



MANAGEMENT FILE

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MEA membership costs £18 a year for people living in the UK/BFPO.
For contact details, see foot of this page.

the ME association



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Alternative and complementary approaches to management

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 management advice.

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

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 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. Fortunately, things are now starting to change and you may well find that an approach

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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?**

This sort of information isn't always easy to obtain. Sometimes the best way to choose a therapist is on personal recommendation from someone else 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 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 things like 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 being 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. If it has, what were the results? And where exactly were they published?

★ **Will you tell my GP about 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, then 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.

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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. 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. It's not possible to cover all these. So this leaflet will concentrate on the most popular.

ACUPUNCTURE

Acupuncture can help to relieve headaches and various types of chronic pain – but there haven't been any proper clinical studies for 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. One 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.

Acupressure, a variant of acupuncture, has been shown to relieve nausea and vomiting effectively.

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 this 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 that are of no proven value. So you could end up being diagnosed as being allergic to some 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, kinesiography and vega testing.

If you want to self-test for food allergy/intolerance, there is some evidence that a blood test produced by York Laboratories can identify specific food allergies/sensitivities in people with irritable bowel syndrome and migraine. But no trials have been carried out on people with ME/CFS.

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 yet proven through proper clinical trials.

◆ *The Complete Guide to Food Allergy and Intolerance* (Bloomsbury Publishing) is 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 an interest in ME/CFS – and Linda Gamblin.

AROMATHERAPY

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 – check with your therapist or pharmacist.

BACH FLOWERS

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 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 practitioners 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 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.

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 continuing speculation

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 their active ingredients do have genuine therapeutic effects. But just as with orthodox drugs – some of which such as aspirin and digitalis are also derived from plants – they can have side-effects, 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.

Among the various forms of herbal medicine are Western, Chinese and Ayurvedic (from India).

Therapies used by people with ME/CFS include:

- **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 benefits whereas the other did not. The oil is usually well tolerated by people with ME/CFS.
- **Echinacea** appears to simulate the immune system. But 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 having an overactive immune response. 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** 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 isn't convincing and no studies 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.
- **St John's Wort** (*hypericum perforatum*) is a herbal remedy that is sometimes used to self-treat mild depression. However, doctors are now warned against recommending or using St John's Wort because it can induce drug-metabolising 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 it, and do not take this herb in combination with a prescribed antidepressant.
- **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 it is worthy of further research.

about 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.

So, before going down this route, it's well worth exploring both sides of the debate. Do check out the information on mercury-free dentistry and the views put forward by the British Dental Association.

Mercury-containing amalgam is the most common type of dental cavity filling but alternatives are available. Discuss this option with your dentist if a new filling is required.

HOMEOPATHY

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

An 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 it is not usually a do-it-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 are three NHS homeopathic hospitals – in Bristol, Glasgow and London. In theory, you should be able to get an NHS referral through your GP, but many authorities are making these type of referrals difficult, or even impossible.

Although many doctors remain sceptical about the scientific basis of homeopathy, there has been 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.

NUTRITIONAL THERAPIES

Although there is no doubt that diet can play an important role in both cause and management of illness, some of the advice that is given to people with ME/CFS by alternative practitioners who advocate dietary modification can be costly, highly speculative, and sometimes even harmful.

At present, most conventional dietitians would go no further than to recommend sticking to 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.

OSTEOPATHY

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 of the brain and muscles along with a build up of toxins.

More information on one particular approach – the Perrin Technique – can be obtained from Dr Raymond Perrin's website at: www.theperrinclinic.com

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 at all convincing. So spending money on these sort of treatments is not something that we would recommend.

Hyperbaric oxygen (HBO), which involves the use of 100% oxygen at higher than normal pressure, is given in a special chamber in a few centres 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 in to treat diving disorders and gangrene. The use of HBO was discussed in more detail in an article in the Spring 2015 issue of *ME Essential*.

TALKING THERAPIES

A growing number of expensive 'talking treatments' are being aimed at people with ME/CFS. Examples include the Gupta Programme, the Lightning Process and Mickel Therapy. They often combine elements of 'brain reprogramming', cognitive behavior therapy, neurolinguistic programming, 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.

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.

More information on most of these talking therapies can be found in the news archive on the MEA website. And if you want to look at feedback from people who have used these type 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**.

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.

Another study has shown a small decrease in **folic acid** – a finding which 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.

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, conventional medical opinion is sceptical about the value of this particular finding. And there is still no good quality evidence to show that vitamins or mineral supplements are of benefit in treating ME/CFS.

Even so, 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.

The one exception to this rule is **vitamin D** – the 'sunshine vitamin' – because some people with ME/CFS, especially those who do not go outdoors, are at risk of developing vitamin D deficiency. Consequently, checking the blood level of vitamin

PROFESSIONAL ORGANISATIONS AND SOURCES OF FURTHER INFORMATION

Acupuncture

British Acupuncture Council
63 Jeddo Road
London W12 9HQ
tel: 0208 735 0400
www.acupuncture.org.uk

British Medical Acupuncture Society

[For medically-qualified acupuncturists]
BMAS House
2/3 Winnington Court
Northwich
Cheshire CW8 1AQ
tel: 01606 786782
www.medical-acupuncture.co.uk

Aromatherapy

Aromatherapy Council
No telephone or address currently available
www.aromatherapycouncil.org.uk

Bach Flower Remedies

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

Dental Amalgams

Holistic Dental Centre
5 Hart House

The Hart
Farnham
Surrey GU9 7HA
tel: 01252 820004
www.holisticdentalcentre.co.uk

British Dental Association

64 Wimpole Street
London W1G 8YS
tel: 0207 935 0875
www.bda.org

Herbal Medicines

National Institute of
Medical Herbalists
Clover House, James Court
South Street
Exeter EX1 1EE
tel: 01392 426022
www.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
CAN Mezzanine
49 – 51 East Road
London N1 6AH
tel: 0203 640 5903
<http://facultyofhomeopathy.org>

NHS website information on homeopathy:

<https://tinyurl.com/y8goyl7>

The British Homeopathy Association has full contact
details for NHS homeopathic
hospitals in Bristol, Glasgow
and London and details of
homeopathic pharmacies:
<https://tinyurl.com/yyxqa3wy>

FURTHER INFORMATION

More information on the approaches
described in this Management File,
as well as several others, can be
found in Chapter 13 of *Living with ME*
(Vermilion paperback).

The ME Association has leaflets on
the following subjects:

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

D is important if you are largely housebound. And the use of a preventative vitamin D supplement is something that you should discuss with your doctor or dietitian if you are at risk of developing vitamin D deficiency.

It is also important to remember that high doses of some individual vitamins and minerals can cause serious side-effects. The MEA has a separate Management File on Vitamins.

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. So it may be worth a try.

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 will need a teacher used to dealing with people who have chronic health problems and who can reliably advise on appropriate movements for someone with ME/CFS.

Medical information contained in this leaflet is not intended to replace medical advice or treatment from your doctor. We recommend that you always consult your doctor or healthcare professional about any specific problem. We also recommend that the medical information we provide is shown to and discussed with your doctor, as appropriate.