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THE ME ASSOCIATION

# Alternative and complementary approaches to management



Including:

- Acupuncture
- Aromatherapy
- Bach Flower remedies
- Candida overgrowth
- Cannabis (CBD)
- Amalgam removal

- Plant-based remedies
- Homeopathy
- Hypnotherapy
- Massage
- Oxygen therapy
- Talking therapies
- Vitamins and minerals

JULY 2024



Alternative and complementary approaches to management was written by Dr Charles Shepherd, Trustee and Hon. Medical Adviser to The ME Association.

#### DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/ CFS or Long Covid.



## ALTERNATIVE AND COMPLEMENTARY APPROACHES TO MANAGEMENT

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Sometimes the best way to choose a therapist is on personal recommendation from someone who has ME/CFS, or possibly your GP.



## IMPORTANT QUESTIONS TO ASK

If you are going to try an alternative approach, here are some questions that are worth asking before you go ahead.

#### Is the therapy or therapist reputable?

Balanced information on alternative therapies isn't always easy to obtain because the internet and other sources can be both reliable and unreliable. But there are some internet sources such as the NHS website, Cleveland Clinic, Mayo Clinic and WebMD that normally provide balanced information on both the effectiveness and safety of many alternative therapies.

Sometimes the best way to choose a therapist is on personal recommendation from someone who has ME/CFS, or possibly your GP. An increasing number of specialties in the alternative sector now have their own regulatory bodies – rather like the General Medical Council for doctors – but they are seldom as strict. Where this is the case it's important to check that the therapist is on an approved professional register.

## How much is the treatment going to cost?

Alternative therapies often require a course of treatments – so find out how long a course is likely to last and if there are going to be any other additional expenses for investigations or supplements.

## Could there be any possible adverse effects?

Although alternative treatments are often promoted as being 'perfectly safe' or 'natural', adverse reactions do occur. Some treatments, such as homeopathy, can be regarded as normally being very safe. But herbal/ plant medicines can affect liver function and some types of allergy treatment can produce serious adverse reactions.

## How will the treatment help in ME/CFS?

Ask if the treatment has been assessed in any form of proper clinical trial to assess both effectiveness and safety in ME/CFS. If it has, what were the results? And where exactly were they published?

## IMPORTANT QUESTIONS TO ASK



## Will the practitioner tell your GP about the findings or treatment?

With GPs becoming much more open-minded about alternative therapies, this type of co-operation should now be occurring as a matter of routine.

## Does the therapist have professional indemnity insurance?

This will cover you and the therapist if anything goes wrong. If answers to questions are evasive or unsatisfactory, it's time to reconsider. Professional organisations – listed later – can supply more information along with contact details of practitioners in your area who have gone through a programme of professional training.

Some treatments, such as homeopathy, can be regarded as normally being very safe. But herbal/ plant medicines can affect liver function and some types of allergy treatment can produce serious adverse reactions.



## INTRODUCTION

With orthodox medicine failing to provide any form of effective treatment aimed at the underlying disease process in ME/CFS, it's not surprising to find that many people turn to the alternative and complementary (ACM) health sectors for help for their symptoms.

The MEA remains open-minded about alternative approaches. But we



Many people with ME/CFS find alternative approaches helpful and the treatment may, of course, be having a genuine therapeutic effect.



© ME Association 2024. Reproduction is not allowed without the written permission of The ME Association can only recommend treatments for which there is good quality evidence to demonstrate that they are both safe and effective. So our advice tends to be very cautious about many of these alternative approaches. At the same time, there are occasions when we feel it is necessary to warn people about new forms of highly speculative treatment which are not only expensive but can sometimes turn out to be harmful.

During the preparation of the new NICE guideline on ME/ CFS the committee considered all the evidence on efficacy and safety from clinical trials that had taken place to assess

alternative and complementary therapies. Many of these trials were small and had significant defects. Consequently the new NICE guideline does not recommend any alternative treatment.

Many people with ME/CFS find alternative approaches helpful – possibly for a number of reasons. The treatment may, of course, be having a genuine therapeutic effect. But the fact that you are paying for something you have been told will help, and at the same time being treated by a very sympathetic and understanding practitioner, can have a very positive therapeutic effect.

In the past, most doctors were either very sceptical or took a hostile view about alternative therapies. The situation is now starting to change and you may well find that an approach such as acupuncture for pain relief, for which there is some evidence of benefit, is available at your local GP surgery or NHS hospital.

#### Treatments on offer

The choice of treatments is vast. And, as we know from all the publicity material that comes into the MEA, a new form of treatment or 'cure' aimed at vulnerable people with ME/CFS is introduced every month or so. As it's not possible to cover all these diverse approaches, this information will concentrate on the most popular ones.

## ACUPUNCTURE

Acupuncture may help to relieve headaches and various types of chronic pain – but there haven't been any proper clinical trials to assess the use of acupuncture in ME/CFS.

This ancient Chinese treatment involves sticking very fine needles into the skin at places known as acupuncture points. Nobody is certain how acupuncture works, but it may stimulate the release of endorphins – the body's own natural painkillers – in the brain. Another possibility is that it helps to 'switch off' areas in the brain involved in the perception of pain.

Acupuncture may be worth trying as an alternative to, or perhaps in combination with, normal painkillers – especially where pain is localised to one or more areas. The treatment is

normally given as a course over several weeks or months because the benefits take time to build up.

There is some evidence to show that acupressure, a variant of acupuncture, can help to relieve nausea and vomiting.

## ALLERGIES

Some people with ME/CFS develop an allergic component to their illness. Where this is the case, it's worth asking your GP if management can be helped by orthodox allergy tests and treatments. If the symptoms are more severe, you could ask for a GP referral to an NHS allergy clinic.

Allergy testing and treatment in the alternative sector is controversial – mainly because there are so many tests of no proven value. So you could end up being diagnosed as being allergic to foods and other substances when this isn't actually so. At the same time, genuine allergies may be missed.

Alternative allergy tests that are considered unreliable, even fraudulent, by doctors include hair analysis, kinesiology and Vega testing.

If you want to self-test for food allergy/intolerance, there are some private laboratories that carry out blood tests to look for a food-specific antibody called immunoglobulin G. But do take medical advice before doing so because some of these private allergy testing services are not providing accurate information.



Acupuncture may be worth trying as an alternative to, or perhaps in combination with, normal painkillers - especially where pain is localised to one or more areas.





The Complete Guide to Food Allergy and Intolerance "It is no exaggeration to say that your book gave

## ALLERGIES

A number of allergy treatments – examples include enzyme-potentiated desensitisation/EPD and neutralisation therapy – are available privately. These are expensive and their value in ME/CFS is purely anecdotal and not proven through proper clinical trials.

■ The Complete Guide to Food Allergy and Intolerance (Bloomsbury Publishing) is still a reliable source of information that covers both alternative and conventional allergy tests and treatments. It is written by Prof Jonathan Brostoff – an immunologist with a longstanding interest in ME/CFS – and Linda Gamlin.

Available from Amazon in paperback:

https://tinyurl.com/y9xpuyxc

## AROMATHERAPY



Aromatherapy involves using small amounts of plant oils that can be massaged into the skin, inhaled, or put in the bath.



This involves using small amounts of plant oils that can be massaged into the skin, inhaled, or put in the bath. The oil enters the bloodstream and may act in a similar way to conventional drugs. Some of these oils may produce symptomatic relief – lavender oil for example is soothing – but there isn't any evidence that any of these oils can treat the underlying disease process in ME/CFS.

As with any plant product, some people find they are sensitive to certain aromatherapy oils. So it's worth testing the skin with a small amount of oil first – especially if you have sensitive skin. Other side-effects may include headaches and nausea. Some of these oils also interact with medicines such as antibiotics – so check with your therapist or pharmacist before you use them.

## BACH FLOWER REMEDIES

Created by Dr Edward Bach, an English physician and homeopath, these consist of nearly 40 flower-based remedies that are usually taken as drops in water.

> Dr Bach believed that illness was caused by emotional imbalance and that flower-based remedies could redress these 'negative emotional states'. But there is no sound scientific research to support these claims and very little feedback on their use in ME/CFS.

Bach flower remedies can be taken singly or in combination with herbal products, homeopathic remedies, or conventional drugs. As with other remedies based on plants, there is a potential for side-effects and interactions to occur with

conventional medicines – so do check with your doctor or pharmacist if you are taking any other treatment.

## CANDIDA OVERGROWTH

Some alternative practitioners still believe that overgrowth of this yeast-like fungus, also known as thrush, is a major component of ME/ CFS. They also maintain that 'candida overgrowth' needs to be treated by a combination of a strict 'anti-candida diet', antifungal drugs, and the use of probiotics ('friendly' gut bacteria).

Claims about a link between candida and ME/CFS have been around for many years but no satisfactory supportive evidence has ever been produced. So orthodox medical opinion believes that there is no point in people with ME/CFS trying to eradicate candida from their body – unless, of course, you do have a proven candida infection on the skin or in the genital area.



Dr Bach believed that illness was caused by emotional imbalance and that flowerbased remedies could redress these 'negative emotional states'.





## CANNABIS AND CANNABIS OIL (CBD)

A wide variety of cannabis oil (CBD) products are now being promoted for pain relief. They are available on the internet and from health food shops. However, there is still no firm evidence from clinical trials to confirm their effectiveness in pain relief and they can cause sideeffects and interact with prescription drugs.

> More information on CBD oil products can be found in an Ask the Doctor Q and A in the Autumn 2024 issue of ME Essential (the magazine for ME Association members) and as a Medical Matters Question and Answer on our website.

Become a member to receive ME Essential

**Read Medical Matters on the MEA website** 

A wide variety of cannabis oil (CBD) products are now being promoted for pain relief. However, there is still no firm evidence from clinical trials to confirm their effectiveness in pain relief.



## DENTAL AMALGAM REMOVAL

Concerns about the use of mercury in dental amalgams, and the possible leakage of mercury vapour into the body, has led to a possible link between this type of dental filling and conditions such as dementia, multiple sclerosis and ME/CFS.

As a result, some people with ME/CFS have their fillings removed – even though there is no conclusive scientific evidence at present to support this. Having your fillings removed is not a procedure that is generally available on the NHS and will probably have to be carried out privately.

There is also a risk that the considerable discomfort caused by removal of multiple fillings will cause an exacerbation or relapse of existing symptoms.

Before going down this route, it's well worth exploring both sides of the debate. So check out the information on mercury-free dentistry and the views put forward by the British Dental Association and speak to your dentist about what sort of fillings are available.

#### https://mercuryfreedentistry.org.uk

https://www.bda.org

Evening primrose oil (EPO) may help to relieve joint pain. This is because it contains essential fatty acids – substances thought to reduce inflammation in the body.



## HERBAL AND PLANT-BASED REMEDIES

Remedies made from plant sources are becoming increasingly popular – often on the basis that they are natural and safe to use. There's no doubt that many of the active ingredients in plants do have genuine therapeutic effects. But just as with orthodox drugs – some of which, such as aspirin and digitalis, are derived from plants – can have sideeffects, particularly on the liver.

So herbal remedies need to be used with care and preferably with the advice of a qualified medical herbalist rather than on a do-it-yourself basis, especially if you are going to try something more unusual.

Plant-based therapies that are sometimes used by people with ME/ CFS include:

## Evening primrose oil (EPO)

Evening primrose oil (EPO) may help to relieve joint pain. This is because it contains essential fatty acids – substances thought to reduce inflammation in the body. As far as ME/CFS is concerned, two small clinical trials have assessed the value of EPO. One reported some minor benefits whereas the other did not. The oil is usually well tolerated by people with ME/CFS.

#### Echinacea

Echinacea appears to simulate the immune system. However, anecdotal reports from people with ME/CFS who have tried it have not always been positive. This may be due to the fact that research now suggests that ME/CFS involves low-level immune-system activation. So echinacea needs to be used with care – especially if you already have flu-like symptoms that could be caused by immune system activation.

#### Ginkgo biloba

Ginkgo biloba is claimed to improve various brain problems – particularly memory and concentration – possibly because it improves blood supply to the brain. However, the evidence from clinical trials in people with dementia is not convincing and no clinical trials have been carried out in people with ME/CFS. One rare but serious side-effect is bleeding into the brain – so this is a herbal remedy that should not be used if you already have any type of blood disorder, or take aspirin.



## HERBAL AND PLANT-BASED REMEDIES

#### St John's Wort (hypericum perforatum)

St John's Wort (hypericum perforatum) is a herbal remedy that is sometimes used to self-treat mild depression. However, doctors no longer recommend using St John's Wort because it can induce drugmetabolising enzymes and cause a number of important interactions with conventional drugs, including antidepressants. This is not a do-it-yourself form of treatment – so do take advice from a doctor, pharmacist or medical herbalist if you are thinking of using hypericum.

Do not take this herb in combination with a prescribed antidepressant.



#### Turmeric

Turmeric is a good example of a plant-based product that appears to have genuine therapeutic effects – in particular the reduction of inflammation. This anti-inflammatory effect is something that could be of value in ME/CFS, where research indicates that low-level inflammation may be occurring.

So this is a plant-based treatment that is worthy of further research.

Turmeric is a good example of a plantbased product that appears to have genuine therapeutic effects - in particular the reduction of inflammation.



## HOMEOPATHY

This works on the principle that 'like cures like'. In practice, this means being treated with very diluted natural medicines that would produce similar symptoms in a healthy person.

> One example would be the use of Allium cepa, a homeopathic remedy derived from onions, to treat someone with hay fever. This is because an onion would normally cause watering eyes and a runny nose.

However, the precise homeopathic medicine, or medicines, would be selected on the answers to a wide range of questions about you and your symptoms that are obtained during a homeopathic consultation. So homeopathy is not usually a doit-yourself form of therapy.

Some homeopaths are medically qualified doctors and will have a good idea about when to use homeopathic medicines alone or when it's better to use them in combination with conventional medicines.

There used to be three NHS homeopathic hospitals – in Bristol, Glasgow and London. However, NHS England no longer allows homoeopathic medicines to be prescribed on the NHS as it views the effects as being purely placebo.

NHS England information on homeopathy:

https://www.nhs.uk/conditions/homeopathy

Most doctors also remain sceptical about the scientific basis of homeopathy. However, there is one published study that demonstrated some benefit in people with ME/CFS: Weatherley-Jones E *et al*, 2004. A randomised, controlled, triple-blind trial of the efficacy of homeopathic treatment for chronic fatigue syndrome. Journal of Psychosomatic Research 56:189-197.



Some homeopaths are medically qualified doctors and will have a good idea about when to use homeopathic medicines alone or when it's better to use them in combination with conventional medicines.





## HYPNOTHERAPY

This involves inducing a trance or dream-like state of deep relaxation in order to treat mainly psychological or emotional problems.

There is evidence that hypnotherapy can be helpful in some cases of anxiety, irritable bowel syndrome and smoking cessation. On the other hand it needs to be used with care as it can cause mental health problems when used inappropriately.

There is evidence that hypnotherapy can be helpful in some cases of anxiety, irritable bowel syndrome and smoking cessation.



The Alexander Technique is normally regarded as a safe form of treatment.



## MASSAGE, TOUCHING THERAPIES AND MANIPUATION

#### Massage

Massage is usually a gentle hands-on approach and generally considered to be safe. Some types of manipulation therapy involve more active movement of tissues and bones and can sometimes cause serious sideeffects. So any form of manipulation needs to be used with care if you have ME/CFS.

## Alexander technique

Alexander technique is claimed to help people become more aware of their body, improve their posture and move more efficiently. So it may help to remove tension in the body and relieve various types of musculoskeletal pain, especially back and neck pain. Research evidence is limited but some people with ME/CFS find it helpful. No manipulation is involved – just gentle touch. So the Alexander Technique is normally regarded as a safe form of treatment.

## Bowen technique

Bowen technique involves a combination of minimal light movements over body tisses which are interspaced with hands-off periods. It is claimed to help with muscle and nerve pain but there is no sound scientific evidence of efficacy.

Some osteopaths believe that this form of treatment can be of benefit in the management of ME/CFS.

## MASSAGE, MOVEMENT AND MANIPULATION THERAPIES

#### **Craniosacral therapy**

Craniosacral therapy is a hands-on therapy that may involve manipulation of the tissues and bones in and around the neck and spine. It is claimed to help migraines, tension headaches, temperomandibular joint disorders, neck and shoulder pain. There is very little scientific evidence to support its use and side-effects can occur, including headaches, vertigo and brain-stem dysfunction.

## **Osteopathy and Perrin technique**

Some osteopaths believe that this form of treatment, which may involve manipulating and mobilising the spine, can be of benefit in the management of ME/CFS. This is largely based on the unproven hypothesis that there is a disturbance of lymphatic drainage in the brain and muscles along with a build up of toxins.

## Pilates

Pilates involves activities and exercises that focus on improving core strength through the use of structured exercises which can slowly get more challenging. So this is a more active approach that should only be tried with caution if you have ME/CFS.

## Reflexology

Reflexology is another type of massage that involves applying different amounts of pressure to the feet, hands and ears. It is claimed to help with a wide range of medical conditions but there isn't any sound evidence from clinical trials to support these claims.

#### Reiki

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Reiki can be a hands-on or hands-off approach that claims to use lifeforce energy to promote healing. Again, there is no sound scientific evidence to support these claims and no evidence that it is an effective treatment for ME/CFS.

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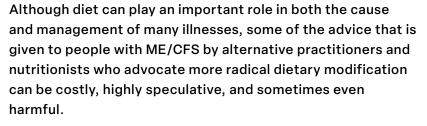
## MEDITATION

Meditation comes in many forms – some of which are based on Buddhism or Hinduism such as transcendental meditation. Some people with ME/CFS report that they have found meditation helpful, especially where stress is a significant factor in their lives.

## NUTRITIONAL THERAPIES



At present, most conventional dietitians would go no further than to recommend a healthy balanced diet that contains a wide range of nutrients.



At present, most conventional dietitians would go no further than to recommend a healthy balanced diet that contains a wide range of nutrients, encouraging the use of foods containing

complex carbohydrates (which help to keep blood sugar levels stable) and only restricting the intake of specific foods, or groups of foods, when there is good evidence of intolerance or sensitivity to support such an approach.

As already mentioned, some of the tests used to diagnose food allergies and sensitivities in the alternative sector are not reliable and bad advice here regarding dietary restrictions could have an adverse effect on your health. It's also worth noting that while some nutritionists do have reputable qualifications others may not.



The MEA has produced a free booklet, **Diet and Nutrition**, in which we examine the role of diet, how it can help to improve health when suffering from ME/CFS or Long Covid and ways we could improve what we eat and how we eat it. We consider malnutrition and how essential nutrition should be provided when severely or very severely affected. We also share diet trends and tips and answer commonly asked questions from the patient community.

#### **Download PDF**





Sarah Hews, ME/ CFS sufferer, experiencing hyperbaric oxygen therapy. Her story was featured in the Spring 2023 issue of ME Essential, the magazine for ME Association members.



## OXYGEN THERAPY AND HYPERBARIC OXYGEN THERAPY

Based on the unproven hypothesis that increasing the level of oxygen in the body, especially to the brain, is beneficial in conditions like autism, MS and ME/CFS, a number of non-prescription oxygen-based treatments have been promoted for use in these conditions. The evidence here is not convincing. Spending money on these sort of treatments is not therefore something that we would recommend.

Hyperbaric oxygen (HBO) treatment involves the use of 100% oxygen at higher than normal pressure in a special chamber. HBO is now available in a few centres around the UK that essentially cater for people with multiple sclerosis.

At present, there is no sound evidence to show that hyperbaric oxygen is an effective treatment for either ME/CFS or MS. It is regularly used to treat diving disorders and gangrene – where there is good evidence of benefit.

The use of HBO is discussed in more detail in a **Medical Matters Question and Answer** 

## MIND-BODY TREATMENTS

A growing number of alternative and often expensive 'talking therapies' are being aimed at people with ME/CFS. Examples include the Chrysalis Effect, Gupta Programme, Lightning Process and Mickel Therapy.

Brain retraining and neurolinguistic programming are two approaches that claim to make use of what is called neuroplasticity – or rewiring the nervous system in simple terms – to return parts that have become dysfunctional to normal. This all sounds very impressive and a lot of the promotional material is now being aimed at people with ME/CFS. However, there is no scientific evidence to support the scientific basis or results from clinical trials to endorse their use in ME/CFS. This is not an approach that we would recommend.

Many of these approaches combine elements of 'brain reprogramming', cognitive behavior therapy, and positive thinking. Consequently, the main aim may be to change illness beliefs and behaviours – as happens with CBT. They may also include manipulation and massage.

From what we know at present, there is certainly no harm in taking a good quality multivitamin tablet, especially if you have any dietary restrictions.



Publicity for these approaches often includes glowing reports from people who have gained benefit – some of whom then go on to become therapists. However, none of these approaches has so far been subjected to proper clinical trials to assess their efficacy and safety.

The MEA does not therefore endorse or recommend any of these treatments/programmes and the new NICE guideline is very specific about not recommending the use of the Lightning Process.

More information on most of these talking therapies can be found in the news archive on the MEA website. If you want to look at feedback from people who have used these types of therapies, there are regular discussions on the MEA Facebook page – previous discussions can be located using the search facility.

## VITAMINS, MINERALS AND SUPPLEMENTS



At present, there is no sound evidence to show that people with ME/CFS have significant deficiencies in either vitamins or minerals – the one possible exception being vitamin D.

While there is still no good quality evidence to show that vitamins or mineral supplements are of benefit in treating ME/ CFS, the use of costly vitamin and mineral supplements is often recommended by alternative practitioners and nutritional therapists.

From what we know at present, there is certainly no harm in taking a good-quality multivitamin tablet, especially if you have any dietary restrictions. But the use of expensive products, or those that contain high doses of individual vitamins or minerals is highly speculative and best avoided.

## **B** vitamins

One study has shown minor decreases in several B vitamins but these results have not been replicated. Ref: Heap LC, *et al* 1999. Vitamin B status in patients with chronic fatigue syndrome. Journal of the Royal Society of Medicine 92: 183-185.



## VITAMINS, MINERALS AND SUPPLEMENTS



There is no sound evidence of **vitamin B12 deficiency** in ME/ CFS. However, it's important to note that vitamin B12 deficiency (pernicious anaemia) can cause ME/CFS type symptoms and can also cause serious damage to the spinal cord. So selftreatment with vitamin B12 supplements is not advised and, if you are going to do so, this should only be done if pernicious anaemia has been excluded.

For more information on vitamins, minerals and supplements, please refer to the booklets in the **free literature** section on the ME Association website:

https:// meassociation.org. uk/free-literaturedownloads/



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#### Co-enzyme Q10

There is some low-level evidence to indicate that Co-enzyme Q10 may improve cognitive function in conditions where there are problems with short-term memory and concentration.

More information can be found in a **Medical Matters Question and Answer** 

#### Eicosapentaenoic acid (EPA)

Eicosapentaenoic acid (EPA) is an omega-3 fish oil supplement that has been shown in one very small research study to help with cognitive functioning in ME/CFS. So it may be worth a try.

#### Folic acid

One research study has reported a small decrease in folic acid – a finding that is important to anyone with ME/CFS planning to have a baby. Ref: Jacobson W, *et al* 1994. Serum folate and chronic fatigue syndrome. Neurology 33: 2645-2647.

#### Magnesium

One study published in The Lancet 30 years ago found a decrease in the blood level of magnesium.

Ref: Cox IM, et al 1991. Red blood cell magnesium and chronic fatigue syndrome. Lancet 337: 757-760. However, this research has not been replicated and conventional medical opinion is sceptical about the value of this particular finding.

Some people with

ME/CFS, especially those who do

not regularly go

outdoors in the

sun, are at risk of developing vitamin D deficiency.

## VITAMINS, MINERALS AND SUPPLEMENTS

#### **Mitochondrial function supplements**

Again, there is no sound evidence to indicate that commercial supplements that are claimed to improve mitochondrial function, or muscle energy performance, are of any value. Specific muscle energy supplements that are sometimes promoted to people with ME/CFS include carnitine (where there is some low-level evidence of benefit) and NADH (which needs to be used with care) and d-Ribose (which is claimed to improve mitochondrial function and energy production). AXA1125 is a mitochondrial supplement that is currently being assessed at Oxford university as a possible treatment for fatigue in Long Covid.

The phase-2 results of this trial are available and are positive:

#### https://tinyurl.com/2bv52dms

Note: NADH/nicotinamide adenine dinucleotide (which raises the level of a brain chemical called dopamine but needs to be used with care because it can cause anxiety, fatigue, headaches, nausea and insomnia).

#### Vitamin D



The one exception to the vitamin rule is vitamin D – the 'sunshine vitamin' – because some people with ME/CFS, especially those who do not regularly go outdoors in the sun, are at risk of developing vitamin D deficiency. Checking the blood level of vitamin D is therefore important if you are largely housebound. The regular use of a preventative vitamin D supplement is also something that you should discuss with your doctor or pharmacist, especially if you are at risk of developing vitamin D deficiency.

Please note that taking high doses of some individual vitamins and minerals can cause serious side-effects.



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## YOGA

Anecdotal evidence to the MEA indicates that some people with mild or moderate ME/CFS find yoga helps them relax, relieves tension and sometimes relieves pain in muscles and joints.

> If you are going to try yoga, you need to find a teacher used to dealing with people who have chronic health problems and who can reliably advise on movements that are going to be appropriate, or not appropriate, for someone with ME/CFS.



Find a teacher used to dealing with people who have chronic health problems.



## Awareness: ME/CFS and Long Covid



## Poster Pack: ME/ CFS & Long Covid

A selection of 5 posters that can help raise awareness of ME/CFS and Long Covid. If you want to share them virtually or print them yourself, you can select the download option at no cost (PDF).

If you require them as hard copies, we ask for just £5 to cover the cost of postage and **they can be ordered here**.



## PROFESSIONAL ORGANISATIONS AND SOURCES OF FURTHER INFORMATION

#### Acupuncture

**British Acupuncture Council** 63 Jeddo Road London W12 9HQ

British Medical Acupuncture Society [For medically-qualified acupuncturists]

Royal London Hospital for Integrated Medicine 60 Great Ormond Street London WC1N 3HR 0208 735 0400 acupuncture.org.uk

0207 713 9437 medical-acupuncture.co.uk

## Aromatherapy

Aromatherapy Registration Council aromatherapycouncil.org

## **Bach Flower Remedies**

Dr Edward Bach Centre Mount Vernon Bakers Lane Brightwell-cum-Sotwell Oxfordshire OX10 0PZ 01491 834678 bachcentre.com

## **Dental Amalgams**

**British Dental Association** 64 Wimpole Street London W1G 8YS 0207 935 0875 bda.org

The MEA offers a huge range of literature, most of which is free to download.









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## PROFESSIONAL ORGANISATIONS AND SOURCES OF FURTHER INFORMATION

#### **Herbal Medicines**

National Institute of Medical Herbalists Clover House James Court South Street Exeter EX1 1EE 01392 426022 nimh.org.uk

The Herbal Safety News pages on the Medicines and Healthcare Products Regulatory Authority (**www.mhra.gov.uk**) give sound advice and information on herbal products and ingredients.

## Homeopathy

Faculty of Homeopathy Hamilton House Mabledon Place London WC1H 9BB 020 3640 5903 facultyofhomeopathy.org

The British Homeopathy Association has full contact details of homeopathic pharmacies: **homeopathy-uk.org** 

## FURTHER INFORMATION FROM THE MEA

## The ME Association has information leaflets on the following subjects:

Dental care – your questions answered Diet and Nutrition Essential fatty acids EPA Muscle Energy Supplements: carnitine, co-enzyme Q10, creatine, NADH. Nutritional supplements Vitamins and supplements Vitamin B12 Vitamin D

Visit the free literature section on the ME Association website:

https://meassociation.org.uk/free-literature-downloads

JULY 2024



"Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful."





## THE ME ASSOCIATION Changing attitudes and improving lives...

**COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ MEMBERSHIP: We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. Join us today!

■ SUPPORT: ME Connect is the charity's support and information service. We listen and we understand. We provide a personalised service and we're here when you need us most. Most of us have personal experience of these medical conditions, or care for a loved one that does. We are here Monday to Friday 10am - 6pm (late night until 9pm on Thursdays) and at weekends, Saturday and Sunday 10am - 12 noon and 7pm - 9pm. We're ready and waiting to take your call, answer your email or respond to your message.

■ INFORMATION: We produce reliable and timely information written by topic experts and have the largest range of literature covering all aspects of life with ME/CFS and Long Covid. We can show you how to recognise and manage symptoms, to get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an e-newsletter and free access on the website to Medical Matters and other relevant information.

■ **RESEARCH**: We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ MEDICAL EDUCATION: We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations from the 2021 NICE



"The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research."





## THE ME ASSOCIATION Changing attitudes and improving lives...

Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

■ LOBBYING: We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ HEALTH & SOCIAL CARE: The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/ CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

**DONATIONS:** Donations: In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.** 

## WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guidelines reproduced in full in an easy to use **database**.

#### MEDICAL MATTERS

**Medical Matters** is an easy to use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

#### NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy to use **database**.

## Freephone 0800 538 5200

Monday to Friday 10am - 6pm (Late night until 9pm on Thursdays)

Saturday & Sunday 10am - 12 noon & 7pm - 9pm

## ME CONNECT

The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid

**Contact ME Connect 3 WAYS TO GET IN TOUCH:** by phone, email or social media private message



HERE TO LISTEN

We are here to listen. validate and empathise with any issues you might be facing.



VITAL SUPPORT We are here to help vou reach an informed

decision.

We're here for you!



SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where vou can be heard and understood.



meconnect@meassociation.org.uk

facebook.com/meassociation



instagram.com/meassociation