some patients find intravenous or high-dose oral Vitamin C to be helpful, apparently by neutralizing some of the oxidative stress characteristic in the disease. Intravenous Vitamin C in high doses will turn into hydrogen peroxide in the space between the cells, making it more difficult for Lyme and other infections to survive and giving many patients a “die-off” reaction.

Alpha Lipoic Acid is thought to have a number of benefits related to M.E., including addressing oxidative stress, support of the liver and detoxification of mercury. It is used in oral and intravenous forms.

Intravenous administration of nutrients had the added value of giving the patient an infusion of saline, helpful since blood volume in the disease tends to be low.

Some doctors believe that many M.E. sufferers are relatively deficient in a variety of nutrients, especially B vitamins (such as B6 and B12) and minerals (such as zinc, lithium, copper, manganese, selenium, chromium, potassium and molybdenum as well as magnesium).

Vitamin D3 levels tend to be low in M.E., although not all doctors agree that it’s a good idea to attempt to fix this.

A few small studies report that M.E. patients may do better as a result of supplementing omega-3 oils (such as fish or flax oil). Some patients report that omega-6 oils (such as black currant seed oil, borage oil or evening primrose oil) may be helpful as well.

Many M.E. sufferers find that supplementing vitamins or minerals can cause them to feel immediately much worse. This seems to be a result of the body’s processes starting up, with pathogens being killed off or toxins released. Thus, they may need to use caution even with supplements that seem that they should be innocuous.

**Hormones:**

The endocrine system is thought to be one of the core dysfunctions in M.E., with the hypothalamic-pituitary-adrenal (HPA) axis being particularly problematic. Addressing hormonal issues thus can be of benefit to some patients, though this has to be done carefully.
Adrenals tend to be shrunken in M.E. and often produce lower amounts of various hormones than they should. Unfortunately, a default for many doctors is to prescribe prednisone or other high-dose steroids, and this can make M.E. patients much worse. More successful tends to be gentler support with supplements (such as ginseng, licorice or adrenal extract), DHEA and/or or very low doses of natural hydrocortone.

Aldosterone is a steroid hormone that controls blood volume and increases blood pressure. Many M.E. patients tend to be deficient in this and as a result have abnormally low blood pressure. Fludrocortisone (an aldosterone analogue) and additional salt intake can sometimes be helpful.

The thyroid is problematic in M.E., but supplements such as Synthroid or Armour (which contain T4) usually are not helpful. Some doctors say that supplementation of T3 can be appropriate for some patients, but others report very negative results.

Some patients, especially those who are very debilitated, are very low in human growth hormone and improve as a result of injections of it.

Some M.E. patients report feeling much improved as a result of supplementing oxytocin, a “feel good” hormone released at especially high levels during childbirth, breastfeeding and orgasm.

Melatonin is a hormone that regulates circadian rhythm and that serves as an antioxidant. Some M.E. patients have found it helpful for sleep and in general.

Although few M.E. doctors prescribe artificial estrogen to their patients, some believe that bioidentical estrogen can be appropriate in some cases. Testosterone can be helpful for both men and women, some doctors suggest.

Natural progesterone can be of help to many women with M.E., particularly those who experience PMS, some doctors believe.

Vasopressin (also known as ADH, anti-diuretic hormone) can be low in M.E. Desmopressin is sometimes used to treat this.

A few M.E. doctors are experimenting with supplementing with Vasointestinal Peptide (VIP), a hormone that appears to have particular potential in treating Multiple Chemical Sensitivity and in promoting flow through the liver.
Immunomodulators:

Inflammation is a major problem for M.E. patients, and is possibly the root of the illness. This seems to stem from environmental toxins, pathogens and dysfunctions in the immune system.

Certain drugs and supplements have the potential of serving to decrease this inflammation. Ampligen (discussed above) seems to be especially effective. Others that can have a bit of an effect include low doses of naltrexone (an opioid antagonist), Immunovir, Nexavir and curcumin.

Intravenous immunoglobulin (IVIG) has antiviral and anti-inflammatory effects, and some M.E. patients report benefiting from it. Unfortunately, it is very expensive.

A few other drugs (such as infliximab) have anti-inflammatory effects, but because they require infusions or injections they are not very commonly used.

Sleep:

Sleep dysfunction is a core problem in M.E. Patients have problems sleeping, and they awake from sleep not feeling refreshed.

Although sleep disorders are not believed to be at the core of the illness, some doctors order sleep studies in the hope that correcting any problems will allow patients’ sleep to improve.

One theory about sleep issues in M.E. is that they are at least partly due to problems with glutamate, an excitatory neurotransmitter that also is an issue in autism. Some patients report getting much better sleep when they use benzodiazapine drugs such as Klonopin or Xanax. A downside of the drugs is that they can cause withdrawal problems if patients decide to discontinue using them.

Other sleep medications or muscle relaxants sometimes are used as well.

Drugs:

M.E. patients often react negatively to a variety of chemicals, including prescription drugs. A few drugs do seem to be helpful, at least for some patients.
M.E. patients suffer from various sorts of pain, especially fibromyalgia/trigger point pain and migraine headaches. Medications used include anticonvulsants, NSAIDS, migraine drugs and opiates.

Beta blockers, antihypotensives and other drugs that act on the circulatory system can be helpful for stabilizing blood pressure and heart beat rate, thus providing some protection against postural orthostatic tachycardia syndrome (POTS), orthostatic intolerance (OT) and post-exertional malaise (PEM).

M.E. patients often have an excess of fibrin in their blood, causing hypercoagulation. This can be treated with heparin or with supplements such as certain kinds of enzymes.

Anticonvulsants (e.g. lamotrigine, carbamazepine, gabapentin, pregabalin) can be helpful with addressing some of the neurological dysfunction in the illness.

Some studies suggest that antidepressants can be useful in M.E., but severely ill patients often get much worse as a result of using them. Even in those cases when they are helpful, usually only small doses are needed or tolerated.

Stimulants (e.g. methylphenidate, modafanil) were frequently recommended in the early days of the illness, but most gains on them tend to be short-lived.

The excitatory NMDA (N-methyl-D-aspartate) receptor appears to be overactivated in ME/CFS, and some drugs (such as memantine) have the potential of addressing that.

Rituximab, a drug mostly used to treat cancer, is a chimeric monoclonal antibody against the protein CD20, found on the surface of B cells. Two studies found that in alone or in combination with methotrexate, it could be helpful for M.E.

Serotonin antagonists and acetylcholine-esterase inhibitors occasionally are used.

Cognitive problems in M.E. sometimes respond to “smart drugs” like piracetam, some doctors treating the illness believe.

**Alternative Treatments:**

M.E. patients generally have lower-than-normal levels of oxygen in their bodies, and some patients report that they benefit from hyperbaric oxygen therapy (HBOT) or regular administration of oxygen. As with most M.E. treatments, some patients report negative results -- apparently, in this case, because the administration of oxygen can kill intracellular pathogens and make the recipient more open to oxidative stress.
A few dozen M.E. patients have experimented with getting stem cell infusions in Latin American countries, and a few of these have reported positive results.

Neural therapy involves the injection of small amounts of procaine, homeopathics or other substances into trigger points or interference fields in the body. Some patients suggest that this treatment has been very helpful in allowing toxins to move through the body rather than remaining trapped in tissues such as the brain, and in providing pain relief.

For M.E. patients who are only mildly or moderately ill, yoga or other exercise that helps the lymph move through the body has been reported to be of benefit for detoxification. Cranial sacral therapy and massage also may be helpful for this.

UVB irradiation of a small amount of the blood is thought by some practitioners to be potentially helpful in addressing pathogens and toxins in M.E.

A number of studies suggest that acupuncture or certain herbs used in Traditional Chinese Medicine can be helpful in M.E.

Some M.E. patients state that other “energetic” treatments, such as homeopathy or Laser Energetic Detox (LED), have been particularly helpful for them.

Ozone therapy is a controversial treatment that some people believe can be helpful in M.E. by killing pathogens and dissolving toxins. Ozone cannot be inhaled, but is administered in a variety of other ways.

Also controversial is the use of Rife, a treatment that uses electromagnetic frequencies to attempt to kill pathogens, as an alternative or addition to prescription drugs or herbs.

Colonics and coffee enemas are used by some patients to help to detoxify the intestines, liver and gall bladder.

Dark chocolate was found in one study to have positive benefits in M.E., apparently because the flavonoids helped to synthesize nitric oxide and reduce the stickiness of the blood.

**Activity:**

A consistent finding across research studies is that M.E. patients do better if they are careful not to push themselves beyond their boundaries to exercise or to be active. This is the case regardless of whether the specific techniques used are called “pacing” or
“graded exercise therapy” or “cognitive-behavioral therapy” or “staying within the energy envelope.”

Being modestly active seems a little better than not being active at all at helping patients to avoid becoming deconditioned, provided that they don’t do too much and crash as a result.

Patients may benefit from having help available, so that they do not have to push themselves as much to do more than they are comfortably able.

**Stress:**

Stress is not a good thing in any illness, and it may be even more detrimental for M.E. patients than for people with other diseases. Stress-reduction techniques may be appropriate.

-Keith Berndtson, M.D.; Lisa Petrison, Ph.D.
M.E. TREATMENTS

MEDICAL LITERATURE

Overview


While conventional and complementary medicines are widely used by CFS patients, the evidence for effectiveness in CFS is very limited.


The literature does not support the idea that complementary and alternative medicine therapies are helpful in CFS.


A literature review suggested that of alternative treatments, acupuncture, several types of meditative practice, magnesium, l-carnitine, and S-adenosylmethionine show the most potential for further research.

The authors summarize their opinions about the use of drugs in CFS: “Antiviral, immunological and antibiotic therapies, although sometimes associated with symptom amelioration, can be more harmful than beneficial. Stimulants seem to benefit some CFS patients but their long-term effects is uncertain. Although antidepressants are not curative for the illness, they might be useful for some symptomatic aspects and co-morbid anxiety and depression. There is little or no evidence that CFS patients benefit from other pharmacological agents (e.g., steroids) or from dietary supplements and complementary medicine products.”


The authors review various drugs that they think could be helpful in CFS.


The authors discuss the dietary supplements glutathione, N-acetyl cysteine, alpha-lipoic acid, oligomeric proanthocyanidins, Ginkgo biloba, and Vaccinium myrtillus (bilberry) to address oxidative stress in CFS. Food intolerances and celiac disease are also discussed.

**Ampligen**


Rintatolimod (Ampligen) produced objective improvement in exercise tolerance and a reduction in CFS/ME related concomitant medication usage.

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Poly(I)-poly(C12U) (Ampligen) is a biologically active drug in CFS, with effects on RNase L activity correlated with cognitive improvement.


CFS patients differed significantly from controls in having a lower mean basal level of latent 2-5A synthetase, a higher pretreatment level of bioactive 2-5A, and a higher level of pretherapy RNase L activity. Therapy with poly(I).poly(C12U) Ampligen resulted in a significant decrease in HHV-6 activity and in downregulation of the 2-5A synthetase/RNase L pathway in temporal association with clinical and neuropsychological improvement.

Rituximab

Major CFS symptom relief during cancer chemotherapy in a patient with synchronous CFS and lymphoma spurred a pilot study of B-lymphocyte depletion using the anti-CD20 antibody Rituximab, which demonstrated significant clinical response in three CFS patients. The delayed responses starting from 2-7 months after Rituximab treatment, in spite of rapid B-cell depletion, suggests that CFS is an autoimmune disease and may be consistent with the gradual elimination of autoantibodies preceding clinical responses.


CFS patients experienced improvements when treated with chemotherapy usually used for cancer patients; this suggests that B-cell abnormalities play a role in the disease.

**Antivirals**


This study looks at the drug valganciclovir, which has been reported to improve physical and cognitive symptoms in patients with chronic fatigue syndrome (CFS) with elevated human herpesvirus 6 (HHV-6) and Epstein-Barr virus (EBV) IgG antibody titers. Patients were categorized as responders if they experienced at least 30% improvement in physical and/or cognitive functioning. Thirty-two patients (52%) were categorized as responders. Longer treatment was associated with improved response.


A group of CFS patients improved on the drug valacyclovir.
Kogelnik AM, Loomis K, Hoegh-Petersen M, Rosso F, Hischier C, Montoya JG. Use of valganciclovir in patients with elevated antibody titers against Human Herpesvirus-6 (HHV-6) and Epstein-Barr Virus (EBV) who were experiencing central nervous system dysfunction including long-standing fatigue. J Clin Virol. 2006 Dec;37 Suppl 1:S33-8. PMID: 17276366

The use of the antiviral drug vanganciclovir resulted in significant improvements amongst a small group of CFS patients.


Valacyclovir may be effective when used to treat persistent Epstein-Barr virus (EBV) in CFS.


The researchers present data that support an endogenous reactivation of EBV infection and suggest a causal relationship with primary amyloidosis.


Therapy with alpha interferon had a significant effect on the quality of life in a subgroup of patients with CFS manifesting an isolated decrease in natural killer cell function.

Acyclovir (a herpes antiviral) was not helpful in a trial.

**Antibiotics**


The antibiotic azithromycin resulted in a decrease in symptoms in a subset of CFS patients, all of whom had lower levels of plasma acetylcarnitine. The authors speculate that the drug protected the patients from oxidative stress.

**Transfer Factor**


Of the 20 patients in the placebo-controlled trial of transfer factor, improvement was observed in 12 patients, generally within 3-6 weeks of beginning treatment.

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Specific Human Herpes virus-6 (HHV-6) transfer factor (TF) preparation, administered to two chronic fatigue syndrome patients, inhibited the HHV-6 infection. Prior to treatment, both patients exhibited an activated HHV-6 infection. TF treatment significantly improved the clinical manifestations of CFS in one patient who resumed normal duties within weeks, whereas no clinical improvement was observed in the second patient.

**IVIG**

Ghio M, Contini P, Setti M, Ubezio G, Mazzei C, Tripodi G. sHLA-I Contamination, a novel mechanism to explain ex vivo/in vitro modulation of IL-10 synthesis and release in CD8(+)

IVIG might modulate IL-10 via the immunomodulatory activities of sHLA-I contaminant molecules inducing transcriptional and post-transcriptional modulation of IL-10 in CD8(+) T lymphocytes and neutrophils.

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A 5-day course of IVIG therapy led to clearance of parvovirus B19 viremia, resolution of symptoms, resolution of cytokine dysregulation and improvement in physical and functional ability in a group of three CFS patients.

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Researchers did a trial of IVIG on a group of adolescents with CFS.

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No dose of intravenous immunoglobulin was associated with a specific therapeutic benefit in a group of CFS patients. Adverse reactions, typically constitutional symptoms, were reported by 70% to 80% of patients, with no relationship to immunoglobulin treatment.

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In a trial of 28 CFS patients, no clinical improvements were noted. Major adverse experiences were observed in 20% of both the IV IgG and placebo groups.


Immunomodulatory treatment with immunoglobulin is effective in a significant number of patients with CFS, a finding that supports the concept that an immunologic disturbance may be important in the pathogenesis of this disorder.

**Arsenic**

Tarello W. Chronic fatigue syndrome (CFS) associated with Staphylococcus spp. bacteremia, responsive to potassium arsenite 0.5% in a veterinary surgeon and his coworking wife, handling with CFS animal cases. Comp Immunol Microbiol Infect Dis. 2001 Oct;24(4):233-46. PMID: 11561958

The blood of a veterinary surgeon (the author) and his coworking wife, both diagnosed with CFS, proved Staph-positive. Micrococi-like organisms in the blood were repeatedly observed in a 3-year period. Several medicaments, including antibiotics, proved unsuccessful. Following treatment with a low dosage arsenical drug (potassium arsenite 0.5%, im., 1 ml/12 h, for 10 days) both patients experienced complete remission. At the post-treatment control made 1 month later, micrococi had disappeared from the blood, and the CD4/CD8 ratio was raising.


Seven dogs and eight cats diagnosed with CFS experienced resolution of their symptoms with a low dosage arsenical drug (thiacetarsamide sodium, Caparsolate, i.v., 0.1 ml/kg/day). Previously observed micrococi disappeared from the blood at post-treatment controls made 10-30 days later.

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Eight birds of prey examined between 1992 and 1995 and sharing common symptoms (asthenia, inability to fly, poor appetite and emaciation) underwent laboratory tests revealing immunodeficiency, anaemia, high creatine kinase levels and low serum magnesium levels. In all patients, micrococcus-like organisms found adhering to the outer surface of many red blood cells, had disappeared at post-treatment controls. An arsenic-based medication was successful in relieving the immune and haematological dysfunctions within 2-4 weeks.

Probiotics


CFS patients who received 24 billion colony forming units of Lactobacillus casei strain Shirota (LcS) daily for two months had a decrease in anxiety symptoms. PMID: 19338686


Severely ill CFS patients were given the probiotics Lactobacillus paracasei ssp. paracasei F19, Lactobacillus acidophilus NCFB 1748 and Bifidobacterium lactis Bb12. The study reported neurocognitive functioning improvements, but no changes in fatigue or physical activity. PMID: 19171024

Nutritional Support

CFS frequently is a folinic acid responsive clinical entity accompanied by B-cell immunodeficiency and inappropriate antibody responses to EBV.


D-ribose was effective at improving CFS patients’ energy, sleep, mental clarity, pain intensity and overall feelings of well-being.


CFS patients have a variety of nutritional deficiencies. Supplementing with B vitamins, vitamin C, magnesium, sodium, zinc, l-tryptophan, l-carnitine, coenzyme Q10 and essential fatty acids may be considered.


CFS patients showed deficiencies in various B vitamins, especially B6. This did not appear to be due to insufficient intake.


Nutritional supplements resulted in a reduction in initial symptom severity, with continued improvement in the period between initial assessment and the follow-up, in a group of CFS sufferers.
Addition of glyconutrient homogenate to PBMC from patients with CFS stimulated with phytohemagglutinin significantly increased the expression of each glycoprotein. The glyconutrient preparation significantly enhanced NK cell activity versus human herpes virus 6 (HHV-6)-infected H9 cells in an 8 h 51Cr release assay compared to placebo for PBMC from patients with CFS (p< .01). Finally, apoptosis was significantly higher in patients with CFS. The percentage of apoptotic cells was significantly decreased in PBMC from patients with CFS that had been incubated for 48 h with glyconutrients.

Carnitine


The possible use of carnitine in CFS and other conditions is discussed.


The authors compared 2 g/d acetyl-L-carnitine, 2 g/d propionyl-L-carnitine, and its combination in 3 groups of 30 CFS patients during 24 weeks. Acetylcarnitine and propionylcarnitine showed beneficial effect on fatigue and attention concentration. Less improvement was found by the combined treatment. Acetylcarnitine had main effect on mental fatigue and propionylcarnitine on general fatigue.


In a group of 30 CFS patients, l-carnitine demonstrated significant improvements within 4-8 weeks. Amantadine, used to treat fatigue in MS, was poorly tolerated by CFS patients.
NADH


Administration of oral NADH was associated to a decrease in anxiety and maximum heart rate, after a stress test in patients with CFS.


NADH was effective in CFS for three months, but the positive results faded after that.


31% of a group of CFS patients responded favorably to NADH, compared to 8% to a placebo.

Magnesium


The use of the "Myers' cocktail" for CFS and other diseases is discussed.

* Manuel y Keenoy B, Moorkens G, Vertommen J, Noe M, Nève J, De Leeuw I. Magnesium status and parameters of the oxidant-antioxidant balance in patients with chronic fatigue:

In a CFS population, lower antioxidant capacity found in moderate Mg deficiency was not due to a deficit in Mg dietary intakes and was not accompanied by increased lipid susceptibility to in vitro peroxidation. Nevertheless, Mg supplementation was followed by an improvement in Mg body stores, in serum vitamin E and its interrelated stage of lipid peroxidation.

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A CFS sufferer was treated successfully with intravenous magnesium.

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Cox IM, Campbell MJ, Dowson D. Red blood cell magnesium and chronic fatigue syndrome. Lancet. 1991 Mar 30;337(8744):757-60. PMID: 1672392

A clinical trial showed that magnesium supplementation may be helpful in CFS.

**Essential Fatty Acids**


Supplementation of an essential fatty acid rid in eicosapentaenoic acid (EPA) was followed by marked improvement in clinical condition after six weeks. Accurate quantification of the lateral ventricular volumes in the baseline and 16-week follow-up registered images of high-resolution magnetic resonance imaging structural scans showed that the treatment was accompanied by a marked reduction in the lateral ventricular volume during this period.

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A series of patients with chronic fatigue syndrome were treated solely with a high-eicosapentaenoic acid-containing essential fatty acid supplement. All showed improvement in their symptomatology within eight to 12 weeks.


Treatment with an essential fatty acid product (Efamol Marine) did not result in benefits compared to a placebo for CFS patients.


High doses of essential fatty acids containing linolenic, gamma-linolenic, eicosapentaenoic and docosahexaenoic acids were helpful in CFS.

**Vitamin C**


A combination of high-dose intravenous Vitamin C and DHEA was effective at treating both CFS and interstitial pneumonia.

* Kodama M, Kodama T, Murakami M. The value of the dehydroepiandrosterone-annexed vitamin C infusion treatment in the clinical control of chronic fatigue syndrome (CFS). I. A

A combination of intravenous Vitamin C and DHEA was effective in treating a CFS patient.


The authors found that a combination of intravenous Vitamin C, DHEA and antibiotics (erythromycin and chloramphenicol) was effective in treating CFS manifested as “chronic pneumonia.”

**Adrenal Hormones**


Treatment strategies addressing cortisol problems may be effective in CFS.

Wheatland R. Chronic ACTH autoantibodies are a significant pathological factor in the disruption of the hypothalamic-pituitary-adrenal axis in chronic fatigue syndrome, anorexia nervosa and major depression. Med Hypotheses. 2005;65(2):287-95. PMID: 15885924

Corticosteroid supplements may be an effective treatment for CFS.

DHEA levels are raised in CFS and correlate with the degree of self-reported disability. Hydrocortisone therapy leads to a reduction in these levels towards normal, and an increased DHEA response to CRH, most marked in those who show a clinical response to this therapy.


Treating the symptoms of rhinitis with topical nasal corticosteroids in patients with CFS does not appear to alleviate daytime fatigue or associated nasal, musculoskeletal, or cognitive complaints.


Low-dose combination therapy of hydrocortisone and fludrocortisone was not effective in patients with CFS.


The authors treat 32 patients with low-dose hydrocortisone and conclude that the improvement in fatigue seen in some patients with CFS during treatment is accompanied by a reversal of the blunted cortisol responses to human CRH.

Low dose hydrocortisone therapy caused increases in plasma leptin levels, with this biological response being more marked in those CFS subjects who showed a positive therapeutic response to hydrocortisone therapy.

* 


Fludrocortisone as monotherapy for was no more efficacious than placebo for amelioration of symptoms in CFS.

* 


In some patients with CFS, low-dose hydrocortisone reduces fatigue levels in the short term.

* 


Hydrocortisone treatment was associated with some improvement in symptoms of CFS.

* 


Low-dose fludrocortisone did not provide enough benefit to be evident in a preliminary blinded trial of unselected patients with chronic fatigue syndrome.

**Growth Hormone**


A group of 20 patients received growth hormone therapy. Although quality of life, as assessed using two different questionnaires, did not improve significantly during GH treatment, four patients were able to resume work after a long period of sick leave.

**Melatonin**


Melatonin was more effective than a placebo at improving CFS patients’ scores on a variety of measures.


Melatonin and bright-light phototherapy appear ineffective in CFS.

*van de Luit L, van der Meulen J, Cleophas TJ, Zwinderman AH. Amplified amplitudes of circadian rhythms and nighttime hypotension in patients with chronic fatigue syndrome:

In a pilot study of four CFS patients, inopamil (200 mg) reduced nighttime hypotension (p < 0.05), whereas melatonin (4 mg) increased nighttime hypotension.

**Orthostatic Intolerance**


Home orthostatic training is well tolerated and generally complied with. A likely physiological rationale for HOT in CFS is related to reductions in orthostatic intolerance. An adequately powered study including strategies to enhance compliance is warranted.

*


The authors describe the effect of propranolol in an adolescent with chronic fatigue syndrome and orthostatic intolerance.

*


Midodrine treatment, directed at the autonomic nervous system, resulted in correction of the dysautonomia followed by improvement of fatigue in one patient.

**Pain Management**

double-blind randomized controlled cross-over trial. Pain Physician. 2013 Mar-Apr;16(2):E61-70. PMID: 23511692

After intake of acetaminophen, pain thresholds increased slightly in CFS/FM patients, and decreased in the RA and the control group. Acetaminophen may have a limited positive effect on central pain inhibition in this disease.


Physiotherapy and complementary alternative medicine treatments may help people manage painful CFS symptoms.


A 30-minute educational session on pain physiology in CFS patients imparted a better understanding of pain and brings about less worry about pain.

**Stimulants**

Young JL. Chronic fatigue syndrome: 3 cases and a discussion of the natural history of attention-deficit/hyperactivity disorder. Postgrad Med. 2013 Jan;125(1):162-8. PMID: 23391682

Case studies of three patients whose CFS symptoms improved after treatment with stimulants for their ADHD are presented.

The use of immediate-release methylphenidate in CFS was shown to be helpful in one small study.


ADHD medications can be effective in CFS.


The amphetamine derivative methylphenidate was better than a placebo at relieving fatigue and concentration disturbances in a minority of CFS patients.


A short trial suggests that dexamphetamine may be useful in the management of CFS.

**5-HT3 Receptor Antagonists**


Ondansetron, a 5-HT(3) receptor antagonist, was no better than a placebo at helping fatigue severity and functional impairment in adults with CFS.

*

Treatment with granisetron, a 5-HT3 antagonist, resulted in significant improvement in fatigue severity and functional impairment in a group of CFS patients. Activity level showed no significant increase.


Patients with CFS improved on both oral tropisetron and oral ondansetron.

**Acetylcholine-Esterase Inhibitors**


CFS patients had lower cortisol levels and higher DHEAS levels than controls. Galantamine hydrobromide treatment was effective in bringing down the DHEA levels.


Galantamine hydrobromide, an acetyl cholesterolone inhibitor, did not demonstrate benefits over a placebo in a group of CFS patients.

Three patients with CFS responded somewhat positively to small doses of pyridostigmine, an acetylcholine-esterase inhibitor.

**Antidepressants**


A literature review suggests that antidepressant use in CFS remains “controversial.”

* Amsterdam JD, Shults J, Rutherford N. Open-label study of s-citalopram therapy of chronic fatigue syndrome and co-morbid major depressive disorder. Prog Neuropsychopharmacol Biol Psychiatry. 2008 Jan 1;32(1):100-6. PMID: 17804135

The use of s-citalopram appears to have potential in addressing a variety of CFS symptoms.

* Thomas MA, Smith AP. An investigation of the long-term benefits of antidepressant medication in the recovery of patients with chronic fatigue syndrome. Hum Psychopharmacol. 2006 Dec;21(8):503-9. PMID: 16981220

Antidepressants can be effective in treating CFS.


In a blinded trial of the antidepressant moclobemide, there were some improvements. This seems to be apart from its effect on mood.

In a trial of 10 CFS patients, 80% reported at least some improvement from fatigue from the antidepressant Nefazodone.


Selegiline has a small but significant therapeutic effect in CFS which appears independent of an antidepressant effect.


The antidepressant moclobemide was not successful in helping a group of CFS patients.


A group of CFS patients responded positively to phenlzine, an monoamine oxidase inhibitor.


Nine CFS patients who either could not tolerate or did not respond to fluoxetine showed significant response when administered 300 mg/day of bupropion for an 8-week period. Measures of T1 microsomal antibodies also decreased over treatment time; increases in
natural killer cell numbers correlated inversely with change in plasma levels of free methylhydroxyphenolglycol ($r = -0.88, p < 0.05$).

**Fezam (Piracetam and Cinarrizine)**

Boiko AN, Batysheva TT, Matvievskaia OV, Manevich TM, Gusev EI. Characteristics of the formation of chronic fatigue syndrome and approaches to its treatment in young patients with focal brain damage. Neurosci Behav Physiol. 2007 Mar;37(3):221-8. PMID: 17294097

Fezam (which contains piracetam and cinarrizine) was helpful in treating symptoms of CFS patients with focal brain lesions.

*Boiko AN, Batysheva TT, Matvievskaia OV, Manevich TM, Gusev EI. The peculiarities of formation and approaches to the treatment of chronic fatigue syndrome in young patients with focal brain damage. Zh Nevrol Psikhiatr Im S S Korsakova. 2006;Spec No 3:122-9. PMID: 17172247*

The drug fezam (piracetam plus cinnarizin) led to a decrease in fatigue severity in a group of CFS patients.

**Other Drugs/Supplements**


This study suggests that the dopaminergic medication lisdexamfetamine dimesylate could be a safe and efficacious treatment for the executive functioning deficits often associated with CFS.

This pilot study assessed the feasibility and safety of clonidine in adolescent chronic fatigue syndrome (CFS).


Of CFS patients treated for sleep disorders with sodium oxybate, 75% experienced significant fatigue relief, and 60% experienced significant relief of pain.


Vasoactive neuropeptides (VNs) such as PACAP and VIP have critical roles as neurotransmitters, vasodilators including perfusion and hypoxia regulators, and immune and nociception modulators, and have the potential of being of help in CFS and other conditions.


Treatment with Acclydine in CFS did not result in significant differences compared with the placebo group.


The NK cell stimulant, BioBran MGN-3, was not successful in reducing fatigue in CFS patients.

SRL 172, a protein derived from a soil-based organism, appears to shift the cytokine profile in persons with Gulf War Syndrome and CFS from TH2 back to the more effective TH1 profile.

**Herbal Medicines**


The Chinese herbals combination Lixu Jieyu was effective at reducing fatigue, increasing Th and T cells, and decreasing the CD4/CD8 ratio in a group of CFS patients.

Kuibitang (KBT) is clinically used to treat patients suffering from chronic fatigue syndrome (CFS) in South Korea. These results provide evidence of a novel activity of the KBT that regulate cytokines production related with CFS.


Overall efficacy for Siberian ginseng in CFS was not demonstrated. However, the findings of possible efficacy for patients with moderate fatigue suggests that further research may be of value.

Bojungikki-tang (BIT), a Chinese herb, significantly inhibited in peripheral blood mononuclear cells LPS-induced tumor necrosis factor (TNF)-alpha, interleukin (IL)-6, IL-10, transforming growth factor (TGF)-beta1 production. It may be useful in CFS.


The herb Ruscus aculeatus may have potential in treating orthostatic hypotension in CFS.


Both echinacea and ginseng significantly enhanced NK-function of CFS and AIDS patients. Similarly, the addition of either herb significantly increased antibody-dependent cellular cytotoxicity of peripheral blood mononuclear cells from all subject groups.

Sauna


A review of the literature finds one study providing weak evidence that far infrared saunas can be of help in CFS.

*

Sauna therapy may act to increase BH4 availability via two distinct pathways.


Far-infrared ray (FIR) dry sauna therapy helped a few patients to experience decreased fatigue and pain. PMID: 17561703

Miscellaneous Treatments


CFS patients receiving 15 treatments of hyperbaric therapy demonstrated improved test outcomes on a visual analog fatigue scale, a fatigue severity scale and a fatigue quality of life scale.


In a group of patients with chronic fatigue or CFS, fatigue symptoms, mental functioning and telomerase activity were significantly improved in a group practicing qigong exercises compared to controls.

A Korean patient’s toxic chronic fatigue symptoms improved after he was given mercury removal therapy.


The researchers’ previous study of whiplash injury found that abnormalities in the cervical muscles cause autonomic dystonia. More than 84% of CFS patients treated for this reported good outcomes.


The Chinese treatment of tuina can improve the symptom of patients with CFS.

* Sathyapalan T, Beckett S, Rigby AS, Mellor DD, Atkin SL. High cocoa polyphenol rich chocolate may reduce the burden of the symptoms in chronic fatigue syndrome. Nutr J. 2010 Nov 22;9:55. PMID: 21092175

A study of 10 CFS patients suggests that high cocoa liquor/polyphenol rich chocolate may improve symptoms.


Many CFS patients have diminished lung function, and breathing retraining can help to address that.

Replacement of incompatible dental materials resulted in down-regulation of metal-induced lymphocyte sensitivity in vitro, as well as in the improvement of health status of majority of patients with unspecific CFS-like symptoms.


Of a group of CFS sufferers, the percentage of users who found a treatment helpful was greatest for coenzyme Q10 (69% of 13 subjects), dehydroepiandrosterone (DHEA) (65% of 17 subjects), and ginseng (56% of 18 subjects). The use of yoga predicted subsequent fatigue improvement and yoga (p = .002). Magnesium (p = .002) was strongly associated with fatigue worsening from 6 months to 2 years. Yoga appeared to be most effective for subjects who did not have unclear thinking associated with the fatigue.


There is weak but equivocal evidence that the effects of homeopathic medicine are superior to placebo in CFS.

**Staphylococcus Toxoid**


This explorative study suggests that repeated administration of the Staphypan Berna vaccine in patients with fibromyalgia/CFS causes a serological response to several
staphylococcal antigens, particularly to certain extracellular toxins and enzymes. This response is related to the clinical outcome of treatment.


Treatment with staphylococcus toxoid injections over 6 months led to significant improvement in patients with FM and CFS. Maintenance treatment is required to prevent relapse.


The effect of vaccination with a staphylococcus toxoid was compared with the effect of injections of sterile water. Results suggest that treatment with staphylococcus toxoid may be a fruitful strategy in patients with fibromyalgia and CFS.

**Acupuncture**


Acupuncture can adjust metabolism of serum oxygen free radicals in rats that have been subjected to a forced-swim condition meant to simulate CFS.

The therapeutic effect of chronic fatigue syndrome treated through acupuncture with coiling dragon needling and moving cupping on back is superior to treatment with prednisone.

* 


Acupuncture at Back-shu point has a good therapeutic effect (including immediate and midterm effect) in the treatment of chronic fatigue syndrome patients.

* 


Acupuncture was more helpful than sham treatment at improving brain, physical and overall treatment in CFS patients.

* 


Compared to conventional massage, the “intelligent turtle” massage used in CFS demonstrates more improvements on IgA, IgM and IgG levels as well as improvement of symptoms.

* 


A literature review suggests that while acupuncture may be helpful for CFS, more studies are needed.

Acupuncture was helpful in improving the quality of life in CFS patients, especially in physiological field and individual perception to well being.


Acupuncture was better than sham acupuncture at relieving CFS patients’ mental fatigue.


Acupuncture helped CFS patients to feel less fatigued and better in general.


The use of cups in Chinese acupuncture was effective at relieving fatigue in CFS, compared to the use of acupuncture alone.


Studies in China suggest that acupuncture can be helpful for CFS, but the poor quality means that more scientifically rigorous studies need to be done.
**Paradigm Change**


Acupressure has the potential of being effective in CFS.

* Yiu YM, Ng SM, Tsui YL, Chan YL. A clinical trial of acupuncture for treating chronic fatigue syndrome in Hong Kong. Zhong Xi Yi Jie He Xue Bao. 2007 Nov;5(6):630-3. PMID: 17997936

Acupuncture is effective for CFS.


Electrical acupuncture was more effective in CFS than oral hydrocortisone.

**Combination Therapies**


An audit of 138 ME/CFS patients revealed that all had measureable mitochondrial dysfunction. A basic treatment regime (including stone-age diet, good sleep, nutritional supplements and getting the right balance between work and rest) improved mitochondrial function in a sample of these.

*

Following therapy consisting of dietary advise, chelating agents, supplements and acupuncture, a CFS patient became symptom free.


Acupuncture plus moxibustion combined with a psychological approach appears to be an effective therapy for CFS.


A group of Japanese researchers reported that Intravenous immunoglobulin therapy, magnesium and sizofirann (a biological response modifier targeting natural killer cells) were successful in improving the health of their CFS patients.

**Oxidative Stress -- Animal Models of CFS**


Shilajit, a traditional Indian remedy, was helpful in reversing the fatigue experienced by rats in a forced-swim trial.

Based on the findings of a forced-swim rat study, the researchers suggest a therapeutic role of lactobacillus acidophilus especially when incorporated into alginate beads for the treatment of CFS.


In a rat model of CFS, treatment with EGCG was helpful in reducing oxido-nitrosative stress and serum TNF-alpha levels and at reversing behavioral changes.


In a mouse model of CFS, the Chinese herb Radix Pseudostellariae was effective.


In a mouse model of CFS, olive extract was helpful in relieving oxidative stress.


In a mouse model of CFS, epigallocatechin gallate was found to be effective at addressing oxidative-nitrosative stress and TNF-alpha levels in the brain.

In a mouse model of CFS, the natural polyphenol naringin was successful in attenuating oxidative stress as well as TNF-alpha levels.


In a mouse model of CFS, epigallocatechin gallate was effective at reversing behavioral deficits and oxidative-nitrosative stress.


In a rat model of CFS, Nardostachys jatamansi extract normalized lipid peroxidation, nitrite, superoxide dismutase, catalase and overall behavior.


In a mouse model of CFS, the antidepressant drugs imipramine, desipramine and citalopram helped with anxiety and oxidative stress, improved locomotor activity, and reduced immobility time.

In a mouse model of CFS, treatment with curcumin resulted in decreased oxidative stress, decreased TNF-alpha levels, and decreased immobility time.


In a rat simulation of CFS, astragalus membranaceus flavonoids helped to normalize cytokines.


In a mouse model of CFS, Hochu-ekki-to (TJ-41) combined with interferon-gamma (IFN gamma) appeared to have a protective effect on host immune responses, but did not seem neuroprotective.


In a mouse model of CFS, trazodone was protective against oxidative damage, especially when preceded with treatment with L-NAME. Pre-treatment with l-arginine removed the protective effect of the trazodone.


In a mouse model of CFS, brewers’ yeast extract seemed to be protective.

In a mouse mode of CFS, green tea extract and catechin were effective at decreasing oxidative stress.

**Stress Reduction**


Studies show that the energy envelope approach, which involves rehabilitation methods, helps patients with ME/CFS pace activities and manage symptoms and can significantly improve their quality of life.

* 


Activity logs can provide investigators and clinicians with valuable sources of data for understanding patterns of fatigue and activity among patients with CFS.

* 


Although energy maintenance may be associated with improved functioning and less severe symptoms for some CFS patients, a subsegment of patients was severely limited in functioning despite using adaptive coping strategies.

*
Based on various studies, it is proposed that pacing can help to stabilize the condition of CFS and avoid post-exertional malaise.


CFS patients who had a “student buddy” to help out with tasks had significantly greater reductions in fatigue severity and increases in vitality than individuals in the control condition.

Reynolds NL, Brown MM, Jason LA. The relationship of Fennell phases to symptoms among patients with chronic fatigue syndrome. Eval Health Prof. 2009 Sep;32(3):264-80. PMID: 19696083

CFS patients who use a crisis approach to coping are less functional than other patients.


Pacing was evaluated as useful by 96% of the participants, rest by 97%, and 96% of the participants considered complete shielding and quietness to be useful. 57% of the participants who had received help to identify and challenge negative thought patterns regarded this useful. 79% of the participants with experience from graded training regarded this to worsen their health status.

Findings suggest no statistically significant association between pet ownership and self-reported health in people with CFS.


CFS patients who were trained in a stress reduction technique demonstrated improvements.


A “hostile resistance” coping strategy seems to trigger both physiological and symptom perception processes contributing to the clinical picture of CFS.


Patients who accept their condition rather than trying to control their symptoms feel less fatigued and more emotionally stable.


The effects of an integrative, consumer-driven rehabilitation program on quality of life and symptom severity for individuals with chronic fatigue syndrome were examined.
M.E. TREATMENTS

MEDIA COVERAGE

“I Was a Zombie for Years, Then A Massage Brought Me Back to Life: ME Treatment
November 12, 2011
Daily Mail (UK)
Which GP’s Don’t Know About”
By Alex Terry

http://www.dailymail.co.uk/health/article-2060818/I-zombie-years-massage-brought-life-ME-treatment-GPs-dont-know-about.html

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August 2011
Ladies’ Home Journal
What Ever Happened to Chronic Fatigue Syndrome
By Margery D. Rosen


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May 14, 2011
KSL-TV
Fibromyalgia to Cause “Bone-Crushing Fatigue”
By Wendy Leonard

http://www.ksl.com/?nid=960&sid=15534055

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October 27, 2009
The Washington Post
Don’t Wait for a Cure to Appear
As Someone with Chronic Fatigue Syndrome, I Had to Change My Life to Get Relief
By Zachary Sklar
Paradigm Change


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December 3, 2009  
Woman's Day  
Understanding Chronic Fatigue  
By Barbara Brody

http://www.womansday.com/Articles/Health-Fitness/Conditions-Diseases/Understanding-Chronic-Fatigue.html

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January 3, 1999  
The New York Times  
Q&A: A Doctor Tackles the Mysteries of Fatigue  
By Karen DeMasters


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October 2, 1991  
The New York Times  
Test Drug Seen as Promising in Study on Chronic Fatigue  
By Lawrence K. Altman


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April 30, 1991  
The New York Times  
Magnesium May Play Role in Chronic Fatigue Syndrome
Rituximab:

May 2013
Discover Magazine
Are B-Cells to Blame for Chronic Fatigue Syndrome?
By Jill Neimark

http://discovermagazine.com/2013/may/01-are-b-cells-to-blame-for-chronic-fatigue-syndrome#.UaWQlY5OTzI

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December 23, 2011
Irish Central (UK)
Irish Doctor Opens New Chronic Fatigue Syndrome Clinic in NYC
By Molly Muldoon


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December 22, 2011
Lab Canada
Plans Unveiled For New Complex Chronic Disease Clinic


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December 6, 2011
The Vancouver Sun
BC Women’s Hospital Named New Medical Centre For Lyme, Chronic Fatigue and Other Complex Diseases
By Pamela Fayerman

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October 26, 2011
Huffington Post
Chronic Fatigue Syndrome -- A Treatable Autoimmune Disease
By Matthew Edlund, M.D.

http://www.huffingtonpost.com/matthew-edlund-md/chronic-fatigue-syndrome_b_1028341.html

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October 24, 2011
ABC News
Chronic Fatigue Syndrome: Study Supports Autoimmune Disease Theory
By Katie Moisse


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October 24, 2011
Daily Mail (UK)
Cancer Drug ‘Key to Treating Chronic Fatigue’ As Experts Say Syndrome May be Caused By Defective Immune System
By Claire Bates


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October 23, 2011
BBC
Immune System May Cause ME
By James Gallagher
Chronic Fatigue Syndrome Eased By Cancer Drug
By Andy Coghlan

“Cure Together” Treatment Ratings

The Cure Together website offers surveys allowing patients with various diseases to rate whether specific treatments were helpful or harmful to them. As of 5/28/13, more than 500 patients had responded to the survey about “Chronic Fatigue Syndrome (CFS).”

Listed here are the percentages of people (out of those who tried it) who found each treatment to be of moderate or major effectiveness.

Also listed are treatments in which 20% or more (out of those who tried it) reported that it had made their condition much or moderately worse.

Treatments with fewer than 20 people responding are not included on this list.

70%+ Effectiveness:

Lifestyle:
* Spend time in low stimulation environment. 72%
* Take frequent rest breaks. 71%
* Wheelchair. 71%

60%+ Effectiveness:

Lifestyle:
* Rest. 64%
* Personal development (learn to say no). 63%

Hormones:
* T3. 65%

Drugs:
* Low Dose Naltrexone (LDN). 62%

50%+ Effectiveness:
Avoidance:
* Avoid allergens. 59%
* Avoid biotoxins. 57%

Lifestyle:
* Ignore people who think ME/CFIDS is not real. 54%
* Mindfulness. 54%
* Meditation. 53%
* Change job. 50%

Diet/Nutrition:
* Diet changes. 52%
* Treat methylation. 51%

Bodywork:
* Invert body position. 56%
* Qi Gong. 52%

Drugs:
* Klonopin. 51%

40%+ Effectiveness:

Avoidance:
* Avoid mold. 49%
* Reduce sugar. 49%
* Avoid gluten. 46%
* Avoid dairy. 44%
* Avoid alcohol. 43%

Bodywork:
* Massage. 49%
* FIR sauna. 47%
* Diaphragmatic breathing. 45%
* Lymphatic Massage. 44%
* Stretching. 43%
* Cranial Sacral. 42%
* Yoga. 41%
* Chiropractic. 40%
Drugs:
* Stimulants. 49%
* Tramadol. 49%
* Ritalin. 47%
* Antivirals. 45%
* Xanax. 42%
* Baclofen. 41%
* Ibuprofen. 41%

Infections:
* Treat yeast. 49%
* Sinus treatments. 43%

Supplements/Nutrition:
* B12 Injections. 46%
* Probiotics. 42%
* Betaine Hcl. 40%
* Electrolyte beverages. 40%

Lifestyle:
* Go to bed early/sleep longer. 43%
* Amygdala retraining. 41%

Alternative:
* Ayurveda. 41%

30%+ Effectiveness

Supplements/Nutrition:
* Oral magnesium. 39%
* Malic acid. 38%
* NAC. 38%
* Stay well-hydrated. 38%
* Sublingual B12. 36%
* Topical magnesium. 36%
* D-Ribose. 34%
* Myers’ Cocktail. 34%
* Acetyl-L-Carnitine. 32%
* B Vitamins 32%
* Chinese herbs. 32%
Eat more produce. 32%
Liposomal glutathione. 32%
Anti-Yeast Diet. 31%
Vitamin D. 31%
Omega 3. 31%
Cerefolin. 31%
Ionized water. 30%
MSM. 30%

Hormones:
* Testosterone. 37%
* Bioidentical Hormones (e.g. progesterone). 36%
* Cortef. 35%
* DHEA. 33%
* Melatonin. 31%

Antibiotics:
* Doxycycline. 39%
* Antibiotics. 37%

Antidepressants:
* Cymbalta. 38%
* Wellbutrin. 35%

Bodywork:
* Osteopathy. 38%
* Tai Chi. 37%
* Soak feet in cold water. 36%
* Cool shower following exertion. 34%
* Root canal/cavitation removal. 33%
* Reiki. 32%
* Acupuncture. 30%

Other Drugs:
* Guaifenesin. 38%
* Chelation. 36%
* Immunovir. 36%
* Provigil. 35%
* Antihistamines. 34%
* Naproxen. 34%
* Beta Blockers. 31%
* Neurontin. 31%
* Tylenol. 31%
* Benadryl. 30%

Lifestyle:
* Emotional Freedom Technique (EFT). 34%.
* Distract attention from symptoms. 33%

20%+ Effectiveness:

Antidepressants:
* Amitriptyline. 29%
* Trazadone. 28%
* Celexa. 28%
* SSRIs. 25%
* Effexor. 23%

Exercise:
* Mild/Moderate Exercise. 29%
* Regular Exercise Program. 25%
* Orthostatic conditioning. 23%

Supplements/Nutrition:
* Alpha Lipoic Acid. 28%
* Licorice Root Extract. 28%
* CoQ10. 27%
* L-Carnitine. 27%
* Inosine. 26%
* Iodine. 26%
* 5HTP. 25%
* Omega 3, 6, 9. 25%
* Vitamin C (Lypospheric). 24%
* Glucosamine/Chondroitin. 23%
* NADH. 22%
* Undenatured whey. 22%
* Gingko Biloba. 21%
* Vitamin E. 21%
* Fresh Juicing/Smoothies. 20%

Alternative:
* Kinesiology. 28%
* Homeopathy. 27%

Other Drugs:
* Aspirin. 27%
* Caffeine. 25%

Lifestyle:
* Psychotherapy. 25%
* Cognitive-Behavioral Therapy (CBT). 24%

Bodywork:
* Rolfing. 21%

Less Than 20% Effectiveness:

Lifestyle:
* Brainwave Audio CD’s. 19%
* Neurofeedback. 17%

Supplements:
* Olive Leaf Extract. 19%
* SAM-E. 19%
* Cat’s Claw. 17%
* GABA. 17%
* Garlic. 16%
* Vitamin A. 13%
* Monolaurin. 8%

Antidepressants:
* Prozac. 19%
* Zoloft. 16%
* Paroxetine. 15%

Bodywork:
* Skin Brushing. 19%
* Detox Foot Baths. 14%
* Rebounder. 11%

Other Drugs:
* Doxylamine. 18%
Alcohol. 14%

Exercise:
* Graded Exercise Therapy (CBT). 18%

**Treatments with 20%+ Reporting Declines:**

Exercise:
* Graded Exercise Therapy (75%)
* Regular Exercise Program (45%)
* Mild/Moderate Exercise (43%)
* Orthostatic Conditioning/Exercise (32%)

Antidepressants:
* Paxil (59%)
* Prozac (46%)
* Zoloft (44%)
* Effexor (43%)
* Elavil (43%)
* SSRI’s (43%)
* Trazodone (40%)
* Wellbutrin (38%)
* Cymbalta (36%)
* Celexa (32%)

Other Drugs:
* Alcohol (57%)
* Caffeine (37%)
* Neurontin (32%)
* Provigil (31%)
* Benadryl (28%)
* SAM-E (23%)

Lifestyle:
* Cognitive/Behavioral Therapy (CBT) 20%

http://curetogether.com/chronic-fatigue-syndrome/treatments/
Survey Discussion:

Only a relatively small number of different types of treatments were reported as helpful by more than half of those survey respondents who had tried them.

Topping the list were “pacing” activities: spending time in low-stimulation environments, taking rest breaks, learning to say no, ignoring people who didn’t believe in the illness, meditation, mindfulness and changing job (presumably to a less stressful one). A high percentage of the relatively small number of participants (n=55) who had tried a wheelchair found it helpful.

Avoiding “biotoxins” (presumably including toxic mold) was found to be helpful for 57% of respondents. About 59% said that they had been helped by avoiding “allergens” (unspecified, possibly including food). Just over half said that they had been helped by changes in diet (also unspecified).

Only a few drugs were found helpful by more than 50% of patients who had tried them: T3 (a form of thyroid hormone), Low-Dose Naltrexone (an immune modulator) and Klonopin (a benzodiazepine often prescribed for sleep). Treating methylation (presumably with supplements such as activated folate and B12) was found helpful by just over half of respondents.

Two other interventions with more than 50% of participants reporting positive outcomes were qi gong and inversion of body position.

Also rating fairly highly in the survey (with 43-49% reporting benefits) were a variety of other kinds of avoidance activities -- mold, sugar, gluten, dairy and alcohol. (About 140 people responded to the item about “avoiding mold,” compared to only 70 to the item about “avoiding biotoxins,”)

Several bodywork treatments (massage, lymphatic massage, far infrared sauna, stretching, cranial sacral, yoga, chiropractic, diaphragmatic breathing) all were found helpful by more than 40% of those who tried them.

Treating yeast and sinus infections (presumably frequently caused by fungi) were reported as helpful by about 45% of those who had tried this. The alternative treatments of amygdala retraining and ayurveda were found effective by about the same percentage, as was simply going to bed earlier and sleeping longer.

Supplements and drugs found helpful by 40-49% of participants who had tried them included B12 shots; probiotics; betaine HCl; electrolyte beverages; Xanax; antivirals; Ritalin and other stimulants; and the pain relievers tramadol, baclofen and ibuprofen.
Reported as helpful by less than 40% of respondents who had tried them were a vast smorgasbord of other drugs, supplements and alternatives. None of these was reported as having prompted a major improvement by any more than a tiny percentage (less than 5%) of people reporting.

Ironically, two treatment types frequently suggested for CFS by non-specialists -- anti-depressants and exercise -- appear to be by far the least appropriate for the disease, based on this survey. Relatively few respondents (less than 30%) reported being helped by these treatments, and relatively high percentages (30-75%) who had tried them said that they had been harmed by them.

Other treatments that were reported as having had negative effects by substantial numbers of respondents were alcohol (57%), caffeine (37%), neurontin (32%), Provigil (31%), Benadryl (28%), SAM-E (23%) and cognitive-behavioral therapy (20%).

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