

Chronic Fatigue Syndrome/ME and Diet

CFS/ME is a chronic, disabling illness affecting both children and adults. It is poorly understood. Diagnosis is made by excluding other causes of the symptoms, as presently, there is no specific diagnostic test. Its name CFS/ME stands for chronic fatigue syndrome/ myalgic encephalopathy or encephalomyelitis. Doctors tend to use the name CFS for the condition, and patients use ME.

What are the symptoms?

Symptoms include-

- Overwhelming fatigue, present for three months or more in a child or teenager, or over four months in an adult
- Sleep disturbance or unrefreshed sleep
- Muscle pain and/or weakness
- Headaches, poor concentration, poor memory
- Nausea and irritable bowel like symptoms such as wind/bloating and abdominal pain. This is reported in 60-70% of cases
- Increased sensitivities to foods, drugs, household chemicals, alcohol.

As with other chronic illnesses, depression and anxiety may also develop. The symptoms and their severity can vary greatly over time and from person to person. The very severely affected can be completely bed bound and unable to carry out any daily self-care such as feeding or washing. They may also be unable to tolerate any sensory input such as light and noise.

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Some, who are mildly affected, will still be able to go out to work, attend school, or university.

Are there any diets that will help recovery?

The body needs a balance of healthy foods to ensure optimum health. If IBS type symptoms are a problem follow the diet advice for IBS symptoms.

A healthy balanced diet contains a variety of foods from each of these groups.

- Bread, other cereals, potato, and rice, especially slow release types of starchy food with a low GI (glycaemic index) such as pasta, porridge or wholegrain cereals. 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 meat, chicken, fish, egg, nuts, quorn, beans, pulses, soya alternatives. Include these in two meals.
- Milk and milk products, including cheese and yoghurts. Calcium enriched milk alternatives such as soya based products.

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There are many diets, (such as the anti-candida diet, or eating dark chocolate), that claim to improve CFS/ME symptoms. Although some people say the anti-candida diet helps, the scientific evidence, (based on clinical trials), does not support this claim. The study on dark chocolate and ME involved only ten people and hence is too small to make any claims.

Some diets can be very restrictive and can create a lot more work and effort for sufferers 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 do not outweigh the extra demands on the sufferer and carers. We recommend that you ask for the support and advice of a dietitian or health professional if you try these restrictive diets.

Weight changes and concerns

Weight changes are common for those with CFS/ME.

1. Weight increase may result from a much reduced activity level. Typically, exercising can make muscle pain worse, restricting the ability for activity. Also, many find they 'comfort eat' more if they are feeling low. To counteract a lower activity level, or negative feelings, focus on positive healthy foods choices with a good intake, (five or more portions), of fruit and vegetables. However, high calorie, (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.

If you are concerned about unintentional weight loss, or gain, ask your GP to refer you to a registered dietitian.

Food allergy and intolerance

CFS/ME may affect or be affected by the immune system, but exactly how is unknown. Many with CFS/ME report an improvement in symptoms after a change in diet. However, any food related problems are more likely to be food intolerances, (not affecting the immune system), rather than true food allergies. There are many commercially available tests claiming that they can diagnose food intolerance and allergy. However, there is no convincing evidence to support any of these tests and they do not diagnose IgE food allergy. Keeping a food and symptom diary may help identify a particular culprit food. 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.

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 3s), and co-enzymes claiming to help tiredness. Some are very expensive and contain mega doses of the active ingredient. Large doses, for instance of Vitamin A and B6, can be harmful. If you are concerned about nutritional intake, keep to a multivitamin and mineral supplement, with no more than 100% of recommended daily amount (RDA). If you are housebound, or go outside little, we recommend that you take a Vitamin D supplement at 100% of RDA. 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. Other Food Fact Sheets giving information on topics in this sheet are: Irritable Bowel Syndrome, Food Allergy and Intolerance/Testing, and Glycaemic Index available at www.bda.uk.com/foodfacts

Useful contacts

(these can change, please check website for latest)

Action for ME

0845 123 2380 or 0117 927 9551

www.afme.org.uk

Association of Young People with ME (AYME)

08451 232389

www.ayme.org.uk

The ME Association

0844 576 5326

www.meassociation.org.uk

TYMES Trust - The Young ME Sufferers Trust

0845 0039002

www.tymestrust.org

25% ME Group (Support for Severe ME sufferers)

01292 318611

www.25megroup.org



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This Food Factsheet is a public service of The British Dietetic Association (BDA) intended for information only. It is not a substitute for proper medical diagnosis or dietary advice given by a dietitian. If you need to see a dietitian, visit your GP for a referral or: www.freelancedietitians.org for a private dietitian. To check your dietitian is registered check www.hpc-uk.org This Food Fact Sheet and others are available to download free of charge at www.bda.uk.com/foodfacts

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