

Nutrition for People with ME/CFS

Nutrition is a vital component of health, and no less so for someone with ME/CFS. In a 2005 survey of Sheffield M.E. Group members, nutrition was named by the largest number of members (15%) as the therapy / treatment which had helped them most – scoring higher than medication from the GP/NHS (9%). What follows is a summary of the main considerations.

The Effects of ME/CFS on Nutrition and Diet

- Weakness or nausea can sometimes make normal eating and digestion so difficult that support is needed from a health professional
- People with ME/CFS have less stamina for shopping, cooking and eating
- Carers and family may be needed to help with shopping and food preparation
- Meal patterns are often severely disrupted

The Patient's Experience of ME/CFS

- Some people with ME/CFS gain weight
- Weight loss is also common - especially in children
- IBS (irritable bowel syndrome) affects 60-70% of patients at one time or another and causes abdominal pain, bloating, wind, diarrhoea and / or constipation
- Food intolerances and sensitivities are more common in people with ME/CFS
- Some people also have sugar cravings when they are tired, indicating low blood sugar at the time

Weight Gain – the reasons

- Less activity
- Eating for energy boost and craving for sweet foods or drinks
- Medication
- Less energy to buy and prepare fresh foods especially fruits and vegetables
- It's easier to grab a biscuit or make a sandwich than to make a salad

ME/CFS can lead to weight gain but is not a symptom of ME/CFS as such

Weight Loss – the reasons

- Nausea
- No energy to prepare food
- No energy to eat
- Lack of appetite
- Not absorbing nutrients in food properly

Excessive weight loss is always something that should be reported to your doctor.

It is important to keep an eye on weight, because large changes either way will make recovery more difficult and can lead to other health risks. Ask to see a dietician if your weight has changed considerably since you have had ME/CFS.

WEIGHT GAIN OR LOSS INCREASED FATIGUE INCREASED PAIN

Top tips for healthy eating with ME/CFS

Eat regularly. Small meals and snacks are preferable to occasional huge meals. This may help to even out energy levels and reduce nausea

Avoid or severely restrict foods with a very high sugar content – sweets, cakes, biscuits etc.

Drink plain water. Keep hydrated (do not allow yourself to become thirsty).

Eat lots of fruit and vegetables (some people may need to avoid citrus fruit for a time)

Keep off stimulants as much as you can (coffee, tea, sugar, salt, alcohol, cigarettes)

Eat a varied, whole food diet and avoid 'junk' food

It's not just what you take out of your diet but also what you put in that counts

Make sure you do not become deficient in iron, by eating plenty of iron-rich foods (meats, oily fish, eggs, dried fruits, fortified breakfast cereals). You also need plenty of vitamin C to help absorb the iron so eat plenty of fresh fruit and vegetables.

Eating a wide range of healthy foods is much better than taking supplements and eating unhealthily.

Dietary management of symptoms

Take your fluids apart from meal times, especially if you are nauseous. Peppermint and also ginger may help with nausea.

Eat little and often.

If you suddenly feel weak and hungry, a banana is an ideal way to deal with the situation. Try not to resort to sweets and biscuits.

If you are overweight, take care with fats, sugars and the size of portions.

If you are losing weight or underweight, make sure you eat foods high in calories such as nuts and avocado, and try to see that you have regular meals and snacks.

If you are very weak you may find it difficult to chew and prefer to eat easily swallowed food like soups and smoothies.



Official guidelines for healthy eating say that the largest components of the diet should be fruits, vegetables and grains. The foods which should form only a small part are those which are high in fat and those which are high in sugar (or both!) However the diet must include the Omega 3 essential fatty acids (more on this later).

Irritable bowel symptoms (IBS)

Symptoms:

- Bloating after food
- Constipation/diarrhoea or both
- Abdominal pain
- Flatulence

Possible solutions for IBS

- Healthy eating self-assessment
- Dietary and nutritional assessment by a health professional
- Adjusting the type and amount of fibre in the diet. Oats and wheat have different types of fibre and you may be able to tolerate whole oats better than wholegrain bread. If you can only digest boiled vegetables, keep the water for soups or just drink it separately for its rich mineral content (it sometimes has more than the remaining vegetables!)
- A careful exclusion diet, with proper advice, to test whether there are any food intolerances. Sometimes these can exist for a while and then disappear.
- Many people find probiotics and / or digestive enzymes helpful

Sheffield M.E. Group has an Information Sheet on Irritable Bowel Syndrome and also one on the wheat-free diet.
Please send a large stamped self-addressed envelope to receive copies.

Food intolerances / sensitivities

As well as abdominal symptoms, these can cause headaches, lethargy and a range of uncomfortable feelings.

The most common suspects are milk, wheat, soya, yeast, caffeine, alcohol and other stimulants – but this is not a complete list!

Do not follow an exclusion diet without professional advice if it means that you are missing any of the staples of your diet.

It is possible to lose a particular sensitivity after avoiding the item for several months.

Allergies are different from sensitivities in that they more fully involve the immune system. This area is under-researched and many GPs are unwilling to carry out allergy tests unless symptoms are very severe. (Dr Hayes Allen is an exception – see below.)

Issues to consider

Is your diet nutritionally adequate and varied? It should include a variety of fresh, whole foods, avoiding sugar and refined carbohydrates as much as possible.

Anyone who is losing weight alarmingly must seek professional advice. Are supplements needed? Vitamin D is recommended if you are unable to get out into daylight. Also, supplementing essential fatty acids is helpful if your diet does not include oily fish or uncooked Omega 3 vegetable oils.

If you feel a particular diet or supplement is not helping, then you should discontinue it. However metabolic changes take up to three months and more, so give it time.

The financial cost of the diet is a consideration. You may wish to eat organic food all of the time, but if this is not possible you could choose to eat just organic bread and / or root vegetables as these absorb particularly high amounts of chemicals from the soil. Fresh fruits and vegetables are cheaper than convenience foods. Preparation time is also a 'cost', for people with ME/CFS. If the work involved in cooking and shopping makes you more tired there could be an overall negative impact.

It is a good idea to prepare extra dishes on a 'good' day and freeze them for later.

It may be better to have a ready-meal occasionally than to go without food or eat unhealthy snacks instead.

Remember that the enjoyment of food is part of its benefit!

Supplements – to take or not to take?

Reports from large numbers of people with ME/CFS say that a supplement of **essential fatty acid** has been beneficial to them. There are new reports that **Vitamin D** is also helping. If you cannot manage 10 minutes of gentle sunshine on your face and forearms most days, for two thirds of the year, then it is recommended to take a supplement, at no more than the recommended dose. Multi mineral / vitamin supplements are safe to take at the recommended dose. Buy a reputable brand, and always read the label. Professor Basant Puri, an eminent scientist in the field of ME/CFS research, emphasises that **it is much more important to eat fresh, whole foods (not refined and not packaged) than it is to take supplements.**

Who are the experts?

Within the NHS you may be referred to a dietician who can help you adjust your eating habits to help with your symptoms. Dieticians are state registered, and their services are free within the NHS. Outside the NHS you may see a nutritionist or nutritional therapist, who can recommend strategies and supplements that are not 'allowed' in the NHS. If you choose to do this, you should ensure that he or she is a registered practitioner member of a professional organisation – the most reputable ones are the British Association for Applied Nutrition and Nutritional Therapy (BANT), the Nutrition Society, and the Nutrition Therapy Council. You will be charged for consultations and for the supplements.

What do the main M.E. Charities say about nutrition?

The M.E. Association

The MEA acknowledges evidence of deficiencies involving magnesium, folic acid and several B vitamins, but because of lack of evidence from clinical trials, the Association's advice to doctors is that "The only clear indication for supplements is in the case of women with ME/CFS who are contemplating pregnancy...." They advise "a well-balanced diet that includes complex carbohydrates (to help stabilise blood sugar levels) and which avoids caffeine. A good fluid intake should also be encouraged."

Action for M.E.

AfME suggests experimenting with the diet with the guidance of a specialist, if digestive or gut problems are experienced, to find out if there is food intolerance. It also advises an adequate intake of fluids and states "If you are concerned about the quality of your diet you may want to consider taking a simple multivitamin on a regular basis."

What do specialist doctors advocate?

Partly because of the complexity of the illness and the differing needs of sub-groups, only a minority of specialists have formulated nutritional protocols for treating ME/CFS.

Dr Sarah Myhill

Vitamin B12 injections and Magnesium supplementation are foundations of Dr Myhill's treatment (see www.drmyhill.co.uk). Her recovery programme is based on reducing stress including toxic stress, and on good nutrition. In her programme, carbohydrates should be cut down during the daytime because they cause drowsiness. Protein and good fats should be the mainstay of daytime meals with bread, potatoes etc eaten only at the last meal. She recommends an initial four weeks on a diet which excludes common allergens and unhealthy foods, i.e. wheat, rye, corn, dairy produce, tea, coffee, sugar, yeast, all chemical additives, plastic wrappings, and over-ripe or mouldy foods. Carbohydrates are obtained from rice, millet, buckwheat, sago, quinoa, all the pulses, potatoes etc. This is NOT a calorie-cutting diet. After 4 weeks foods can be returned individually and monitored to test for intolerances.

Dr Myhill is currently developing a nutritional protocol for addressing a model of ME/CFS as heart weakness secondary to mitochondrial malfunction (as described in work carried out by Dr Arnold Peckerman for the U.S. National Institutes of Health). Her new protocol provides specific nutrients aimed at restoring mitochondrial function but full results over a long period are not yet published at the time of writing (July 2008).

Professor Basant Puri

Essential Fatty Acids (EFAs) are one of the most studied aspects of nutrition in ME/CFS. Professor Puri's protocol is set out in his 2005 book *Chronic Fatigue Syndrome: a natural way to treat M.E.* This is based on previous research into fatty acids and ME/CFS and also on his own research as consultant at Hammersmith Hospital, London. Based on the theory that viral infection destroys enzymes involved in fatty acid synthesis, his programme involves supplementing with a specific EFA supplement called VegEPA which contains only virgin evening primrose oil, pure EPA and NO DHA, for reasons he explains in the book (summary available from Sheffield M.E. Group).

In addition he advocates a nutrition approach aimed at boosting the vital enzymes involved with EFA metabolism. This means a diet based around lean beef and lamb (organic if possible), oily fish, vegetables (such as vitamin B-rich leafy greens), fruit, (especially vitamin C-packed kiwi fruit and strawberries), peas and beans, pulses and lentils, whole grains, brown rice, seeds, (particularly pumpkin and flax), nuts (such as almonds and brazil) organic whole milk and yeast extract. He recommends supplements if deficiency is suspected.

Dr M Hayes-Allen

Dr M Hayes-Allen is a GP specialising in ME/CFS who has a private practice in Sheffield. He looks at thyroid function and prescribes immune system and allergy tests, mineral status tests done on the patient's hair, and tests for gut infections and 'leaky gut'. He recommends a diet rich in B vitamins, EFAs and minerals, especially magnesium, zinc and selenium – including supplements, though secondary to food sources. He sometimes recommends Magnesium injections.

What then are the main concerns for people with ME/CFS?

Essential Fatty Acids

Though evidently not all practitioners agree on the best nutrition for people with ME/CFS, they do agree that essential fatty acids are very important. Some of the most extensive research has been carried out by Professor Basant Puri at Hammersmith Hospital, as mentioned above.

Deficiencies of essential fatty acids in the modern western diet are of particular interest to people with M.E. because these nutrients are involved in brain function and in immune function.

What are essential fatty acids (EFAs)?

EFAs are the only fats that we actually need to eat. The EFAs are 'polyunsaturated' fats, as opposed to the 'mono-unsaturated' and the 'saturated' fats, which are the other main groups of dietary fat.

EFAs are needed by each body organ to produce prostoglandins, which act like hormones and regulate the continual functioning of every part of the body. They also become part of the membrane fabric of every body cell, enabling the transfer into the cells of vital oxygen and nutrients. They keep the immune system healthy, and reduce inflammatory conditions such as in arthritis and allergies. And most importantly, the brain is 60% fat, with EFAs forming the larger part.

Omega 3 Fatty Acids – Alpha-Linolenic Acid

Omega 3s are found in oily fish (like herring, mackerel, sardines, pilchards) but also in flaxseeds, pumpkin seeds, and other foods, including soya bean, walnut, hemp oil and rapeseed oils, green leafy vegetables, grains, and sea vegetables.

Some nutritionists advise taking oily fish rather than relying solely on vegetable sources of essential fatty acids.

Sheffield M.E. Group has an information sheet about essential fatty acids, and also a report on a talk given to us by Professor Puri in 2007. Please send a large stamped self-addressed envelope to receive copies.

Glycaemic Index (GI)

This is sometimes mentioned in the context of ME/CFS. The glycaemic index is the rate at which food converts to glucose (energy) in the body. All carbohydrate foods are ultimately converted to energy in the form of glucose. If sufficient calories are not taken in the form of carbohydrates, even fats and proteins are converted to glucose because it is so crucial for the operation of each cell in the body. If the glucose is not used for immediate energy requirements, it is converted to fat and stored in the tissues. Foods with a high GI rating convert quickly to glucose, and those with low GI take longer.

The aim of the GI principle is for the food to deliver energy gradually throughout the day, rather than in sporadic bursts. This will prevent energy slumps and keep the blood sugar levels at a healthy balance. Whole grain foods take longer to digest, thus releasing their energy more gradually. Refined carbohydrates such as sugar and white bread are high GI foods and deliver glucose to the cells rapidly. Because high blood sugar levels are dangerous, the body produces an 'insulin rush' to deal with the situation and so there may follow a rapid lowering of the blood sugar – hypoglycaemia. If this cycle continues, weight gain and even type 2 diabetes can result.

The GI diet is implemented by concentrating on foods low on the index. However, the situation is complicated when the accompanying foods are taken into account. For instance, a jacket potato – which is evidently a healthy, wholefood source of carbohydrate and other nutrients – has a very high glycaemic index because its carbohydrate is very easily converted to glucose. However, because the potato would usually be eaten with butter or olive oil, and ideally accompanied by salad vegetables, the overall glycaemic index of the meal would be lowered. When fat accompanies the carbohydrate, the GI is lowered – hence, a Mars bar has a much lower index (68) than a jacket potato (85)!

These complications mean that implementing a GI diet needs careful thought, which may not always be easy for people with ME/CFS. However the principle is valid. It is unhealthy to eat high sugar foods which in the long run can cause weight gain and hypoglycaemia. Whole foods release energy more slowly and are more healthy.

Candida – a brief overview

Candida or candidiasis (Candida overgrowth in the gut) is ignored by many doctors though it is frequently linked with ME/CFS. The medical profession sometimes denies its existence, except in very limited cases, making it difficult to get a medical diagnosis even when an overgrowth has been confirmed by a laboratory test. Moderate amounts of the yeast Candida live in everyone without causing harm, but naturopaths say that when the surrounding bacteria which normally check their spread are destroyed (for instance by antibiotics) Candida can change into its fungal form and spread through the intestinal wall into the bloodstream. Incompletely digested products and compounds resulting from breakdown of the Candida can then also pass into the bloodstream, where they cause a multitude of symptoms in addition to problems already in the gut (indigestion, bloating and pain). This crossing of

the gut wall is what is known as 'leaky gut', and its symptoms are many of the M.E. symptoms. However 'leaky gut' is not considered by most doctors.

Treatment - Many naturopaths, nutritionists, homeopaths and medical herbalists will treat Candida using a protocol aimed at removing the sugars that feed the overgrowth, providing antifungal agents, eliminating food triggers and healing the leaky gut. Most importantly, the diet recommended would eliminate all sugars, all yeast containing foods and all fermented foods (bread, vinegar, mushrooms) and also tea, coffee and alcohol.

Dr Anne Macintyre describes Candida overgrowth as causing dysbiosis in the gut (rather than leaky gut as such) and she sets out the anti-candida diet in her book *M.E. a Practical Guide*. This is one of the widely used 'standard texts' for self-help with ME/CFS. The anti-Candida diet has not been shown to be successful in controlled tests, but many individuals with ME/CFS have found it has improved their health.

A study published in the Journal of Human Nutrition and Dietetics in March 2008 showed that the symptoms of ME/CFS are not improved by extreme low sugar, low yeast diets. **However** this study has been criticised for the criteria used to select its subjects, for the fact that the subjects were not tested for signs of gut abnormalities to start with, and for the relatively high drop-out rate during the research. Nevertheless it has played a big part in discrediting the usefulness of addressing the possibility of candida overgrowth for people with ME/CFS.

New thinking on Candida?

New thinking amongst some naturopaths points to a different cause and treatment of Candida. In this view, excess fat is the culprit, not sugar as such. When fat levels in the blood rise, so does blood sugar, because excess fat inhibits insulin from its function of taking sugar out of the blood. The excess fat lines the blood vessel walls and the contents of the blood vessel, including the insulin receptor sites, and the sugar and insulin themselves, thus slowing the normal process of glucose absorption. In this naturopathic view, Candida is constantly present in the blood, with the function of blooming when there is an excess of sugar, so that the blood sugar is brought down to a non-threatening level. When the fat and sugar metabolism is as it should be, the Candida quickly dies off to its non-symptom-causing level.

So, according to this view, when fat levels stay high because of a poor diet, sugar remains in the bloodstream and feeds the Candida rather than delivering energy. Therefore the way out of the situation is not to eat less sugar, but to eat less fat. When the fat content of the bloodstream drops, sugar starts to be processed and distributed again, and Candida dies out because there is no longer excess sugar available. A low fat diet is in any case a healthy diet provided that essential fatty acids are included.

Some other nutrients and supplements which have been associated with ME/CFS

Echinacea

This is a herb which supports the immune system when used correctly. It has helped some people with M.E. for a short time only and should not in any case be taken over extended periods.

Coenzyme Q10

This is a nutrient which the body makes for itself naturally, to help the cells produce energy. It is used by many nutritionists and by Dr Sarah Myhill as part of an overall package of supplementation.

NADH

This is another coenzyme, which the body makes from vitamin B3. As a supplement it seemed to help many people when it was first used for ME/CFS but did not prove to have permanent benefits for the majority.

L-Carnitine

This is an amino acid (protein) and where there is a deficiency it has been shown to help some people with ME/CFS. It is likely to be most helpful when used in conjunction with other supplementation. Food sources include red meat, dairy products, avocado, and tempeh (made from fermented beans, available in wholefood shops).

Magnesium

Every cell in the body uses magnesium for energy and protein metabolism. Many people with M.E. are found to be deficient in this mineral, and in these cases supplementation and even magnesium injections have been found to be helpful. Food sources include nuts, seeds, pulses and green vegetables.

DHEA

This is a hormone secreted by the adrenal glands and if it is deficient its supplementation may help with memory, stress, anxiety and sleep.

Digestive Enzymes

These help break down food and can be useful in ME/CFS. Fresh uncooked foods (salads and fruit) also support the body's enzyme activity

Liquorice

This is highly valued in Chinese medicine and an ingredient in most of their herbal formulae. It helps combat fatigue.

Tyrosine

This is a protein which supports certain neurotransmitters which are known to cause low energy when deficient. It is found in many protein-containing foods including meat, fish, milk, wheat and oats.

D-Ribose

This is a very specialised part of the carbon/sugar chemical chain which acts within the cells to help produce energy. The body makes it own, and it is also available as a supplement.

It should be evident from the above that nutrients are wide ranging and inter-related. As a science, nutrition is really in its infancy and new findings are constantly being published.

The most important things for someone with ME/CFS to bear in mind are that your food should be:

- As varied as possible
- In the most natural state possible (wholefood)
- As fresh as possible
- Including a good amount of uncooked fruits and salads
- Enjoyed!

We have many library resources on this important topic:

Allen, Darina	Healthy Gluten-free Eating
Barnard, Neal (M.D.)	Foods that fight pain
Brostoff, J (Prof) / Gamlin, L	Food Allergy & Intolerance
Chaitow, Leon	Candida Albicans
Cousins, B	Vegetarian/Cooking Without
Craggs-Hinton, Christine	The Chronic Fatigue Healing Diet
Desmaisons, Kathleen	Potatoes not Prozac
Dibb, S & Lobstein, Tim Dr	GM Free - Shopper's Guide
Duke, James A. (Ph.D)	The Green Pharmacy
Geary, Amanda	The Food and Mood Handbook
Graham, J / Odent, M (Dr)	The Zinc Factor
Greer, R	Gluten Free - Cooking
Harries, Jane	Eat to Beat Fatigue
Holford, Patrick	The Optimum Nutrition Bible
Holford, Patrick	Optimum Nutrition
Jacobs, Gill	Beat Candida through Diet
Kenton, L & S	Raw Energy
McKenna, J (Dr)	Natural Alternatives to Antibiotics
McKully, K & M	The Heart Revolution
McTaggart, Lynn	Allergy Handbook
Paterson, B	The Allergy Connection
Puri, Professor Basant K.	C.F.S, a natural way to treat M.E.
Rogers, Sherry A	Chemical Sensitivity
Savill, A/Hamilton, D	Lose wheat lose weight
Steincamp, Jacqueline	Overload: Beating M.E.
Straten, M. V	Good Mood Food
Wheater, Caroline	Juicing for Health
White, Erica	Erica White's Beat Fatigue Handbook
White, Erica	Erica White's Beat Candida Cookbook
Wing, N	Sugar Free

College of Natural Nutrition Natural Nutrition Approach/ M.E. (for practitioners) CD

If you haven't already joined the postal library, just call the office on 0114 253 6700.

Sheffield M.E. Group
July 2008