



Diet and nutrition

Updated: March 2025

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Managing your diet

Eating balanced and healthy meals is important during your illness, to provide you with the energy and nourishment you need for better health.

It is important to note that, due to the varying ways ME affects people, dietary advice must be personalised to the individual as what works for one person could be detrimental for another.

Some of the medical conditions commonly seen in conjunction with ME, such as autonomic dysfunction or mast cell activation syndrome, have their own specific dietary advice.

PoTS UK have more on this, [here](#).

Maintaining a good intake of fluids is important too, as well as reducing your consumption of stimulants such as caffeine and depressants like alcohol.

The effort required to buy food and prepare nutritious meals can mean that some people with ME find it difficult to maintain a healthy diet.

This can be made harder by loss of appetite or food intolerance (see below), which may mean that you consider taking vitamin/mineral supplements.

If you are experiencing significant problems with your diet and struggling to maintain an adequate food intake, discuss the possibility of a referral to a dietician with your GP or specialist.

Dietitians are qualified and regulated health professionals that assess, diagnose and treat dietary and nutritional problems.

Some people also look to nutritional therapists as a self-funded, alternative approach.

We shared a [useful article](#) on this in a recent issue of our *InterAction* magazine.

Other people find smaller, more frequent meals easier to digest and maintain energy levels.

Severe ME a guide to living, available from our shop, has a useful chapter on managing diet and nutrition.

Some adults especially those living alone find it helpful to have pre-prepared meals delivered or to get friends and family to donate frozen portions of their meals.

This applies equally to those mildly affected who work and need to save energy as those severely affected who aren't able to shop, prepare and cook healthy meals.

Vitamins and supplements

The 2021 NICE guideline for ME/CFS advises health professionals as follows (sections 1.12.23 and 1.12.24):

"Be aware that people with ME/CFS may be at risk of vitamin D deficiency, especially those who are housebound or bedbound. For advice on vitamin D supplementation, see the NICE guideline on vitamin D. Explain to people with ME/CFS that there is not enough evidence to support routinely taking vitamin and mineral supplements as a cure for ME/CFS or for managing symptoms. If they choose to take a vitamin or supplement, explain the potential side effects of taking doses of vitamins and minerals above the recommended daily amount."

The [British Dietetic Association \(BDA\)](#) recommends seeking an appointment with "a dietitian within the NHS after being referred by your GP or multi-disciplinary team. Your GP may make this referral, or you may request a referral yourself."

It may also be possible to see a knowledgeable Practice Nurse.

With regards to supplements, the BDA says:

"There are many claims that nutritional supplements help CFS, including multi vitamins, B vitamins, magnesium, essential fatty acids (omega-3s), carnitine, and co-enzyme Q10. Any benefit of supplements in CFS is unproven and there is need for further research in this area. Some are very expensive and contain huge doses of the active ingredient. Large doses, for instance of Vitamin A and B6, can be harmful.

"If you are concerned about your nutritional intake, a multivitamin and mineral supplement, that provides no more than 100% of the recommended daily amount, (RDA - see the ingredients label), may be recommended. If you are housebound, or don't go outside much, your doctor should check your vitamin D levels, as you are at risk of low Vitamin D status. A Vitamin D supplement of 10 Micrograms daily is recommended all year round for those at risk."

Cutting out certain foods

Some people with ME find symptomatic relief from cutting out dairy, gluten or other food groups.

If you are considering restricting your diet to help with ME, please seek the support of an appropriate healthcare professional.

The BDA has [useful guidance](#) on what constitutes bad dietary advice.

Writing in our membership magazine, InterAction, nutritionist, health journalist, and author Dr Carina Norris RNutr (Public Health), who has lived with ME for more than 20 years, offers the following information:

- it is common for people with ME to experience gut symptoms such as IBS, or migraines, pain other inflammation and hear the suggestion that food intolerances may be the culprit
- without careful support, monitoring of symptoms via food/symptom diaries and knowledgeable advice, it can be difficult to pinpoint specific intolerances and to avoid nutrient deficiencies from cutting out food groups
- this can increase problems with food sensitivities, increase stress about what to eat and lead to unplanned weight loss or gain, eventually leading people to fear food and eat very restrictively
- it is therefore not advised to try exclusion diets without support of a dietician or nutritional therapist.



Registered office:

Action for ME
Unit 2.2 Streamline
436-441 Paintworks
Bristol, BS4 3AS




Telephone: 0117 927 9551

Info & Support: infosupport@actionforme.org.uk

Fundraising: fundraising@actionforme.org.uk

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