

ARE SUPPLEMENTS IMPORTANT IN ME/CFS?

First of all we need to decide what we mean by supplements. They are in fact extras that we take, over and above what we normally obtain in the daily diet, and for most of us, the diet is more than adequate. There is good evidence that for healthy people supplements are unnecessary. There is a great deal of advertising hype around that makes even the most healthy of us feel that we are somehow lacking, and need to be firing ourselves up with many things, which if over-indulged could in fact prove toxic. The main side effect however is on the pocket, with ever increasing costs and a feeling enhanced that the more costly the preparation the more good it is likely to do. I know of many mothers who are made to feel quite guilty because they are not tanking up their offspring with the latest marvel! However there are occasions when some form of supplement maybe entirely appropriate, and we all need to take a common sense approach to this. There are probably 5 main areas where supplements can be important.

1. The person maybe on a restricted diet of some sort, and may need for example to add extra calcium if they have no dairy products, or iron if they are vegetarian. Or they maybe unable to eat properly because of illness.
2. There maybe a proven deficiency on testing such as iron deficiency anaemia or low potassium, indicating a need for added iron or potassium. However the cause of the deficiency should always be carefully investigated as other treatment strategies maybe needed. Deficiencies may occur as a result of lack of absorption, loss (eg diarrhoea, blood loss), metabolic disorder or endocrine problems. For example a woman with very heavy periods may well become anaemic, but she should be thoroughly investigated, as there are many causes of anaemia, and her problem should be treated medically if possible.
3. There maybe phases in life when a particular supplement is recommended such as in pregnancy or inactivity. However these days most deficiencies are avoided in most health situations by care with diet.
4. There are certain supplements which may be indicated as a preventative approach. We now know for example that there is less likelihood of neural tube defects if a woman takes folic acid in pregnancy or calcium can be taken to help minimise the ageing effects of osteoporosis.
5. There maybe certain supplements over and above dietary intake which have a beneficial effect in a particular disease. This is where we come into the realm of CFS/ME.

Over the years many people with this illness have tried a wide range of supplements in the hope of finding the magic cure, but in general there has been very little benefit despite spending often enormous amounts of money. There have however been some interesting areas of research which give some guidelines as to what maybe appropriate. It is always hard to measure effects, particularly if one is taking a number of different things, and there are so many other variables. You can certainly be tempted by some of the mixed preparations, with sometimes a list of 30 components on the side of the container. These things will rarely be of much use as there usually too little of anything to be of much value if it happened to be needed. They may also contain some things to which the person with CFS maybe very sensitive even in small quantities or the person may already have too high a blood level of a particular component. Some of the potential benefit therefore maybe offset by a small toxic reaction. If one is going to take anything at all, it is better to stick to trialling one preparation at a time, and concentrating on those things where there has been some proven research benefit, or some research showing potential. You really need to try something for a month at least before you can judge if there is any benefit, or before you add anything else to the "cocktail".

Most minerals and vitamin supplements have not been shown to be of particular benefit in CFS, but there are a few areas of interest and potential. Salt supplementation has certainly been shown to have use in those with CFS who have a very low blood pressure, causing symptoms of light-headedness and slow thinking, which is often due to poor brain oxygenation. Extra salt taken regularly through the day can expand the blood volume, which maybe low, and improve circulation. Salt can of course easily be incorporated into the diet, but some find this hard and salt tablets or capsules may be easier. If you are having this high salt intake, it may be necessary to have added potassium, and this should be carefully monitored with regular blood tests as potassium can be very toxic. There has been some research to show that some with CFS have low total body potassium, but extra supplementation does not appear to improve this.

A number of researchers have looked at the issue of magnesium supplementation after the idea was raised some years back by researchers in England. There was an era when it was being given intramuscularly, but it seems likely that taking a magnesium supplement by mouth is well absorbed, cheap and easy, and there is no apparent extra benefit from injections. Magnesium is an important body mineral and it is thought that for some with CFS, some of the muscle problems and cramps may be helped. However it is important to have blood levels of magnesium checked as it can be toxic and some people do find it gives them abdominal cramps and diarrhoea even in small amounts. If you are going to take magnesium, do not be tempted to buy the expensive combination with malic acid. While malic acid does improve absorption, it is in fact a main component of apple juice, so the old adage of "an apple a day" seems highly appropriate here. You can just take the magnesium with a swig of apple juice or a piece of apple.

Zinc is used up a great deal by the typically active immune system in CFS, so again a small supplement can be useful for some. We can however check blood levels easily to see if it is likely to be of use. Zinc is stored well, so that often

short courses are all that is needed – say month on, month off etc. If you are having too much zinc, there is usually a metallic taste in the mouth. Zinc can also be a little nauseating, particularly if you do not actually need it.

Calcium can be helpful for several reasons. If a person is very inactive, they are more prone to osteoporosis, which can be serious, and extra calcium can help to prevent this, particularly if the diet is low in dairy products, our main source of calcium. Calcium should be taken late in the day, and can also help those who are troubled by legs cramps at night. If a person is inside a lot because of illness, the lack of sunlight can affect their vitamin D absorption, which is all tied in with calcium metabolism, so a blood test to assess vitamin D maybe useful, and this supplemented if necessary. However vitamin D is not a water soluble vitamin, and care should be taken to not take more than required.

The B vitamins have been of interest in CFS. Vitamin B12 injections have been used for over 40 years to alleviate fatigue particularly in the elderly, and apart from those suffering pernicious anaemia, due to poor B12 absorption, we have not really understood what mechanism is actually involved. However research continues, and we are getting a better idea now of what maybe going on. Certainly a number of people with CFS do seem to improve with a course of B12 injections, and the benefits seem to last far longer than we would expect from a simple placebo effect. Some Scandinavian research has indicated that the levels of B12 maybe low in the cerebro-spinal fluid, while the blood levels appear normal. This is the fluid surrounding the brain and spinal cord. B12 is needed by brain cells for efficient function. Having B12 by mouth has very little benefit as you only absorb it minimally and probably not at all if your blood levels are normal. So, having it by injection maybe useful for possibly about 60% of CFS people. The benefit may not be apparent immediately, some people find it takes about a month of weekly injections before they feel any better. B12 is a water soluble vitamin, and the body can therefore easily rid itself of any excess. In quite big dose trials being done overseas, there seems little risk of side effects or long term ill effects. If you are having B12, it is important to also take a mixed B complex tablet daily as the other B vitamins (particularly folic acid) can get out of kilter. Some women with CFS, who may have a worsening of symptoms premenstrually do find vitamin B6 (pyridoxine) can be helpful, but it is of no use taking it just around period time, as it needs to build up to be of benefit and taken daily regularly.

Work in Newcastle, NSW has indicated that some amino acid imbalances can occur in CFS. It is hard to suggest suitable supplements for this unless you have had some of their tests done, as the discrepancies can be very individual. The one amino acid that does however seem to be frequently depleted in this illness however, is serine. Serine is a precursor of serotonin, an important brain chemical giving a sense of wellbeing and energy. While the hit and miss approach is generally to be avoided, serine does seem to be very safe, and a trial maybe worth considering. Again though, it is wise to use this alone rather than in a mixture of amino acids. Another amino acid called carnitine has created a lot of interest in CFS following research in Japan and Belgium. Carnitine has been shown in some studies to be depleted in certain parts of the body, but although there is some potential here, the dose would probably need to be very high and taken long term, and this is an expensive supplement. More studies are needed in this area. Other Japanese research is showing some benefit with the use of the sugar D-Ribose for some with CFS. However there is no particular benefit shown from the previously fashionable idea that glyconutrients (8 simple combined sugars) are of any particular benefit in this illness.

A lot of the rheumatologists are now recommending glucosamine for those with joint problems, particularly osteoarthritis. While this may not be useful for the majority of those with CFS, some of you will perhaps have early arthritic problems just because you have got older, and this seems a safe and reliable supplement, and could alleviate one area of added pain. Co-Enzyme Q10 has been shown to be helpful in some patients with muscle pain (myalgia) particularly those who are on lipid lowering drugs, or who have post-polio syndrome.

Fatty acid supplements using evening primrose oil (or its equivalent marine source) or flax seed oil have also been researched. An early study in Glasgow showed that about 60% those with CFS had some improvement with evening primrose oil. Some people do feel worse on this. And more recently, the Newcastle team have shown that there are some changes in blood lipids which tie in with this and help to explain why some do benefit and some feel worse. However they find that for the 40% who do not benefit, about 20% should possibly try flax seed oil, as they have a different lipid profile. However you should not take both, as they tend to offset each other. More recent research has shown Omega 3 fish oil may provide some cognitive benefits.

It was fashionable for a while for those with CFS to go onto very high dose mega vitamin preparations. This approach is certainly not recommended. We now know for example that many with this illness maybe worsened by high dose vitamin C, as the immune system is often already very overactive, and Vitamin C may aggravate this condition. It has also been shown that many cases of Irritable Bowel Syndrome (a closely related condition) have been due to or aggravated by vitamin C excess and sufferers improve enormously once they stop the supplement. This does not mean avoiding vitamin C altogether as you need a regular daily intake as a food source (eg fruit/vegetables) to maintain normal health.

With all the above suggestions, it is important to realise that everyone is different and there are also many sub-categories of CFS, so what helps one person, maybe totally inappropriate for the next. Also it is important to always remember that more is not necessarily better, and may in fact be dangerous, toxic effects should be watched for and blood levels monitored when possible. Remember too that you are more likely to absorb a mouth-watering tasty meal than a handful of vitamin pills. Once you start to salivate when you see or smell good food, the digestive process has already begun. I wonder how many people salivate in response to pills! Cost should always be a consideration too, and just because something is more expensive, it is not necessarily better. Often the cheapest specials at the supermarket or chemist are your best bet. Some of the above are also available on prescription.