



Information Sheet 3: Alternative Approaches to ME/CFS

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This information sheet looks at alternative and ‘complementary’ therapies - exploring alternatives to conventional medicine can be helpful as there is no proven ‘cure’ for ME/CFS. While alternative approaches cannot promise a cure either, they can help relieve symptoms. NHS approaches to treatment and symptom management are covered in the ‘What is ME/CFS?’ information sheet. ME/CFS can be very variable from one person to the next, so no single approach suits everyone.

This information sheet discusses treatments which people with ME/CFS have said they find helpful - anecdotal evidence is available for all having beneficial effects for some, but not for everyone. It is important to bear in mind that there is no solid evidence base for any of these approaches working for ME/CFS, which means that they have either not been subject to scientific trials or that research has shown no statistically significant effect. Inclusion on this sheet is for information only; it is not an endorsement or recommendation by Hampshire Friends with ME.

It is important that you approach anything new with caution, considering costs, merits and risks. Gather as much information as you can from reliable independent sources and take time to consider whether it is a good fit for you. Unfortunately many of the professions involved are unregulated, and sometimes unethical practitioners can try to exploit vulnerable people. When searching for a practitioner be wary of:

- treatments for ‘chronic fatigue’ which is not the same as ME/CFS
- anything very expensive
- anything promising ‘cure’ or ‘the answer’ to ME/CFS
- a new ‘breakthrough’ treatment
- anything marketed with secrecy, or asking for payment before you receive detailed information about what is involved.

Most importantly check the practitioner’s qualifications, which professional bodies they belong to, and that they are insured. In particular ask about their experience of working with people with ME/CFS: their understanding of it, what they can offer and the results they have had with other people. Avoid practitioners who have no knowledge or experience of working with this complex condition.

Bodywork

Physical therapies which are sometimes offered as helpful for ME/CFS are: massage, shiatsu, acupuncture, myofascial release, craniosacral therapy, Bowen Technique, reflexology, reiki (and other types of 'energy healing'). These approaches are holistic because they are underpinned by theories about how the body and mind work as an integrated whole – for example: the idea that stress affects physical symptoms and vice versa.

While there have been no research trials showing the effectiveness of bodywork for ME/CFS, people who have experienced improvements in their symptoms, and in some cases fully recovered, have often incorporated one or more of these approaches into a programme including several other strategies. All these physical treatments can feel soothing as you receive human care and/or touch. They can also be extremely relaxing, which is in itself beneficial when living with a chronic health condition.

Psychoneuroimmunological Approaches

Psychoneuroimmunology is the study of the interaction between the nervous and immune systems and psychological processes. Two programmes that take this approach to ME/CFS are the Gupta Programme Amygdala Retraining¹ and Dan Neuffeur's 'ANS Rewire'². These are multidisciplinary DVD programmes that aim to correct what they believe to be an underlying neurological dysfunction. They include meditation, Neuro-Linguistic Programming (NLP), relaxation, breathing techniques, nutrition, and other lifestyle changes.

Although these programmes incorporate psychological elements, both were developed by people who have had ME/CFS and believe it to be a physical illness caused by unconscious malfunctions in the way the brain controls the body's systems, and that these can be 'reset' using the plasticity of the brain. The theory behind them is consistent with how symptoms in ME/CFS are experienced across the endocrine, neurological, digestive, circadian, cognitive, and immune systems. These programmes have not yet undergone large scale scientific trials but are inexpensive, provide detailed free information and patient case studies, and online support is available via webinars, chat rooms and buddy systems.

Holistic Medicine.

Holistic Medicine sees each person as a whole integrated mind and body, unlike conventional western medicine where specialists focus on separate parts in isolation. Naturopathic, Functional Medicine and Ayurveda are types of holistic medicine taking an individualised view of the underlying causes of ill health, for example: imbalances in the body, environmental factors, lifestyle, nutrition and family history.

Practitioners may run tests that are not available on the NHS, prescribe supplements or herbal remedies and can incorporate bodywork and psychological therapies into treatment. Practitioners are sometimes medically qualified doctors with additional training. Be aware that while herbal remedies may be 'natural' they can interact with other supplements and medication you are taking, and cause serious side effects if given at too high doses. Again, it is important to check that anyone you see understands the physiology of ME/CFS.

Homeopathy.

Homeopathy is a form of alternative medicine underpinned by the principle of 'like cures like' - that a substance taken in tiny amounts will cure the symptoms it causes if taken in large amounts by

encouraging the body to heal itself. Herbal remedies are tailored to an individual's specific symptoms. Homeopathy is offered privately and by some NHS Trusts, despite there being no convincing evidence for any significant effect other than as a placebo³. However, people do report improvements in many physical conditions, including ME/CFS, after seeing a homeopath. One possible explanation is how it's delivered: long consultations in which the patient feels heard, has their condition acknowledged and is given hope can all have positive effects on health outcomes, especially when you have a poorly understood illness like ME/CFS.

Rituximab.

Rituximab is a medical treatment that is licensed in the UK for the treatment of some cancers, rheumatoid arthritis and also used to treat lupus. It is a monoclonal antibody, a type of biological therapy. A few studies have been carried out on Rituximab in Norway related to the energy metabolism and immune system in ME/CFS patients and some people have travelled abroad to obtain it privately.

However, despite some positive stories, it is still considered by researchers to be 'at best experimental³' and is not licensed to treat ME/CFS as trials have been small, and side effects extreme. It is also very expensive. Further trials are currently being planned, including one in the UK in Norwich.

Psychological Therapies

Some talking therapies are well suited to helping people cope with living with chronic physical illness. Some of the ways they can help are: developing techniques that calm the nervous system, teaching coping strategies or breaking unhelpful patterns. Examples are: Acceptance and Commitment Therapy (ACT), Mindfulness-based Stress Reduction (MBSR) and Emotional Freedom Techniques (EFT).

While they are not a cure for ME/CFS, some people have found they have transformed how they relate to their illness, resulting in improved mental health, a better ability to cope, improved quality of life and even reduced symptoms. See the 'Living Well with ME/CFS' sheet for more on mindfulness, integrative counselling and emotional support.

Dietary Supplements.

Your GP or consultant should have tested for deficiencies to rule out any other possible causes of your symptoms before diagnosing ME/CFS, but if you are unsure whether this has been done it is worth checking. Magnesium, vitamin B12, vitamin D and iron are some of the deficiencies that people with ME/CFS report. While there is no evidence that any of these are its cause, all these vitamins and minerals can have an impact on energy levels and sometimes pain.

Some people with ME/CFS say that taking supplements has improved their condition. Other supplements such as Co-enzyme Q10 and D-ribose have been said to improve energy in some people with ME/CFS, but can have unpleasant side effects. Prescribed food supplements may be considered by your doctor if your symptoms are so severe that you are having difficulty eating.

Nutritional Approaches.

People with ME/CFS can have strong reactions to certain foods and medicines, experiencing intestinal and digestive problems, and sometimes irritable bowel syndrome (IBS). As with vitamin

and mineral deficiencies, these are likely to be symptoms rather than the cause of ME/CFS, but dietary changes can sometimes help reduce their severity.

If you have a reaction that seems to be linked to certain foods you might try an exclusion diet, which means avoiding those foods temporarily, then reintroducing them gradually to see how your body responds. While testing for food and drug allergies, which can be life-threatening, is available on the NHS, food sensitivities such as those experienced in ME/CFS are not scientifically proven, so testing is not. Some people seek private 'intolerance' testing to identify problematic foods. You may need to be careful about the ingredients in prescribed medications, for example lactose if you find this triggers a gut reaction. Speak to your GP or a pharmacist, but bear in mind alternatives are not always available.

Gluten intolerance is commonly reported in people with ME/CFS who can experience bloating and increased pain, energy crashes and brain fog after eating foods that contain gluten, such as wheat. If you decide to reduce or exclude gluten from your diet be aware that many pre-packaged 'gluten free' foods are high in sugar and of low nutritional benefit. Substituting carbohydrates that contain gluten, such as bread, with whole grains such as brown rice and quinoa rather than processed food is better for energy and overall wellbeing.

There is evidence of increased inflammation in the bodies of people with ME/CFS. An anti-inflammatory diet involves reducing your consumption of sugar, dairy, meat, wheat, alcohol and caffeine and has been found by some people to help with pain levels, fatigue and gut symptoms. You could also introduce anti-inflammatory spices such as turmeric and ginger. However, if you restrict your intake of groups of nutritious foods you must be careful to ensure you still get a good balance of carbohydrates, fats, protein, fibre and essential nutrients in your diet.

People with ME/CFS often test positive for candidiasis, or thrush, which is an overgrowth of naturally occurring yeast in the body. It is linked with having a weakened immune system, a common symptom of ME/CFS. Being treated with antifungal medication, then probiotics and avoidance of certain foods such as dairy products and gluten can be beneficial for this symptom. You may need support and advice, and you can ask your GP to refer you to an NHS dietician if you have serious digestive problems. However, they may not have specific knowledge about ME/CFS. See 'Living Well with ME/CFS' information sheet for topic Eating for Energy Management.

Conclusion.

It is important to be realistic about what any of the approaches to treating ME/CFS discussed on this information sheet can achieve. There are many other approaches too numerous to cover here, and you should thoroughly investigate any that you come across before you try them. Whatever you consider, remember there are still a lot of unknowns about ME/CFS.

The placebo effect can also play a part, as it does in the efficacy of treatments for many health problems. Numerous studies have shown a powerful effect on the physical self from a belief in the effectiveness of a treatment, even when the patient is just given a sugar pill³.

You may hear how someone with ME/CFS puts their recovery down to one particular approach, but it is actually rare that anyone with ME/CFS is only trying one thing. Usually there is a combination of pacing, other self-management strategies, alternative approaches and a lot of trial and error. Much

like diets for weight loss, if there was one thing that worked for everyone, the world would know about it.

References:

- 1) Gupta Programme <http://www.guptaprogramme.com/causes-of-me/>
- 2) ANS Rewire <https://ansrewire.com/the-science/>
- 3) Placebo effect: <http://www.nhs.uk/livewell/complementary-alternative-medicine/pages/placebo-effect.aspx>
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