

Chapter 12

Nutritional Supplements

This is a controversial subject. Some argue that if you eat a well-balanced diet of good, fresh foods, then it should not be necessary to take extra vitamins or minerals. For someone in perfect health this is probably true.

However, the Recommended Daily Allowance (RDA) for each nutrient is calculated for the average adult of average weight, in health, and is often the amount which is just sufficient to prevent deficiency disease. The RDA may be much less than the amount required for optimum health, and in disease states the body's requirements may increase dramatically to a level which cannot be met by abnormal diet, particularly if there is reduced appetite or digestion.

Many M.E. patients have problems with digestion and absorption of food. Signs suggesting this are:

- Weight loss in spite of good food intake
- Stools that contain undigested food
- Stools that float, and difficult to flush away
- Diarrhoea, distension, abdominal pains

If you have these symptoms, especially weight loss with a good appetite, assume that you are not getting the full value from what you eat. As well as losing protein and fats, you may be losing calcium, iron, zinc, folic acid, vitamin B₁₂, and the fat-soluble vitamins A, E and D. Poor appetite or nausea will also lead to nutritional insufficiency. Even when there is fluctuating weight gain, nutrition may be poor, as sudden weight gain in M.E. is usually due to fluid retention.

Possible Causes of Poor Absorption in M.E.

- Virus infections may cause flattening of the microvilli (tiny projections) on the surface of cells lining the small intestine, hence loss of absorptive surface.
- If the pancreas has been involved in a present or earlier virus infection, there may be reduced production of pancreatic digestive enzymes.
- There may be overactivity of the gut in general, leading to the food being rushed through the small bowel, with too little time there for digestion and absorption. This overactivity results from an upset control of the autonomic nervous system, part of a hypothalamic disorder.

Aside from the digestion/absorption factors, M.E./CFS is now known to be a disease that causes excessive cytokine production, which is known to produce blocks in vitamin utilization, so extra vitamins are needed to overcome this defect in their use in the body.

Supplements may also be needed to provide enough of the nutrients that are essential for the body's immune system, nervous system and the various glandular functions.

In addition, even before the onset of M.E. there may have been some nutritional deficiencies, due to earlier poor diet, or maybe prenatally from poor maternal health.

So, for all these reasons, it is logical to take whatever is necessary to restore the body to health. It may also be safer to correct nutritional imbalances than to take drugs, which only modify the symptoms instead of treating the underlying cause of illness.

A problem for many M.E. people who are trying to decide about supplements is cost. A few (e.g. evening primrose oil) can be obtained on prescription, if your doctor can be persuaded that this is worthwhile. Otherwise, it helps to work out how much the supplements are going to cost per day, then to see what can be given up to pay for this. There are less important things in life, for example, the cost of newspapers. . . . Like a lot of decisions with M.E., it is a matter of deciding on priorities.

Digestive Enzymes

If you or your doctor think you have poor absorption of food due to lack of digestive enzymes, then taking a preparation of these makes sense. They are obtainable on prescription, and are all made from pancreatic extract, with various trade names, e.g. Pancrex, Nutrizyme. The preparation may be in granules or powder, and should be taken just before or with a meal, as it is inactivated by stomach acid.

Hydrochloric Acid

The stomach normally secretes digestive juices containing hydrochloric acid in response to and in anticipation of food. In allergic people or those with chronic viral illness, fevers, diabetes, or rheumatoid arthritis, there is frequently achlorhydria - lack of gastric acid. This may lead to fermentation in the stomach, bad breath, gas, and poor digestion, especially of protein. The enzyme pepsin needs acid to work properly to start digesting protein. Acidity is also needed to absorb calcium and iron.

Hydrochloric acid can be taken in various preparations, on prescription, starting with a small dose with meals. (But not by those with proven overacidity or symptoms of an ulcer, so consult your doctor first.)

Vitamin C

This is one of the most essential vitamins to help you with M.E. It is not stored in the body, and is needed daily in food. A cytokine, interleukin 2, when infused into cancer patients produced a vitamin C-deficiency state by suppression of vitamin-C utilization. For this reason alone M.E. patients should take extra vitamin C.

What Does Vitamin C Do?

Vitamin C (ascorbic acid) is needed to make collagen, the fibrous framework of most of the body. It is vital for the continuous repair and regeneration of body tissues. It is also used by the adrenal gland to make the hormones noradrenaline, and cortisol. The adrenal gland in health is rich in ascorbic acid.

Vitamin C is a powerful anti-oxidant - it mops up free radicals of oxygen which are released in various biochemical reactions, and which may cause cell damage.

Vitamin C has important effects on the immune system: it promotes the formation of lymphocytes, lymphocyte mobility, and phagocytosis - some white cells can engulf and destroy bacteria and dead cells. They can only be efficient at this if they contain ascorbic acid. It is also involved in the manufacture of antibodies (immunoglobulins).

In addition, vitamin C acts as an antiviral agent, and in high doses activates T lymphocytes. In 1979, at the National Cancer Institute, USA (Pauling, 1986), an investigation found that giving vitamin C (5 gm per day) to healthy people aged 18-30 led to doubling the rate of formation of new lymphocytes.

An increased intake of vitamin C also leads to greater production of interferon. Interferons are proteins with anti-viral activity, produced by virus-infected cells. Vitamin C inhibits the synthesis of PGE2 prostaglandins, and therefore reduces the pain and swelling these chemicals cause.

Much valuable work on the use of high-dose vitamin C to treat infections, cancer, and many disorders of immunity such as rheumatoid arthritis has been done by Dr Linus Pauling. While many sceptics have dismissed his work, Pauling argues that in tests where people took vitamin C and no benefit was found, they did not take a large enough dose. The RDA of vitamin C in Britain is 30 mg (obtained from half an orange!), but a more realistic minimum amount for good health would be 100 mg, and much more in illness.

Much of Dr Pauling's reasoning for a greater need of vitamin C comes from his calculations of the amounts of various nutrients in the diet of our ancestors. As man evolved he became unable to make vitamin C in the body, as most other mammals do, so he would only have survived by having enough in daily food. The daily amount of food that a hunter-gatherer would have needed to keep him active would have contained about 3 gm of vitamin C - a hundred times the modern 'daily Allowance'. Early man's diet had a much greater ratio of raw fruits, vegetables, nuts and berries than that of a twentieth-century Western diet; however his total calorie intake was very poor by our standards.

Someone with an infection, undergoing major surgery, or in emotional shock needs far more vitamin C than 100 mg a day. It is used up by the adrenal glands in response to stress; wound-healing requires extra vitamin C, and it is used by the immune system to fight infection.

Vitamin C cannot be stored in the body, and any that is not used is excreted in the urine. The main undesirable effect from taking more than is needed is diarrhoea. This is why the term 'bowel tolerance' is used when advising people how much to take.

It is suggested that you take vitamin C in divided doses rather than one large dose, and start with 1 gm daily (500 mg in the morning and 500 mg in the evening). Increase this by 1 gm daily until you have loose bowel motions, then cut it back to 1 gm less. Because of the occasional risk of increased formation of kidney stones, the total daily dose should never exceed 9 gm, and should always be taken in divided doses and with plenty of fluids. Most M.E. people do not need more than 3 gm daily except at times of unavoidable extra stress - e.g. when they have a bacterial infection or are about to undergo surgery. People with a history of kidney stones should take no more than 1 gm daily.

Pure vitamin C is ascorbic acid, a weak acid, but still an acid. The cheapest way to get it is as pure ascorbic acid powder from a supplier. One level teaspoon of powder is about 3 gm. It should be completely dissolved in water or fruit juice, and taken with or just after food to avoid irritating the stomach (which it rarely does). To counter the acidity, a little bicarbonate of soda can be added.

Vitamin C can be also taken as calcium ascorbate, or in buffered 1 gm tablets which dissolve in water to make a fizzy drink. The latter are more expensive.

Vitamin B₆ - Pyridoxine

Vitamin B₆ is important in many chemical processes, including the production and reactions of brain chemicals, which affect mood and behaviour, and in the pathways of essential fatty acids (EFAs), which are needed for the immune system. B₆ is needed for some minerals to work, especially magnesium.

Signs of lack of vitamin B₆ are: Depression, irritability, and red, greasy, scaly skin on the face. However, a lack of vitamin B₆ alone is unusual - there is usually a multiple B vitamin deficiency.

The recommended supplement level is about 20 mg daily, as part of a B-complex preparation. Women with premenstrual syndrome benefit from 50 mg daily during the premenstrual week.

All the B vitamins work and interact together, so individual B supplements are not recommended, apart from the extra B₆ before a period.

Vitamin B₁₂

This is normally only required in small amounts daily, about 1 microgram (mcg). It is found in meat, fish, and eggs; vegans risk a deficiency of it. As it is absorbed in the small intestine and needs a substance secreted by the stomach to combine with before absorption, people with deficient stomach juice or malabsorption in the small intestine are at risk of B₁₂ deficiency. It is concerned with red cell production, and with nervous system functions. B₁₂ deficiency can lead to anaemia, abnormal fatigue, pins and needles in the feet, stumbling gait, and mental confusion.

It is worthwhile for chronic M.E. sufferers to have their blood B₁₂ level checked, especially if these neurological symptoms are prominent, if there are digestive / absorption problems, and if the patient is middle-aged or elderly. With the current publicity about M.E., there may well be people who think they have M.E., especially in the older age group, who in fact have a vitamin B₁₂ deficiency, which is easily treatable.

Some M.E. sufferers do report an improvement in energy level and in neurological symptoms from B₁₂ injections, although no clinical trials have yet been done. Dr Paul Cheney, of Charlotte NC, USA, uses vitamin B₁₂ as part of his treatment regime, especially for treating fatigue. He recommends a trial dose of 3 mg twice a week (by injection). If there is a response, patients usually report improvement after two weeks, then can continue self-injecting 2-3 mg weekly. Dr Cheney says, 'We do not understand exactly why B₁₂ works in CFS. . . an effect lasting only a few days does not fit in with normal B₁₂ pharmacokinetics.'

High-dose B₁₂ must trigger some other effect, that lasts longer than the B₁₂ itself' (Cheney, 1991).

The best sources of B₁₂ (providing it is being absorbed) from food are liver, other organ meats and brewer's yeast (if tolerated; many cannot take yeast - see Chapter 13).

A good vitamin B-complex should be yeast-free and contain all the B vitamins, as follows:

- Thiamine B₁
- Riboflavin B₂
- Pyridoxine B₆ (about 10-20 mg daily for each of these)
- Niacin B₃
- Pantothenate B₅
- Cyanocobalamin B₁₂
- Folic acid
- Para Amino Benzoic Acid(PABA)
- Biotin

Information about the functions of other B vitamins, which are all needed, as they are interdependent, can be found in books about nutrition.

Vitamin A

Vitamin A itself occurs in animal produce; the best sources are animal and fish livers, kidneys, eggs and milk products. Beta-carotene, a precursor of vitamin A, is obtained from vegetables, particularly carrots, and other green-, yellow-or orange-coloured plants.

It is needed for maintaining mucous membranes, skin, and cell membranes, and is important in resisting infections. Vitamin A is one of the 'anti-oxidants' (along with vitamins C and E, and selenium), and therefore prevents damage to cell membranes, and has an important role in cancer prevention.

Vitamin A deficiency is one of the most common causes of blindness in poor countries, especially in small children, as a result of a poor diet.

As it is fat-soluble, and stored in the body, very high doses can accumulate and cause toxicity. Doses of up to 20,000 units daily are safe, but 7-15,000 units a day are sufficient unless there are particular indications of deficiency. The best way to supplement vitamin A is as part of a balanced multi-vitamin preparation, or in fish-or liver-oil capsules, which also provide essential fatty acids.

Pantothenic Acid (Vitamin B5)

This little known vitamin is one of the B family. It occurs widely in many foods; it is essential for the proper function of adrenal glands, and for making antibodies. It is one of the anti-stress vitamins and is important for fighting infection and allergies.

It is present in most B-complex preparations. It seems to be helpful in high doses in stress-related diseases and in conditions where the immune system is not working properly, such as

allergies or rheumatoid arthritis. It is recommended for M.E. and can be taken as calcium pantothenate in doses of 300-1,000 mg.

The symptoms of pantothenic acid deficiency (produced in volunteers) are remarkably similar to those of M.E. and of multiple allergies. It has even been suggested that members of families who are all allergic may have some inherited increased need for this vitamin.

Vitamin E

This is another fat-soluble vitamin, and most important for its anti-oxidant properties (like A, C, and selenium) It occurs in vegetables, nuts and eggs, and the recommended supplement is 100-200 IU daily. It is essential for proper wound-healing.

What Do Anti-oxidants Do?

Oxygen is essential for cells to live. However, in certain circumstances oxygen produces toxic derivatives, which can combine with other molecules and cause damage to cells and alter their function, or cause them to become cancerous, or to die. These nasty oxygen products are called 'free radicals', and are mopped up and made safe by anti-oxidants, Anti-oxidants are vitamins A, C, and E, and various enzymes that contain trace elements such as selenium, zinc, manganese, and copper. The free radicals cause damage to the fatty acid part of cell walls.

Free radicals have multiple sources, including chemicals in air pollution and food, and cigarette smoke, but are also produced by lymphocytes in inflammation, e.g. when the lymphocytes are killing virus-infected cells.

In M.E., there seems to be a persistent low-grade viral infection, and disordered cell functions all over the body. Some doctors have used the term 'sick cell syndrome' about M.E. So it seems logical to minimize damage to the cells from free radicals by ensuring a good intake of the nutrients needed for a good anti-oxidant system.

Zinc

Zinc is a trace element which is necessary for a wide range of chemical reactions in the body. Studies of zinc and its many roles have begun relatively recently, and there is still much to discover.

Signs of a Zinc Deficiency

- impaired wound-healing
- loss of sense of taste or smell
- slow growth
- infertility
- hair loss
- skin problems (including acne)
- allergies
- poor resistance to infection
- depression and other mental disturbances
- white spots on nails

Those at Risk of Zinc Deficiency

- Those with a poor intake of zinc due to:
 - a vegan diet
 - slimming
 - a strict allergy diet
 - poor appetite
 - being elderly
 - suffering from alcoholism
 - undergoing intravenous feeding
- Those who suffer poor absorption due to:
 - a high-fibre diet with lots of bran
 - low stomach acid
 - lack of pancreatic enzymes
 - iron tablets
- Malabsorption: due to gluten sensitivity (coeliac disease)

The daily requirement is about 15 mg for a healthy adult; more in pregnancy; much more after major surgery, burns, or any severe stress.

The assessment of zinc status is not satisfactory at present. Levels measured in blood plasma, urine or hair do not seem to be accurate. The blood level can vary enormously throughout a 24-hour period. The most reliable method of measurement is by analysis of sweat, but this requires specialist apparatus. A rough estimate of body zinc status can be done by a patient, using the fact that taste becomes dulled in zinc deficiency. A solution of zinc is swilled round the mouth, and if a sharp bitter taste develops afterwards, the zinc status is probably near normal. If there is little or no taste, zinc is low or very low. This test is commercially available; it is called Test-Zinc.

Since in M.E. there is immune dysfunction and probably persistent virus infection, also maybe poor digestion and absorption of food, it is sensible to take extra zinc. A zinc supplement is best not taken with food, since its absorption is inhibited by various foods. A preparation giving 20-50 mg elemental zinc, as zinc orotate, zinc sulphate, or amino chelated zinc, can be taken at bedtime.

Therapists with access to accurate assessment of zinc levels (e.g. Biolab of London) report that almost every M.E. patient tested is low in zinc.

Magnesium

Magnesium is absolutely vital for normal cell function. It is present inside every living cell as well as in teeth and bones. The correct balance of calcium and magnesium across cell membranes is essential for transmission of nerve impulses, and for muscle contraction and relaxation.

Magnesium is also involved in many enzyme systems and chemical reactions in the body. Magnesium occurs naturally in hard water, in whole grains, green vegetables, nuts and beans. A deficiency is most likely in someone on a poor diet, living in a soft water area, or with poor intestinal absorption.

Magnesium Deficiency Leads to

- Many neurological symptoms, tingling and numbness
- Poor co-ordination of limbs
- Muscle weakness, muscle cramps or twitching
- Heart rhythm abnormalities
- Hyperactivity in children
- Mental confusion
- Depression
- Anorexia, nausea, constipation

Many features of M.E. are similar to magnesium deficiency. In a recently published trial, Dr David Dowson and colleagues at Southampton University (Cox et al., 1991), found that magnesium in red blood cells of M.E. (designated CFS) patients is low. 20 patients and 20 matched controls were used. Average red cell magnesium for patients was significantly lower than for the controls. In a double-blind treatment trial magnesium sulphate was given by intramuscular injection weekly for 6 weeks to 17 of 34 M.E. subjects. The others received 2 ml water injections. At the end of the trial 80 per cent of those who had magnesium had significant improvement in energy, emotions, and pain levels, compared with 18 per cent of the controls. After treatment, red cell magnesium was normal in all of those who received magnesium, but only in one of the 17 controls.

Those who improved with magnesium need to be monitored to see how long the benefit lasts, and how often the treatment should be given. The results of this important study are encouraging, and hopefully the trial will be repeated to confirm the role of magnesium. Many sufferers have already found some benefit from taking magnesium by mouth, but it is more effective when given by injection. The treatment is safe, so long as injection into a vein is avoided. At the time of writing, it is suggested that patients have their red cell magnesium level tested first before having a course of injections.

In M.E., there is a delay in recovery of muscle fibres after contracting, and a low level of magnesium in the cell may contribute to this.

If you supplement magnesium by mouth, take enough to give about 500 mg elemental magnesium a day, until there is improvement. Then about 300 mg daily as maintenance, depending on your symptoms of muscle weakness, twitchings, or mental symptoms such as panic attacks and insomnia. Amino acid chelated magnesium is a good form to take.

Some doctors advise that calcium should be taken as well, as a separate supplement, about 500 mg a day.

Selenium

This mineral occurs widely in food, and its functions are not yet fully understood. The important role of selenium which has been researched is as an anti-oxidant, mopping up free radicals, and thus it helps protect cells from damage, ageing, and cancerous changes.

The relevance of selenium to M.E. is that sometimes severe chemical sensitivity develops, and it is thought that free radicals plus chemical molecules can further impair cell membranes, and contribute to muscle weakness and mental dysfunction. (This may explain

why it is not uncommon for a patient to find that he or she has greater muscle power when in an unpolluted area, but collapses in a narrow street full of petrol fumes.)

Many M.E. patients with chemical sensitivities have improved on a regime which includes all the anti-oxidants (vitamins A, C, and E, and selenium). However, selenium is toxic in high doses, and a supplement should not exceed 200 mcg a day.

Essential Fatty Acid Supplements

If one is having pure vegetable oils, vegetables, nuts, and fish in a good diet, why is there any need for supplements?

Linoleic acid in food is converted to prostaglandin E1 (which is anti-inflammatory and boosts white cell function), via gamma linoleic acid on the pathway. The conversion of linoleic acid to GLA can be blocked by several things, including viral infections. Taking GLA in evening primrose oil by-passes this block, and the GLA can go on to form the helpful prostaglandin E1.

EFA's and their products are needed to make cell membranes, and are important constituents of white matter in nervous tissue. EFA supplements are used with success to help patients who have Multiple Sclerosis. MS is a disease of myelin tissue, but defects in cell membranes have been discovered, and present evidence suggests that the underlying problem is an inability to handle fats properly. An initial virus infection may be implicated.

Professor P. O. Behan and colleagues at Glasgow carried out a double-blind trial of EFAs on post-viral syndrome (Behan, 1990). 63 patients received either Efamol Marine (8 x 500 mg a day) or a similar looking placebo (liquid paraffin) for three months. After three months, 85 per cent of the patients receiving EFAs and 17 per cent of those on the placebo noted overall improvement, and the level of improvement was much greater in the treated group. In the treated patients, blood levels of EFAs which had been abnormal before the trial returned to normal.

What seems clear is that not only is EFA supplementation advisable for M.E., but that high doses are needed, at least 3 gm per day. The Glasgow trial used Efamol Marine, which contains fish oil as well as evening primrose oil. Although there has been no tested comparison between the effectiveness of evening primrose oil alone, or combined with fish oil, anecdotal evidence suggests that the combination of GLA (in evening primrose oil, and also in borage oil) with fish oil is best.

EFAs need adequate zinc, magnesium, and vitamins B₆, C, and E to work properly.

Amino Acids

Amino acids are the basic building blocks for the manufacture of all proteins in the body, including antibodies, all the lymphokines produced by white cells, digestive enzymes, neurotransmitters and hormones. Without these building blocks, taking vitamin and mineral supplements may be a waste of money. Certain amino acids are known to be needed for proper brain function, and the amino acids tryptophan and phenylalanine can improve mood.

Unless you can have a full analysis of your amino acid levels carried out, you will not know which, if any, you are short of. Anyone with M.E. who has symptoms that suggest poor absorption together with depression is advised to try taking a supplement of 'free-form amino acids'. These are available either on prescription or as capsules in most health food shops, and should be taken between meals with some water three times a day.

I know of a number of M.E. people who did not improve with a very nutritious diet, plus supplements, but felt an increase in strength and clearing of the mind after starting to take free-form amino acids - myself included.

Summary of Supplements

Ideally, someone considering taking nutritional supplements should consult a physician or biochemist who specialises in nutrition, and have his or her individual nutritional needs worked out. This is not usually possible, due to distances and the cost of a consultation and tests. Failing the opportunity for such advice, then suitable supplements for someone with M.E. would be:

- A good quality multivitamin and mineral tablet daily - ideally one with high levels of B vitamins, and which is yeast-free.
- Evening primrose oil (or equivalent): 3 gm daily
- Zinc: 20-50 mg, at night
- Magnesium: 200-300 mg daily
- Selenium: 100 mcg daily
- Vitamin E: 100-200 I.U. daily
- Calcium Pantothenate: 300 mg daily (up to 1,000 mg a day if very stressed or if badly allergic)
- Vitamin C: minimum 1-3 gm a day, more if very unwell or exposed to infection.
- If indicated, amino acids, pancreatic enzymes, or hydrochloric acid.

There will be no benefit in exceeding these doses without medical supervision. There may be ill effects from overdosing, and certainly loss of money. Most will be excreted from the body if taken in excess.