

## **A Natural Way to Manage ME/CFS a talk by Professor Basant Puri**

MA (Cantab), PhD, MB, BChir, BSc (Hons)  
MathSci, MRCPsych, DipStat, MMath

Consultant, Hammersmith Hospital, London, Head of Lipid Neuroscience Group, Imperial College, London

Despite the dreadful weather, more than 150 members, carers and friends attended University House, Sheffield, on 13 May 2007 to hear Professor Basant Puri.

The presentation concentrated particularly on nutrition and fatty acids and included much of the information contained in his popular book *Chronic Fatigue Syndrome: a natural way to treat M.E.*, which is available in our library. Sheffield M.E. Group also has an information sheet on fatty acids, updated in the light of these findings, which is available from our office on receipt of a large stamped addressed envelope.

The talk firstly made it clear that this information also applies to Fibromyalgia and that in fact there is a 70% symptoms overlap between the two conditions. It is possible that ME/CFS has been around for a very long time, and we were shown pictures of famous figures from the 19<sup>th</sup> Century, notably of Florence Nightingale, who it is now thought may have suffered from the illness.

### **What Causes M.E?**

The cause of ME/CFS is not known but it is likely, on current evidence, that an **infection** – whether of viral or bacterial origin – together with the inter-action of **environmental factors**, could be involved. The first outbreaks that were studied by physicians occurred in Los Angeles County Hospital in 1934 and in London's Royal Free Hospital in 1955. In both cases, many nursing and medical staff became ill, with flu-like symptoms, enlarged lymph nodes, crushing fatigue, muscle tremors and a host of other symptoms. All this pointed to infection. However, in 1970 the British Medical Journal published an article by two psychiatrists who had studied the case notes from the Royal Free Hospital outbreak more than ten years before. This article described M.E. as “mass hysteria”, a description which unfortunately was taken on board by the medical establishment and was even taught in some medical schools. The illness has been surrounded by uncertainty and has been dogged by lack of research ever since.

Professor Puri then described some of the main physiological differences that recent research has uncovered in people with M.E. compared with healthy people. Studies have shown specific evidence of abnormalities in the immune system which are likely to be the product of **persistent latent infection**, rather than the result of auto-immune responses. Studies of the brain chemistry of people with ME/CFS during the last five years have shown raised levels of choline (a nutrient of the Vitamin B complex) which would indicate a **deficiency of essential fatty acids** (EFAs) in the brain. Additionally, studies on gene expression (meaning, how genes affect the behaviour of the cells) have indicated metabolic differences in people with ME/CFS from control groups, in recent years.

An illustration of a **latent viral infection** would be a cold sore, which appears from time to time as a skin eruption - but between episodes the virus persists in nearby nerve tissue, creating innumerable copies of itself. This is what may be happening, with another virus, in

ME/CFS. In the case of ME/CFS possibly being of **bacterial origin**, a strong suspect is the *Borrelia burgdorferi* bacterium. This causes Lyme Disease, which appears to be on the increase in recent years and is now being studied in relation to ME/CFS.

## What Can Help?

Professor Puri's talk then concentrated largely on nutrition.

Professor Hugh Sinclair was a researcher who from the 1950s did a great deal to promote awareness of the value of the right kind of fats in the diet. One of his important studies was with the Inuit people, and this led him to conclude that their 'Eskimo diet' was a preventive of heart disease and other illnesses common in developed countries. The 'Eskimo diet' of the people studied was high in fish but with hardly any fruit or vegetables and with no convenience foods or refined foods. The Inuit people had very little heart disease, and almost no arthritis or skin disorders. Sinclair then went on to study Inuits who had migrated to Canada and taken on a different diet with hardly any natural foods or fish oils. He found that within one generation they had become prone to well known degenerative diseases such as heart conditions, arthritis and type 2 Diabetes. Sinclair concluded that a vital component of the 'Eskimo diet' was the fish oil – long chain **fatty acids** – and that these should be incorporated into a healthy diet. However this became controversial because the consensus at the time was that animal fats were generally harmful, whereas vegetable oils were generally healthy. So it took almost half a century before the research which began in the 1950s led to official recognition of the nutritional importance of long chain fatty acids.

**Long chain fatty acids**, incorporated into **phospholipids**, are complex chemicals, and are of two types – Omega 6 and Omega 3. These **omega oils** are vital components of the membrane of every cell in the body and they also have many structural functions inside the cell. Choline inter-acts with phospholipids and its raised levels in the brain tissue of people with M.E. indicate that it is not being 'used' by these essential fats, in other words that they could be deficient.

In theory our bodies can make most of the phospholipids ourselves, from the two basic **essential fatty acids** which **must** be incorporated in the diet. These essential fats are **Linoleic acid** and **alpha-linolenic acid**. Natural sources of these are:

### Linoleic acid

\*Oily fish (mackerel, wild trout, herring, sardines, tuna and salmon)

Also: most plant foods, especially sunflower, safflower and sesame seeds, corn and walnuts

### Alpha-linolenic acid

Oily fish (as above)

Also: berries, leafy vegetables, flax seeds and oil, hemp seeds and oil, walnuts.

*\* bear in mind that because of pollution of the sea and waterways, official government advice is now to eat oily fish no more than twice a week, and once only if you are pregnant.*

A simplified summary of the various essential fatty acids, or long chain fatty acids, which our bodies manufacture from these basic essential fatty acids, is shown below. The arrows show the order in which our bodies make the various phospholipids from the 'raw materials' of Linoleic and alpha-linolenic acid.

## OMEGA-6 FATTY ACIDS

### Linoleic acid

↓

Gamma-linolenic acid (**GLA**: also in blackcurrant, evening primrose and borage oils)

↓

Dihomo-gamma-linolenic acid (**DGLA**)

↓

Arachidonic acid (**AA**: the only food sources are of animal origin e.g. fish oil)

## OMEGA-3 FATTY ACIDS

### Alpha-linolenic acid

↓

↓

Eicosapentaenoic acid (**EPA**: the only food sources are of animal origin e.g. fish oil)

↓

↓

Docosahexaenoic acid (**DHA**: available from fish oil and some marine algae)

At each of the above stages, **enzymes** are needed to make the transitions to the full range of fatty acids needed by the cells. Delta-6-desaturase is a particularly important enzyme in this process.

\*\*\* Because a **viral infection could damage the enzyme**, people with M.E. may be helped by ensuring that they are well supplied with the fatty acids at the end of the chain, as well as the basic Linoleic and alpha-linolenic acid that need to be part of all diets. \*\*\*

## Prostaglandins

The fatty acids at the end of the chain (especially DGLA, AA and EPA) are essential building blocks of **prostaglandins**, chemicals which our bodies manufacture and which are essential for the health of every type of cell in our bodies. They are involved with memory and other brain functions, with the signalling of pain, with blood clotting, with breathing, with stomach acid secretions, reproduction, breast feeding and child development, the blood vessels and blood pressure, the joints, and the body's 'thermostat'.

As well as viral infections, other things which can damage the fatty acid conversion process are:

- Stress
- Deficiency of other essential nutrients (vitamins and minerals)
- Reliance on refined foods such as white sugar, white flour, white rice, pasta etc.

- Caffeine drinks (tea, coffee, cola)
- Smoking

**Stress:** There are many different ways of combating stress and some of the complementary therapies available can be helpful for people with ME/CFS. For instance, yoga, aromatherapy, or the Alexander technique could help, and this depends on individual preferences.

As regards nutrition, there are many nutrients which act as cofactors in the metabolism of fatty acids. Of particular importance are:

- Folic acid
- Vitamin B12
- Vitamin B6
- Niacin
- Biotin
- Vitamin C
- Zinc
- Selenium
- Magnesium

Water is the recommended drink.

### **Other Pieces in the Jigsaw**

Large studies have shown that there is a link between fish eating and mood disorders including depression, bipolar disorder and post-natal depression. A smaller study that Professor Puri undertook with patients suffering from advanced Huntington's Disease looked at the effect on the brain of taking **EPA supplements**. It was found that the brain ventricles (spaces) actually shrank and the brain tissue grew after taking the supplements.

\*\*\* The fatty acids **AA and EPA** are doubly valuable for people with ME/CFS in that as well as all the functions mentioned they are viricidal and **inhibit the actions of viruses in the body**. \*\*\*

There have been two major studies on fatty acids with people with ME/CFS but unfortunately the encouraging results of a 1990 study were not replicated in the later 1999 study (which took place in Sheffield) – possibly because different criteria were used to select the patient groups. Therefore more research is urgently needed and a large scale trial should be carried out. In particular it would be useful to conduct such a trial using the MRI scan technology used by Professor Puri, but unfortunately there is no funding for such a trial at present.

At the end of his talk, Professor Puri acknowledged his colleagues Professor Graeme Bydder, Dr Nick Davey, Professor David Horrobin and Dr Alexandra Richardson.

The refreshment break was followed by a short question and answer session, when Professor Puri gave more views and information:

- It is of crucial importance to eat a variety of wholesome fresh foods.
- Sometimes there simply is not a deficiency of EFAs and in these cases, supplements will not help. If ME/CFS is caused by a definite infection, then tackling the infection should be the first priority.
- We do not know all the answers.
- If there are difficulties swallowing or digestive difficulties, then there could be a problem taking either capsules or oils. **EFAs can be absorbed through the skin** and Evening Primrose oil (GLA) is suitable for this, though fish oils would not be so pleasant.
- In the EFA supplements which trials found to be beneficial for people with depression and Huntington's disease, DHA is usually left out. This is for several reasons including: 1) EPA converts easily to DHA and usually there is not a problem with DHA deficiency 2) trials have shown that it makes sense to maximise the ratio of EPA to DHA in supplementation 3) DHA is more susceptible to deterioration 4) DHA actually showed no benefit in trials with attention deficit hyperactivity disorder.
- More research is needed before definitive recommendations can be made.
- The dietary recommendations for people with ME/CFS are quite general and not necessarily specific to the illness: choose less refined foods and reduce white sugar, white flour, rice and pasta etc. (NB – if you have an irritable bowel syndrome, seek advice). Whole grains are just as easy to prepare, and much tastier. Professor Puri uses and recommends a bread machine!
- **Food is the best way to receive nutrients**, and not supplements. For instance, do not take vitamin A (not even in its precursor form beta carotene). The complexity of nutrients available in food cannot possibly be replicated in supplements.
- Professor Puri **does not recommend graded exercise** if it means pushing beyond your limits. His clinical experience has shown that it is wise to keep within your limits and do only half of what you think you can manage.

Footnote: it is possible to get GLA (Evening Primrose oil) on the NHS when it is given its chemical name, gamma-linolenic acid. However, this is at the discretion of the GP. EPA is not yet available on the NHS.