



MANAGEMENT FILE

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the ME association



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Alternative and complementary approaches to management

With orthodox medicine failing to produce any form of effective treatment aimed at the underlying cause of ME/CFS, it's not surprising to find that many people turn to the alternative and complementary (ACM) health sectors for management advice.

The ME Association remains open-minded about alternative approaches, but we can only recommend treatments for which there is good quality evidence to demonstrate that they work. So our advice tends to be very cautious about many of these 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 combination of reasons. The treatment may, of course, be having a genuine therapeutic effect. But the fact that you are paying for something that 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 the use of alternative therapies. Fortunately, things are now starting to change and you may well find that an approach such as acupuncture for pain relief is now available at your local GP surgery or NHS hospital.

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 and sometimes the best way to choose a therapist is on personal recommendation from someone else who has ME/CFS, or possibly even 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 seldom as strict. Where this is the case it's worth checking 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 supplements.
- ★ **Does the treatment have 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 perfectly safe. But herbal/plant medicines can affect liver function and some types of allergy treatment can produce serious adverse reactions.
- ★ **How is the treatment supposed to help in ME/CFS?**
Ask if it been tested in any form of proper clinical trial. If it has, what were the results and where were they published?
- ★ **Will the therapist be informing your GP about any 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 the answers to your questions are evasive or unsatisfactory, then it's time to reconsider.

Professional organisations can usually supply more information along with contact details of practitioners in your area who have gone through a programme of professional training.

TREATMENTS ON OFFER

The choice of alternative treatments is vast and, as we know from all the publicity material that arrives at The MEA, a new form of treatment or 'cure' aimed at vulnerable people with ME/CFS is introduced every few weeks. It's not possible to cover them all the treatments so this leaflet will concentrate on the most popular of them.

ACUPUNCTURE

Acupuncture can help to relieve headaches and various types of chronic pain – but there haven't been any proper scientific studies conducted that involve people with ME/CFS.

This ancient Chinese treatment involves sticking very fine needles into the skin at places known as acupuncture points. Nobody is certain how it 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 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 accrue.

Acupressure, a variant of acupuncture, has been shown to be effective in relieving nausea and vomiting.

ALLERGIES

Some people with ME/CFS develop an allergic component to their illness and, where this is the case, it's worth seeing if this can be helped by orthodox allergy tests and treatments. If the symptoms are more severe, it will be worth seeking a referral to an NHS allergy clinic.

Allergy testing and treatment in the alternative sector is controversial – mainly because there are so many allergy tests that are of no proven value. So you could end up being diagnosed as being allergic to a range of foods and other substances

when this isn't actually accurate. 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 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 yet been carried out on people with ME/CFS.

A number of allergy treatments – examples include enzyme-potentiated desensitisation/EPD and neutralisation therapy – are available in the private sector. Their value in ME/CFS is anecdotal and not yet proven through proper clinical trials.

- *The complete guide to food allergy and intolerance* (Bloomsbury Publishing) covers both alternative and conventional allergy tests and treatments. It is written by Professor 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 used in the bath. The oil then 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 they 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 with a small amount of oil first – especially if you already 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.

BACH FLOWERS

Created by Dr Edward Bach, an English physician and homeopath,

these consist of nearly 40 flower-based remedies usually taken as drops in water. Dr Bach worked on the theory that illness was caused by emotional imbalance and believed that flower-based remedies could redress these 'negative emotional states'. However, 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 with conventional medicines – so do check with your doctor or pharmacist if you are taking any other treatment.

CANDIDA OVERGROWTH

Some alternative 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 going to the time and expense of 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, has led to speculation about a link between this type of dental filling and conditions such as dementia and multiple sclerosis.

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 idea.

Having your fillings removed is not a procedure that is generally available on the NHS and will probably have to be carried out privately at considerable expense.

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

So before going down this route, it's well worth exploring both sides of the debate into this controversial form of treatment by checking out 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 alternative methods are available. Discuss the option with your dentist if a new filling is required.

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 affecting 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 that are commonly used by people with ME/CFS include:

- **Evening primrose oil** may be helpful in relieving joint pain. This is because it contains essential fatty acids – substances that are thought to reduce inflammation in the body. As far as ME/CFS is concerned, two small clinical trials have assessed the value of evening primrose oil. One reported some benefits whereas the other did not. The oil is usually well tolerated by people with ME/CFS.

- **Echinacea** appears to have a stimulatory effect on the body's 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 some people with ME/CFS already have 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 terribly 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 shouldn't be used if you already have any type of blood disorder, or take aspirin.

- **St John's Wort** is one of the few herbal remedies that has been assessed in well-organised clinical trials. Results suggest that it can be an effective alternative to orthodox antidepressants in the treatment of mild to moderate depression. Again, this is not a do-it-yourself form of treatment as it can have side-effects and interact with other drugs, including antidepressants – so do take advice from a doctor, pharmacist or medical herbalist.

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 – because an onion would normally cause watering eyes and a runny nose. But 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

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 health 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 [ref: 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 dieticians 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 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 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 on the basis 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 idea that increasing the level of oxygen in the body, especially to the brain, a number of oxygen-based treatments have been claimed to be of benefit in conditions such as ME, autism, Lyme disease and MS.

Hyperbaric oxygen, 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 or MS. It is regularly used in to treat diving disorders and gangrene.

TALKING TREATMENTS

A growing number of 'talking treatments' are being aimed at people with ME/CFS. They often combine elements of 'brain reprogramming', cognitive behavior therapy, neuro-linguistic programming, and positive thinking. Consequently, the 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 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 detailed information on talking therapies, including the Lightning Process and Mickel

Therapy, can be found on the MEA website.

VITAMINS AND MINERAL SUPPLEMENTS

At present, there is little evidence to show that people with ME/CFS have significant deficiencies in either vitamins or minerals.

One study has shown minor decreases in several B vitamins [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 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. From what we know, there is 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, the use of a vitamin D supplement is something that you may want to discuss with your doctor or dietitian.

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.

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

WHERE TO FIND OUT MORE

Acupuncture

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

British Medical Acupuncture Society

BMAS House
3 Winnington Court
Northwich
Cheshire CW8 1AQ
tel: 01606 786782
www.medicalacupuncture.co.o.uk
[For medically qualified
acupuncturists]

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.holisticdentalcare.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
website: www.nimh.org.uk

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

Homeopathy

Faculty of Homeopathy
British Homeopathic Association
Hahneman House
29 Park Street West
Luton LU1 3BE
tel: 01582 408675
www.britishhomeopathic.org

The BHA has full contact details
for NHS homeopathic hospitals and
details of homeopathic pharmacies.

FURTHER INFORMATION

Detailed information on the
approaches described in this
leaflet, as well as several others,
can be found in Chapter 13 of
Living with ME.

The MEA has information leaflets covering:

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

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.