



Chronic Fatigue Syndrome (CFS) and Myalgic Encephalopathy (ME) & Diet



What is CFS/ME?

Chronic Fatigue Syndrome (CFS) and Encephalopathy (ME, also known as Encephalomyelitis) are classified as neurological illnesses by the World Health Organisation.

It can affect children as young as five years, but mostly it affects teenagers and adults. Diagnosis is made by excluding other causes of the symptoms, as presently, there is no specific diagnostic test.

What are the symptoms?

Symptoms include-

- ◆ Overwhelming fatigue, present for 6 months or more, not refreshed by sleep.
- ◆ Muscle pain and/or weakness
- ◆ Headaches, poor concentration, poor memory
- ◆ Nausea and irritable bowel like symptoms (IBS)
- ◆ Increased sensitivities to foods, drugs, household chemicals, alcohol etc.

As with other chronic illnesses, depression/ anxiety may also develop. The symptoms and their severity can vary greatly over time and from person to person. Some, who are mildly affected, will still be able to go out to work, attend school, or university. The very severely affected can be completely bed bound, unable to carry out any daily self-care such as feeding or washing, or tolerate any sensory input such as light and noise.

Are there any diets that will help recovery?

The body needs a balance of healthy foods to ensure optimum health. Eat regularly. Many people find small meals and snacks are helpful. Foods to choose are

- ◆ Bread, other cereals and potato including rice, pasta- eat a portion at every meal.
- ◆ Fruit and vegetables- aim to eat five or more portions a day. Fruit makes an ideal snack.
- ◆ Meat, Fish and Alternatives- such as chicken, egg, nuts, quorn, beans, pulses, soya alternatives. Include these at two meals.
- ◆ Milk and milk products including cheese and yoghurts

There are many diets (such as the anti-candida diet) that claim to improve CFS/ME symptoms. Although some people find them helpful, there is very little scientific evidence (evidence based on clinical trials) to support these claims.

These diets can be very restrictive and can create a lot more work and effort for the sufferer and their carers. Care needs to be taken that the diet remains healthy, nutritionally adequate, and there is no unwanted weight loss or gain. Also, that any benefits outweigh extra demands on the sufferer and carers.

Weight changes and concerns

It is common for there to be weight changes in those with CFS/ME.

1. Weight increase may result from a much reduced activity level, when appetite remains unchanged. Typically, exercising can make muscle pain worse, so restricting the ability for activity. To counteract a lower activity level chose healthy foods with a good intake (5+ portions) of fruit and vegetables. Energy-rich (high fat/sugar) foods such as biscuits, chocolate, cake, crisps and sugary drinks need to be kept to a minimum.
2. Weight loss can occur if the appetite is poor and nausea is present, or if it is difficult to buy and prepare foods due to fatigue. To help minimize this eat regularly. Try small, quick and easy meals and nourishing snacks.

Food allergy and intolerance

CFS/ME may affect or be affected by the immune system, but exactly how is unknown. As some people find that symptoms can worsen after eating it is not surprising that food is blamed. True food allergies (IgE mediated) are fairly rare in CFS/ME type symptoms. More often symptoms may be caused by food intolerance. There are many tests available commercially claiming that they can diagnose food intolerance and allergy e.g. Kinesiology, Electrodermal (Vega) testing or hair analysis.

There is no convincing evidence to support any of these tests and they do not diagnose true food allergy. The only reliable way to identify the problem foods is by following an elimination or exclusion diet. Your doctor can refer you to a registered dietitian if you would like further advice on food

allergy or intolerance. For more information see BDA Food fact sheet on Food allergy and intolerance.

What about supplements?

There is need for further research in this area. There are many nutritional supplements, including vitamins, minerals and essential fatty acids (omega 3's) and co-enzymes claiming to help tiredness. Some are very expensive and contain mega doses of the active ingredient. Large doses can be harmful, for instance of Vitamin A and B6. If you are concerned about nutritional intake, keep to a multivitamin

and mineral supplement, with no more than 100% of recommended daily intake.

If you are housebound, or go outside little, we recommend that you take a Vitamin D supplement at 100% of RDA (recommended daily intake). This is especially important in adolescence and in women after the menopause to reduce the risk of future bone problems (osteoporosis and osteomalacia). See BDA Vitamin D Food fact sheet.

If you need further help, ask to be referred to a registered dietitian.

Useful contacts (these can change please check websites for latest)

Action for ME

PO Box 2778
Bristol BS1 9DT
Telephone support: 0845 123 2314
Web: www.afme.org.uk

Association of Young People with ME (AYME)

10 Vermont Place
Tongwell
Milton Keynes MK10 8JA
Tel: 08451 232389
Web: www.ayme.org.uk

The ME Association

Appollo Office Court
Radclive Court
Gawcott
Buckingham MK18 4DF
Tel: 0871 222 7824
Web: www.meassociation.org.uk

TYMES Trust - The Young ME Sufferers Trust

PO Box 4347
Stock
Ingatestone
Essex CM4 9TE
Tel: 0845 003 9002
Web: www.tymestrust.org

25% ME Group (Support Group for Severe ME Sufferers)

21 Church Street
Troon, Ayrshire
KA10 6HT
Tel/Fax: 01292 318611
Charity No: SC034265
Web: www.25megroup.org

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