

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.

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.

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 because wheat and root vegetables absorb particularly high amounts of chemicals from the soil. Fresh fruits and vegetables are cheaper than convenience foods, so you will save money there.
- 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.**

What 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. Refer to the separate information sheet.

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 evident 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 and which is also involved with the production of energy in the cells. 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 involved with a number of other marginal nutritional deficiencies and 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. Because it is a hormone it should not be taken by people with hormone related cancers.

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 and has traditionally been used medicinally for Addison's disease and adrenal insufficiency.

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, and is also supplemented in ME/CFS by many nutritionists.

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!