

DIET AND NUTRITION

Expert help and ideas for eating well with ME/CFS and Long Covid



Eating well for ME/CFS and Long Covid

The NICE Guideline on ME/CFS

Healthy eating - The NHS Eatwell Guide

Malnutrition - Are you at risk?

Diet trends

Diet change risks

How to improve your diet

Nutritious recipes

Community feedback



Diet and Nutrition was written by **Sue Luscombe, Honorary Diet and Nutrition Adviser to the ME Association**

Sue is a Registered Dietitian with a wealth of experience in improving people's health and treating illness through diet changes. Her NHS career has spanned over 40 years. She has been especially interested in ME/CFS after her daughter, Becki, was diagnosed with the illness in 2002, at age 12. For many years, the family lived with the debilitating fatigue and practical consequences of ME.



DIET AND NUTRITION

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DISCLAIMER

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or other medical professional about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor or other medical professional.

Good nutrition is important for good health and providing the right balance of nutrients for energy and wellbeing.



EATING WELL FOR ME/CFS AND LONG COVID

INTRODUCTION

ME/CFS and Long Covid can have an impact on eating, drinking and nutrition. This booklet aims to provide clear guidance based on current evidence.

■ We'll consider how diet changes may help symptoms, such as feeling sick, (nausea), some types of gut symptoms, unwanted weight changes, energy fluctuations, caffeine or alcohol intolerance, and orthostatic intolerance.

■ We'll offer helpful tips to prepare and cook food, including from the online ME/CFS community.

■ We'll explore pitfalls, claims and trends with diet information.

■ Just one note. In this booklet we won't discuss the complex topic of vitamins and supplements as an intervention or therapy. We have **another booklet** about these.

Other leaflets are also available within Diet and Nutrition and Vitamins and Supplements sections on the **MEA website: Free literature**.

RECOMMENDED DIET GUIDELINES

Diet recommendations for ME/CFS (NICE Guideline 2021) have a starting point at the NHS Eatwell Guide. This is shown as a circle with a balance of different amounts of key foods.

However, the diet guidelines for post-Covid illness or Long Covid start from a different point, using the Mediterranean-type, or Anti-Inflammatory diet. This is represented by a pyramid.

One reason for some persistent post-Covid symptoms, is thought to be that the immune system no longer works properly. Diet advice focusses on helping the immune system and reducing inflammation in the body. The Mediterranean-type diet is also considered to be an anti-inflammatory diet. Its key messages are similar to the Eatwell Guide, but include specific guidelines on eating more legumes, pulses and nuts, fish rather than meat, and Omega-3 rich food, (such as oily fish).

Unfortunately, there is no one agreed and researched Mediterranean or anti-inflammatory diet, which makes it difficult to give exact dietary advice.

EATING WELL FOR ME/CFS AND LONG COVID

Both the Eatwell and Mediterranean diets advise less processed food, especially refined carbs and sugar, and processed red meat. They encourage more plant-based foods and wholegrains, which are higher in fibre.

For the purposes of this booklet and to avoid confusion, we will use the Eatwell Guide to explain diet for both ME/CFS and Long Covid.

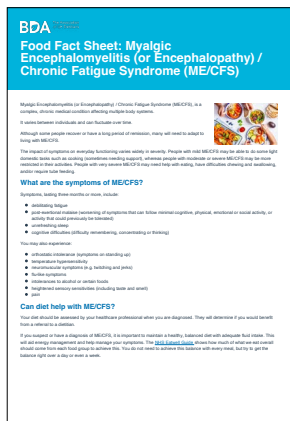
The British Dietetics Association, in association with Sue Luscombe, have produced two Fact Sheets on diet that provide more information. Each can be downloaded for free from the ME Association website:

Food Fact Sheet: Long Covid and Diet

Food Fact Sheet: ME/CFS and Diet

Further help

NHS: Your Covid Recovery: This addresses healthy eating, taste changes, issues of unwanted weight gain and unintentional weight loss and poor intake.



Both the Eatwell and Mediterranean diets advise less processed food, especially refined carbs and sugar, and processed red meat.



The MEA has produced a booklet called **NICE Guideline on ME/CFS: An ME Association Summary**



Encourage people with ME/CFS who have nausea to keep up adequate fluid intake and advise them to try to eat regularly, taking small amounts often.



THE NICE GUIDELINE ON ME/CFS

- The National Institute of Health and Care Excellence (NICE) produces Guidelines that provide a framework of evidence-based clinical recommendations to the NHS and social care services.
- In regard to ME/CFS, these recommendations are aimed at clinicians working in primary care (GPs etc) and secondary care (hospital-based ME/CFS specialist services), and at professional paid carers.
- We strongly suggest that, where able, patients and/or their families read the recommendations in full and discuss it with their healthcare professional at the next opportunity. The Guideline is a good reference tool and one that we are happy to endorse. Work continues to try and implement the recommendations across the whole of the UK.

We have taken sections from the Guideline that are most relevant to the topic of this booklet:

Dietary management and strategies

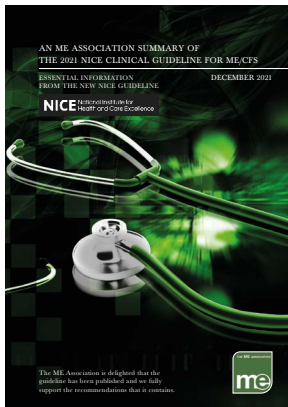
1.12.19 Emphasise to people with ME/CFS the importance of adequate fluid intake and a well-balanced diet according to the NHS Eatwell Guide.

1.12.20 Work with the person and their family or carers (as appropriate) to find ways of minimising complications caused by gastrointestinal symptoms (such as nausea), changes to appetite, swallowing difficulties, sore throat or difficulties with buying, preparing and eating food.

1.12.21 Encourage people with ME/CFS who have nausea to keep up adequate fluid intake and advise them to try to eat regularly, taking small amounts often. Explain that not eating or drinking may increase their nausea.

1.12.22* Refer people with ME/CFS for a dietetic assessment by a dietitian with a special interest in ME/CFS if they are:

- losing weight and at risk of malnutrition
- gaining weight
- following a restrictive diet.



Follow the recommendations on screening for malnutrition and indications for nutrition support, in the NICE guideline on nutrition support for adults.



THE NICE GUIDELINE ON ME/CFS

1.12.23* 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](#).

1.12.24 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.

1.12.25 Refer children and young people with ME/CFS who are losing weight or have faltering growth or dietary restrictions to a paediatric dietitian with a special interest in ME/CFS.

1.12.26 For advice on food allergies in children, see the [NICE Guideline on food allergy in under-19s](#).

In addition to the recommendations above:

1.17 Care for people with severe or very severe ME/CFS.

1.17.10* Refer people with severe or very severe ME/CFS for a dietetic assessment by a dietitian with a special interest in ME/CFS.

1.17.11 Monitor people with severe or very severe ME/CFS who are at risk of malnutrition or unintentional weight loss because of:

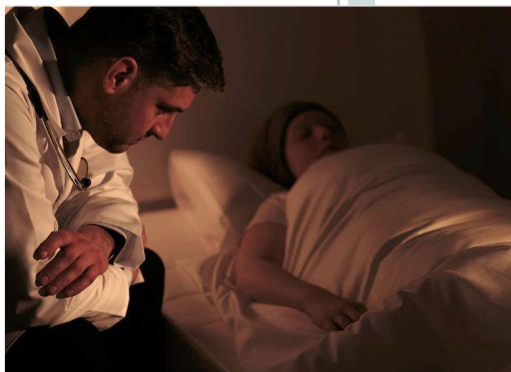
- restrictive diets
- poor appetite, for example linked with altered taste, smell and texture
- food intolerances
- nausea
- difficulty swallowing and chewing

■ Follow the recommendations on screening for malnutrition and indications for nutrition support, in the [NICE guideline on nutrition support for adults](#).

1.17.12 Give advice to support people with severe or very severe ME/CFS, which could include:

- eating little and often
- having nourishing drinks and snacks, including food fortification

Give advice to support people with severe or very severe ME/CFS.



THE NICE GUIDELINE ON ME/CFS

- finding easier ways of eating to conserve energy, such as food with softer textures
- using modified eating aids, particularly if someone has difficulty chewing or swallowing
- oral nutrition support and enteral feeding.

Source:

- The NICE Guideline on ME/CFS (NG206):

You can view the complete guideline by visiting the [MEA website](#).

- The following links will take you to the NICE website:

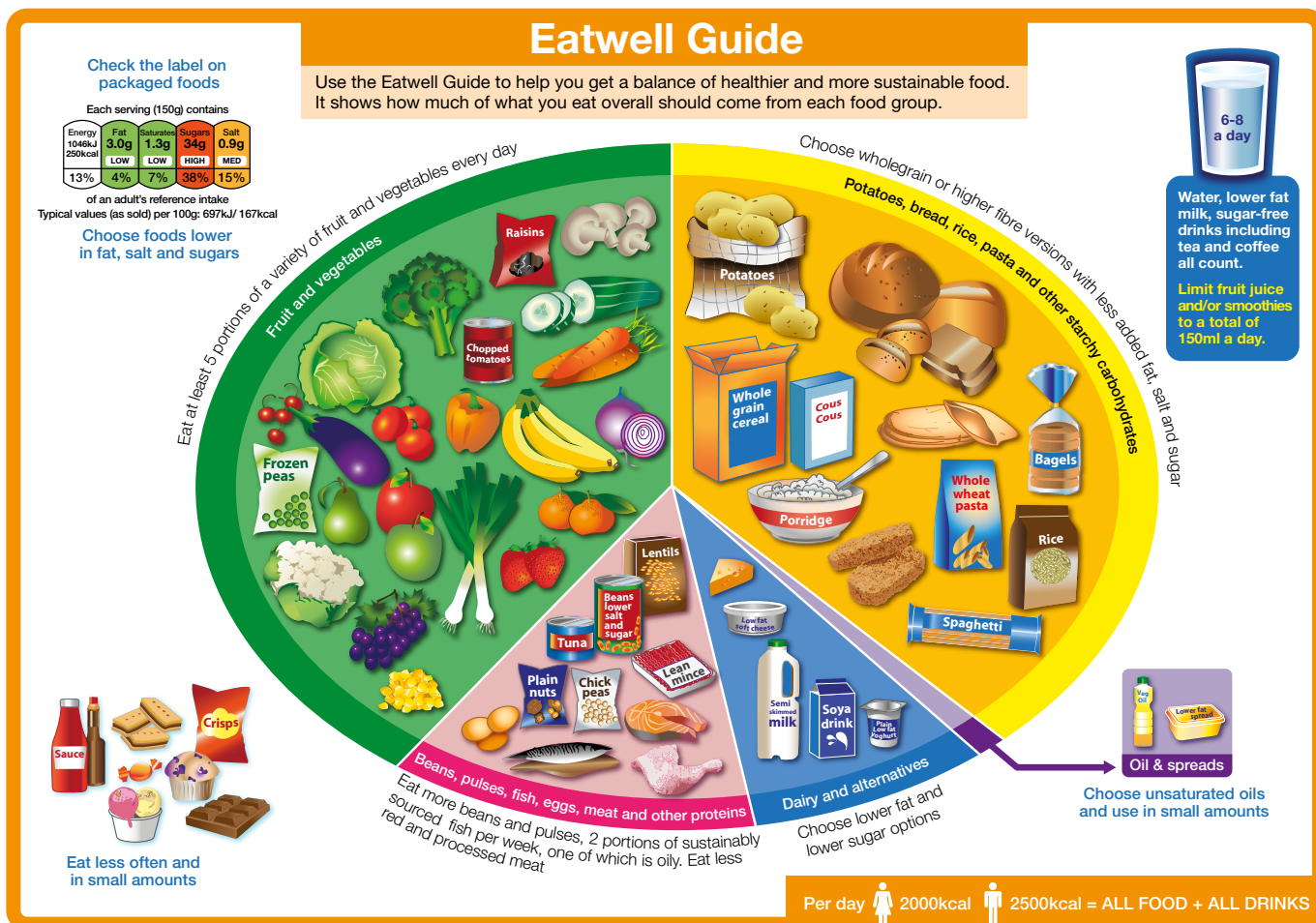
[Diagnosis and Management](#)

[Care for people with severe or very severe ME/CFS](#)

** Please note that in the NHS there are very few funded NHS dietitians for ME/CFS and Long Covid so there is, unfortunately, often very limited access to a dietitian with expertise in ME/CFS or Long Covid. However, dietitians with skills in nutrition support, for example, can help with boosting nutritional intake. Please talk with your dietitian to let them know how your ME/CFS or Long Covid symptoms affect your eating.*

THE NHS EATWELL GUIDE

The Eatwell Guide divides food and drink into five main groups. It helps you choose a varied and healthy balance. [You can download it here.](#)



Source: Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

DAILY CALORIE CONSUMPTION

- The recommended daily calorie intake shown in the chart above (2000kcal for women and 2500kcal for men) is unlikely to be a realistic guide if you have ME/CFS or Long Covid and are prevented from being as active as an able-bodied person.
- Therefore, and ideally under guidance from a dietitian, the average number of calories you consume each day will likely need to be adjusted downwards. Eating too many calories while being unable to effectively and regularly exercise, for example, can lead to problems with weight gain and weight retention.



THE NHS EATWELL GUIDE



We need many different nutrients for the constant, complex, interactions in our bodies. They provide energy and help our immune systems to function properly.

■ Being or becoming overweight can be harder to address when exercise remains an issue, as it can for other disabled people. A dietitian might best address this by recommending a sensible reduction in calorie intake while maintaining a healthy and balanced diet.

■ If you are underweight and experiencing problems consuming an adequate amount of food then a dietitian can take this into account when establishing a suitable dietary regime and work with you to establish a more realistic and achievable calorie goal that can help you reach a healthier weight over time. See also the section below on Malnutrition.

■ For more information please see **Other Common Topics** on **page 20** in this booklet.

1) POTATOES, BREAD, RICE, PASTA AND OTHER STARCHY CARBOHYDRATES

Potatoes, bread, rice, pasta and other cereals, especially wholegrain, are carbohydrates and provide energy and fibre. Try to include low Glycaemic Index (GI) foods, such as oats and wholegrains, which slowly release energy to keep your energy levels stable. Eat a carbohydrate portion at every meal. If you are less active, because of your ME/CFS, you use fewer calories, so choose healthy carbohydrates over those high in added sugars. Don't stop eating carbohydrates.

2) BEANS, PULSES, FISH, MEAT, EGGS AND OTHER PROTEINS

These provide proteins and fatty acids, (especially in oily fish), and many important vitamins and minerals. Eat two portions a day. Eat more pulses, beans and fish, and less processed meat. Beans and pulses include any canned beans, baked beans, peas (frozen or fresh), chickpeas, lentils, and hummus. They can be easy and quick to add to soups, curry, mince, pasta or salads. Nuts are also nutritious as a snack or added to a salad or cereal.

THE NHS EATWELL GUIDE

3) FRUIT AND VEGETABLES



Remember to keep an eye on your portion sizes. It's easy to overeat if you get them wrong!

These contribute essential vitamins and fibre and should make up just over a third of your daily intake. Aim to eat at least five portions of a variety of fruit and veg each day. Choose from fresh, frozen, tinned, dried or juiced. Fruit and vegetables make an ideal snack; try cherry tomatoes, carrot sticks or grapes.

How to get your Five-a-Day

- **Fresh, tinned or frozen fruit and vegetables.** 80g counts as one portion of your five-a-day (this doesn't include potatoes and some other starchy veg). If you're using tinned fruit or veg, choose those in natural juice or water, with no added sugar or salt.
- **Dried fruit.** 30g counts as one portion of your five-a-day.
- **Fruit juice, vegetable juice or smoothie.** You should limit these to a combined total of 150ml a day. And, no matter how much you consume, it only counts as one portion!
- **Beans and pulses.** A portion is 80g but, again, if you eat more, it still only counts as one portion! This is because, although they're a good source of fibre, they have fewer nutrients than other fruit and veg.

Portion sizes: Fruit

Small fresh fruit: A portion is, for example, either 2 plums, 2 satsumas, 2 kiwi fruit, 3 apricots, 6 lychees, 7 strawberries or 14 cherries.

Medium fresh fruit: A portion is one piece of fruit, such as one apple, banana, pear, orange or nectarine.

Large fresh fruit: A portion is half a grapefruit, one slice of papaya, a 5cm slice of melon, one large slice of pineapple, or two 5cm slices of mango.

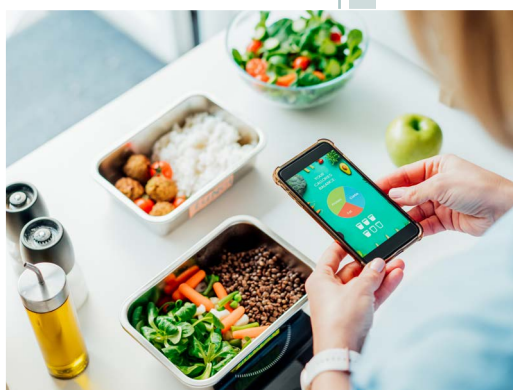
Tinned or frozen fruit: A portion is roughly the same quantity of fruit that you would eat for a fresh portion. Always choose fruit canned in natural juice, rather than syrup.

Dried fruit: A portion is around 30g (about 1 heaped tablespoon of raisins, currants or sultanas, 1 tablespoon of mixed fruit, 2 figs, 3 prunes or a handful of dried banana chips). However, dried fruit can be high in

THE NHS EATWELL GUIDE

sugar and bad for your teeth, so try to eat more fresh fruit, especially between meals. To reduce tooth decay, have dried fruit as part of a meal, not as a between-meal snack.

Portion sizes: Vegetables



Fresh, tinned or frozen vegetables: A portion is 2 broccoli spears, 2 heaped tablespoons of cooked spinach, 4 heaped tablespoons of cooked kale, spring greens or green beans, 3 heaped tablespoons of cooked vegetables, such as carrots, peas or sweetcorn, or 8 cauliflower florets.

For tinned, choose those canned in water with no added salt or sugar.

Salad vegetables: A portion is 3 celery sticks, a 5cm piece of cucumber, 1 medium tomato or 7 cherry tomatoes.

Keep an eye on your portion sizes. Too big can cause weight gain, too little may trigger a loss.

Pulses and beans: A portion is 3 heaped tablespoons of baked beans, haricot beans, kidney beans, cannellini beans, butter beans or chickpeas. Remember, however much of these you eat, beans and pulses still only count as one portion of your five-a-day

Potatoes: Potatoes don't count towards your five-a-day. They're classified as a starchy food, because, in a meal, they're usually eaten instead of other sources of starch, like bread, rice or pasta. However, as a starchy food, they are still important to your diet.

4) MEAT AND FISH

These are good sources of protein, vitamins and minerals. Pulses, such as beans, peas and lentils, are good alternatives to meat, because they're low in fat and a good source of fibre and protein.

Choose lean cuts of meat and mince. Eat less red and processed meat, such as bacon, ham, or sausages.

Aim for at least 2 portions (2 x 140g) of fish every week, 1 of which should be oily, such as salmon, sardines or mackerel.

THE NHS EATWELL GUIDE

5) MILK AND DAIRY



Milk, cheese, yoghurt and fromage frais are good sources of protein and some vitamins. They're also important sources of calcium for healthy bones.

Dairy and alternatives are highly nutritious, providing protein, some fats, and important vitamins and minerals. They include milk, cheese, yoghurts and calcium-enriched milk alternatives, such as soya-based products. Please note, though, that not all milk alternatives are calcium-enriched.

Milk, cheese, yoghurt and fromage frais are good sources of protein and some vitamins. They're also important sources of calcium for healthy bones.

Use lower-fat and lower-sugar products where possible, like semi-skimmed, skimmed or 1% fat milk, reduced-fat cheese or plain low-fat yoghurt.

6) FAT, SUGAR AND SALT

High-fat, sugary, and salty foods and drinks are outside the Eatwell Guide. Eat these less often and in small amounts. Examples are chocolate, cakes, biscuits, sugary soft drinks, butter and ice cream. We all enjoy our favourite treats, but they are less nutritious and not part of a healthy diet.

Choose unsaturated oils and spreads in small amounts. Unsaturated fats are healthier and include vegetable, rapeseed, olive and sunflower oils.

Be aware that, if you have orthostatic intolerance, your doctor may recommend more salt.

People with ME/CFS or Long Covid are likely to need a lot less calories than the average person, because of fatigue and lower activity levels. This is one reason weight gain is so common.



Nutrition Assessment in ME/CFS was written by Dr Charles Shepherd, Trustee and Hon. Medical Adviser to The ME Association.

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MALNUTRITION - ARE YOU AT RISK?

If you have a moderate or severe form of ME/CFS or Long Covid, you are likely to experience difficulty obtaining, preparing, and eating a healthy and balanced diet and you may be underweight as a result.

Not being able to eat enough because you are so unwell or cutting out, or reducing, specific food groups such as dairy and wheat because you have an allergy or intolerance or are trying to follow a restrictive diet, might also mean that you are malnourished or at risk of malnutrition.

The issues of nutritional assessment in people with ME/CFS, along with the risk of malnutrition in those more severely affected, was raised when preparing the 2021 NICE Guideline on ME/CFS.

Malnutrition is surprisingly common among people with long-term medical conditions:

- It significantly affects health; can repress immune responses and enhance viral vulnerability, reduce muscle strength, delay wound healing and increase the risk of falls.
- It reduces available energy and exacerbates cognitive problems - both of which are particularly relevant to ME/CFS and Long Covid.

Nutritional assessment

A nutritional assessment covering both food and fluid intake should ideally form part of your initial diagnosis and any ongoing care that you receive:

- a dietitian should complete the assessment and, if possible, one who works in a multidisciplinary ME/CFS specialist service or Long Covid clinic or who has experience of these conditions.
- diet and nutrition as well as the risks of malnutrition should form part of any care and support plan.

The assessment and any subsequent plan to address malnutrition should take account of all the factors that increase your risk:

- physical factors include the presence of nausea and/or loss of appetite, swallowing difficulties, food allergies and intolerances, and irritable bowel type symptoms that might affect both digestion and absorption of food.

It's worth noting that people who are overweight can also become malnourished if they are not eating a healthy diet.



MALNUTRITION - ARE YOU AT RISK?

- psychological factors can include anxiety and depression and the effect on appetite.
- social factors can involve the ability to obtain food and prepare healthy meals.

The assessment should record your normal daily intake of food and fluid in terms of total energy, and other nutrients as clinically indicated, for example:

- Fruit and vegetables are very healthy, but they contain very few calories and should form part of a balanced diet.
- Dairy products might need to be avoided if you have an allergy or intolerance, but they provide an important source of calories, protein and calcium, and suitable alternatives will need to be found.

Physical signs of possible malnutrition should also be noted. These include:

- loss of hair,
- changes in facial features (including prominent cheek bones and sunken eyes),
- a swollen red tongue (which may add to swallowing problems),
- loss of skin elasticity when pinched (also a sign of dehydration),
- brittle nails,
- muscle wasting.

The Malnutrition Universal Screening Tool (MUST)

MUST is a validated five-step screening tool widely used in the NHS. It uses weight loss as a predictor, alongside the starting weight for malnutrition risk. The scoring system identifies people who are at high, medium or low risk of malnutrition.

- It's worth noting that people who are overweight, can also become malnourished if they are not eating a healthy diet.

MALNUTRITION - ARE YOU AT RISK?



If a person has evidence of malnutrition, or is identified as being at risk of developing malnutrition, they should be referred to a registered dietitian for nutritional assessment and a nutritional plan.

■ A blood test to check for Vitamin D status is also important in anyone who is housebound and whose skin is not being exposed to sunlight, which is how most Vitamin D is produced in the body.

Nutritional Plan

A dietitian's first step, the nutritional assessment, will be to find out what you are eating and drinking, and any issues or symptoms you have that are impacting on your intake. A nutritional assessment will also include your weight, weight changes, and relevant medical history. Using the "Food First" approach they will work with you on ways to boost your nutritional intake using your preferred foods and drinks and fortifying your foods.

If this fails to improve your nutritional intake and/or achieve weight goals, the use of oral nutritional supplements (ONS) will be considered. ONS come in powdered sachets or ready-made drinks and are prescribed by your doctor on the recommendation of the dietitian.

Getting Assessed

If you are at all concerned about your weight and ability to eat sufficient food or drink, please consult your GP at the first opportunity.

■ If you want to check your risk of malnutrition you might find these self-assessment tools to be useful:

Malnutrition Universal Screening Test (MUST)

Patients Association Nutrition Checklist

Feedback

Please let us know if you have experienced problems with malnutrition, needed a nutrition assessment or the outcome from a referral to a dietitian, and if any sort of care and support plan was arranged as a result.

Email: feedback@meassociation.org.uk





A person with very severe ME/CFS being too debilitated to eat or drink will probably require nutritional support in the form of tube feeding.

MALNUTRITION - ARE YOU AT RISK?

Life-Threatening malnutrition in Very Severe ME/CFS

As a result of eating and/or swallowing difficulties, gastrointestinal problems tolerating food, and a person with very severe ME/CFS being too debilitated to eat or drink, some people will require nutritional support in the form of tube feeding - either in hospital or at home.

Eating and swallowing difficulties in people with severe and very severe ME/CFS should not be misdiagnosed and treated as a psychogenic eating disorder. This can easily result in a significant delay in initiating appropriate management and life-threatening malnourishment and/or dehydration.

The possibility that nutritional and hydration support may be required is acknowledged in the section covering the management of severe ME/CFS (1:17) of the [2021 NICE guideline on ME/CFS](#).

For more information see the paper from Helen Baxter, Nigel Speight (MEA Paediatric adviser) and William Weir:

Life-threatening malnutrition in very severe ME/CFS

DIET TRENDS

INTRODUCTION



There are many and complex reasons underlying these trends, including the cost of living crisis, and environmental concerns.

- Claims that certain diets can improve your health seem to be everywhere. It can be quite the minefield trying to determine which might be suitable and which are best avoided.
- The internet and social media have served to increase the volume around diet and nutrition and have made it harder to work out if there is any evidence for the claims being made.

- It's always worth checking to see if those promoting a particular diet have the necessary formal training and qualifications and that they are not selling something based solely on so-called testimony or anecdotal claims.
- While it is perfectly understandable to want to do 'something' that might improve your health, we would always recommend caution before starting a new diet. You should also discuss it first with a qualified dietitian or your GP.

Feedback

If you have come across claims that you feel are unsubstantiated on the internet about diet and ME/CFS or Long Covid, please let us know.

Email: Feedback@meassociation.org.uk

SHOULD I AVOID ULTRA PROCESSED FOOD (UPF)?

- This term has been much used recently. It is thought about 60% of our diet consists of UPF, and it is linked to a range of conditions including obesity, cancer, depression and dementia. It's worth noting that the name UPF is derived from Nova Classification, as a way of classifying foods only on the level of their processing.
- The Eatwell Guide and the Mediterranean-type diet have long recognised that too much processed food is not good for our health. The consensus from nutrition experts is that we should all eat less UPF. However some UPF can contribute to a healthy, balanced diet.

For instance, ready meals, any shop-bought bread, wholegrain breakfast cereals and any alternative milks, such as soya or oat, are all UPF, but they do contain important fibre and other nutrients.



DIET TRENDS

- If you suffer from fatigue, taking shortcuts with food preparation and using more ready-prepared food is often a necessity.



Preparing a vegan diet may need more time and energy to include healthy vegetables and fruit in tasty recipes.

WILL BEING A VEGAN HELP MY SYMPTOMS?

A vegan diet containing a wide range of veg, fruit, beans, pulses, nuts and seeds is healthier than a diet of mostly processed high-fat and high-sugar foods. However, plant-based diets are naturally low in Vitamin B12 which are only found in animal and dairy foods.

Vitamin B12 is essential for healthy blood production and a lack of it causes anaemia, tiredness, and nervous system damage.

The only proven reliable sources for vegans are fortified foods and supplements. Fortified foods include vegan spreads, nutritional yeast flakes, yeast extracts, breakfast cereals and some alternatives to milk products; one of these foods should be eaten twice a day at least.

The alternative is to take supplements: either at least 10mcg daily or at least 2000mcg weekly. The weekly supplement dose is far higher due to lower absorption in one dose.

Preparing a vegan diet may need more time and energy in order to include healthy vegetables and fruit in tasty recipes. If you are more severely affected, easy vegan meals or snacks may offer less nutrition unless you have support with preparation.

HOW MIGHT A HISTAMINE INTOLERANCE AFFECT MY DIET?

For those with histamine intolerance (HIT) caused by Mast Cell Activation Syndrome (MCAS), symptoms can be wide-ranging, including migraines, rashes, gut symptoms, dizziness, anxiety and insomnia.

A low histamine diet, alongside medication, may be recommended by your specialist doctor. The British Dietetic Association specialist group advises 2-4 weeks of a low histamine diet, then a step-by-step reintroduction of high histamine foods to test tolerance.

The diet is complex and challenging, not least because it cuts out many basic foods, and there is no universally accepted histamine content of foods. The histamine level of a food may also vary with how long it is kept, since fresher foods have lower histamine.

DIET TRENDS

Foods to be avoided include oily fish and fermented foods, but these are exactly the foods recommended on an anti-inflammatory, Mediterranean diet. People struggle to follow a low-histamine diet, so it is important to speak to a dietitian. [There is more information here.](#)

DOES A KETO DIET HELP FATIGUE?



The Keto diet is very low in carbohydrate, high in protein and fat.

The Keto diet is very low in carbohydrate, high in protein and fat, and has been a proven medical treatment since the 1920's, but only for those with severe epilepsy.

We know that the Keto diet causes ketones in our blood, which are then used as an energy source rather than the usual glucose. Whilst there has been some research on this diet in ME/CFS, it is too early to draw any conclusions.

The Keto diet is very restrictive and has profound limitations on food choice - very little fruit, healthy wholegrains and cereals - all things which contain fibre and lack of fibre potentially could negatively impact a healthy gut microbiome.

PERSONALISED NUTRITION

The saying, "One person's meat is another's poison" acknowledges that no one diet fits all. In the future, it is likely that diet treatments will become more tailored to people's individual health needs, taking into account our genome sequence and scientific research data.



It is very important, if you cut out milk and cheese, to make sure you have other high calcium alternatives, such as calcium-fortified soya milk, or canned fish (with bones).



OTHER COMMON TOPICS

DIET CHANGE RISKS

Are there risks to making diet changes myself?

- The more food items you cut out, the more you could compromise a healthy diet. An example is avoiding dairy, a main source of calcium for bone health. It is very important that, if you do cut out milk and cheese, you make sure to have other high calcium alternatives, such as calcium-fortified soya milk, or canned fish (with bones).
- If you are reducing, or cutting out, wheat or gluten, ensure that you eat other fibre-rich foods, such as oats, pulses, seeds, nuts, wholegrains, vegetables and fruit.
- Cutting out too many foods may also lead to unwanted weight loss with poor energy, deficiencies in important nutrients and a decline in emotional health.
- It's also worth pointing out that ME/CFS and Long Covid are difficult enough to live with. Avoiding certain foods or restricting your diet without a good medical reason might only add complications and bring little benefit.

SELF TREATMENT

Are there risks to self-treating gut symptoms with diet?

- Although Irritable Bowel Syndrome (IBS) is relatively common, there are several other conditions with similar symptoms. It is important that IBS symptoms are properly assessed by a doctor to make sure that other causes of gut symptoms, such as Coeliac Disease, Inflammatory Bowel Disease (IBD), and more serious causes, such as cancer, are excluded before concluding that IBS is the correct explanation.
- If you have any of the following symptoms, please seek urgent advice from your GP: unexplained weight loss, blood from your rectum, abdominal pain, anaemia, or a change in your bowel habits (over three weeks).
- If you think wheat upsets your gut, talk to your GP about a blood test for Coeliac disease. It is essential to exclude other causes for your symptoms before putting yourself on, for example, a gluten-free diet.
- IBS symptoms, such as wind/bloating, abdominal pain, constipation or diarrhoea are common. If you need further help managing your symptoms, ask your GP to refer you to a dietitian. They may, for

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example, suggest you trial a diet which reduces short-chain fermentable carbohydrates (also known as a Low FODMAP diet).



■ Any diet changes for co-existing conditions, such as food allergy, Irritable Bowel Syndrome, Coeliac Disease, or Inflammatory Bowel Disease (IBD) should only be made by a registered dietitian.

In our free leaflet, **Stomach & Irritable Bowel Symptoms**, we examine the symptoms, explain how they should to be investigated, and discuss available treatments.

NAUSEA

If I feel sick (nausea), is there anything that will help?

- Eating little and often, especially dry food, such as ginger biscuits, toast or crackers, can help relieve the feeling of sickness.
- Some people find it helps to sip a drink often, rather than drinking large amounts in one go – as does avoiding drinks around mealtimes.
- Cold food has less smell than hot food, so may be easier to manage.

WEIGHT CHANGE

What can I do about unwanted changes in weight?

■ You should see your GP if you have unexplained weight changes, (5-10% of your body weight in 3-6 months if you are over 18 years, or weight change outside the normal growth if you are a child). There are medical conditions that can cause weight changes, (e.g. an under/overactive thyroid gland, or polycystic ovary syndrome).

Weight gain:

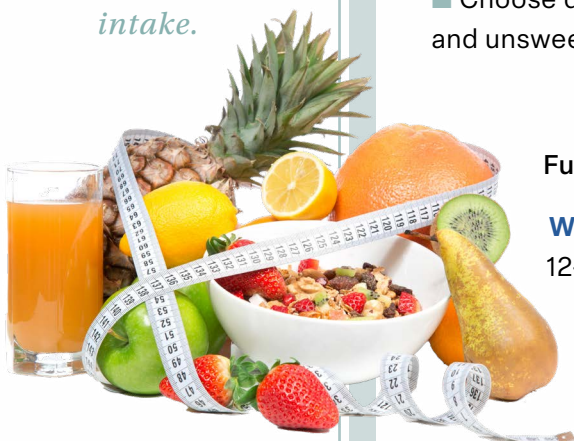
■ Unwanted weight gain is a fairly common side effect for some medications taken by people with ME/CFS, (e.g. amitriptyline and gabapentin). Your GP can consider dosage or alternative options and check to make sure that there isn't another medical explanation.

It is also relatively common for people to gain weight as they are unable to be as active.

You should see your GP if you have unexplained weight loss or weight gain.



Try to counteract weight gain by focusing on healthier food choices and reducing calorie intake.



To prevent weight loss, or to increase your weight, you will need to eat more often.



OTHER COMMON TOPICS

This means they eat more calories than they burn off. Low mood is common, and can lead to emotional or comfort eating as well.

- Some people report that they feel much hungrier (polyphagia). It is not known why this happens, but it may be linked with hormonal changes and poor sleep patterns.
- Try to counteract weight gain by focusing on healthier food choices and reducing calorie intake. Try to eat five or more portions of fruit and vegetables a day and healthy wholegrain carbohydrates to help you feel full.
- Keep higher-calorie foods, that have high fat and/or sugar, (such as biscuits, chocolate, cakes, crisps and sugary drinks), as occasional treats.
- Choose drinks that have few calories, such as water, tea, herbal tea, and unsweetened coffee to regularly hydrate.

Further help:

Weight loss help with the NHS weight-loss plan: A free 12-week diet plan. This also includes an exercise plan which is not appropriate for either ME/CFS or Long Covid. Always follow the guidelines on activity from your specialist. Avoid exercise if it makes you feel worse.

Weight loss:

- Unwanted weight loss is not unusual, especially when severely, or very severely, affected, or in an extended relapse, if your appetite is not so good, or because you are physically unable to maintain a healthy diet.
- To prevent weight loss, or to increase your weight, you will need to eat more often, and include snacks and nutritious drinks, such as milk or soya milk, or smoothies.
- If you can't eat normally, then you might consider vitamin and mineral-fortified supplement drinks, available from supermarkets and pharmacists, such as Complan. If this poor intake persists, consider speaking with your GP, who may refer you to a dietitian for further nutritional assessment and support.

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FOOD ALLERGY OR INTOLERANCE

What if I have a food allergy or intolerance?

■ A bad reaction to food might involve the immune system, in which case it is called a 'food allergy'. If it does not involve the immune system, it's called a 'food intolerance'.



Food allergy is diagnosed by your clinical history together with IgE blood tests and Skin Prick Tests.

■ A food allergy is caused by your immune system overreacting to certain types of food. It is diagnosed by a review of your clinical history together with IgE blood tests and Skin Prick Tests. Specialist input is required for diagnosis and management.

■ The most common allergenic foods include cow's milk, eggs, peanuts, soybeans, peas and chickpeas, tree nuts, shellfish, and wheat.

■ Many people find that certain foods will make an existing condition - such as Irritable Bowel Syndrome (IBS) - worse. These are usually intolerances not allergies.

■ Lactose (milk sugar) intolerance, one of the most common intolerances, occurs because people have either too little or no lactase - the enzyme which helps to digest lactose. Avoiding lactose in your diet will resolve your gut symptoms.

■ Keeping a food and symptom diary may help identify any food that is causing a reaction. The only reliable way to identify the suspected problem is by excluding the food, or foods, for a period and seeing if symptoms improve. If, on systematically reintroducing the foods one by one, symptoms worsen it is best to avoid the food that causes symptoms. You may need to seek guidance from a dietitian before doing this.

■ There are many commercially available "alternative" tests that claim they diagnose food allergy and intolerances. None are proven to be reliable as diagnostic tests, and this includes IgG blood tests. They are not recommended by the NHS. These tests do not diagnose IgE food allergy.

■ Your GP can refer you to a registered dietitian if you would like further

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advice on food allergy or intolerance.

CAFFEINE OR ALCOHOL

Should I avoid caffeine or alcohol?

■ Some people with ME/CFS find they are sensitive to caffeine. Many report alcohol intolerance and feel better by cutting it right down or avoiding it altogether. But, if you do tolerate caffeine or alcohol, there's no need to give up on them completely. Just make sure you do everything in moderation!



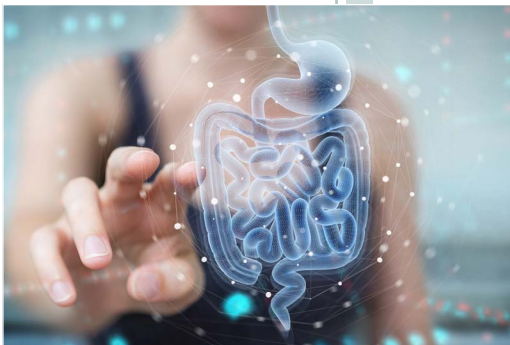
Night-time sleep is restorative, but day-time sleep may disrupt your circadian rhythm and prevent good sleep.

SLEEP AND DIET

Are there any diet changes to help sleep?

- If you have sleep problems, try to avoid drinks like coffee, cola or tea in the evening as caffeine is a stimulant.
- Try to get plenty of night-time sleep. Night-time sleep is restorative, but daytime sleep may disrupt your circadian rhythm and prevent good quality sleep at night. Try to sleep during dark hours and get plenty of good daylight in the morning to maintain or re-establish a good sleep rhythm .
- If you have ME/CFS or Long Covid, your sleep and sleep quality are likely to be affected.
- Unrefreshing sleep or sleep disturbance (or both) is a key symptom of both conditions.
- The NICE Guideline on ME/CFS makes a series of recommendations about Rest and Sleep in section 1.12.1.
- Night-time sleep is restorative, but daytime sleep may disrupt your circadian rhythm and prevent good quality sleep at night.
- Clinicians at an ME/CFS specialist service or Long Covid clinic should be able to help with tailored advice about rest and sleep and include it within a care and support plan.
- Try and avoid drinks like coffee, cola or tea in the evening or before trying to sleep as caffeine is a stimulant.

There is quite a lot of research being carried out in both the UK and USA into the possible role of the gut microbiome in ME/CFS with different theories emerging about how this may affect ME/CFS.



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GUT MICROBIOME

What is known about the role of my gut bacteria (microbiome)?

- The gut microbiome – the collection of viruses and bacteria that live inside the gut – not only helps to digest and absorb food, metabolise vitamins, nutrients and medicines, but also has a key role to play in how the immune system functions.
- We know that a balanced and varied diet can maintain and improve the health of the gut microbiome, but there is no firm research evidence that concludes people with ME/CFS or Long Covid have specific problems in this area or that any treatments are especially effective.
- There is research being carried out in the UK and USA on a theory that the gut membrane or lining may be involved, ('Leaky Gut'), causing malabsorption of nutrients. However, it is too early to draw any conclusions and we can't recommend that you should, for example, exclude any specific food such as gluten, take medical-grade probiotics or consider Faecal Microbiota Transplantation (FMT), until we know more.

ORTHOSTATIC INTOLERANCE AND POTS

I have been diagnosed with Orthostatic Intolerance and PoTS - Why is salt and fluid intake important?

- Postural Orthostatic Tachycardia Syndrome (PoTS) can develop when your autonomic (involuntary) nervous system is not working properly and your heart rate and blood-pressure control is affected. Symptoms include dizziness on standing, sweating, nausea, and fainting and it can be very debilitating. The diagnosis is made by a specialist doctor and treatment must be under medical supervision and can include medication, and an increase in fluid and salt intake.
- An increase in fluid intake, together with more salt in your diet, may help to increase your blood volume, which typically is low in PoTS. This may also help to stabilise or improve your symptoms. Common ways are by using salt in cooking, sprinkling it over your meals and eating more high salt foods. This should always be on the advice of a doctor, as increasing salt intake is not advised for some medical conditions. For most people, healthy eating involves reducing salt intake.



OTHER COMMON TOPICS

MEAL SIZE AND SYMPTOMS

Will my meal size affect my symptoms?



Eating small, regular meals and avoiding large meals is likely to help your symptoms.

- Eating too infrequently can cause major spikes and crashes in your blood-sugar levels, whereas eating small, regular meals can help to maintain blood sugar levels.
- Balanced, frequent meals can help regulate your energy levels throughout the day, and help keep you from giving into sugary cravings.
- Whether you hope to lose or to gain weight, or simply want advice on the most suitable diet for you, we recommend that you obtain a referral to a dietitian and one who specialises in ME/CFS and Long Covid.

DIETARY CLAIMS

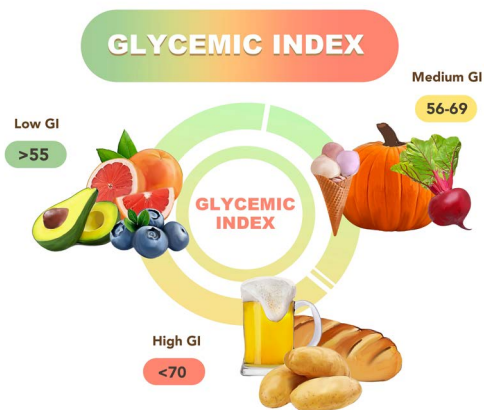
What about other diet claims?

- Some diets or foods are promoted as being capable of helping you recover from ME/CFS or Long Covid.
- Examples have included: The low sugar and yeast diets (anti-candida diet), the Stone-Age or Paleo diet, the Keto diet, or blood-type diets, or eating dark chocolate etc.
- There is, however, no research evidence to back up these claims, so they cannot be recommended. Indeed, if you come across a claim that a particular diet or food is supposed to reduce your ME/CFS or Long Covid symptoms, in our current state of knowledge, don't believe it!
- There is also no evidence that a 'sugar-free' diet is best or helps boost energy levels.
 - Natural sugar is found in fruit and milk, which should be important parts of healthy balanced diet.
 - Reducing your intake of 'added' sugar - confectionery and processed food and drinks - as part of a healthy diet, may help to

OTHER COMMON TOPICS

keep your blood-glucose level steady.

- If you want to know more about the sugar level in foods, we suggest you read about the [glycaemic index](#).



HOW TO IMPROVE YOUR DIET



*Vegan Beetroot
Soup. Recipe on
page 31.*

We provide some helpful suggestions that might improve your diet and its nutritional value.

■ **Soups:** Tasty homemade soups, packed full of vegetables, fibre and vitamins can be an easy, nourishing meal. It's the preparation that requires the effort. Consider using ready-prepared frozen onion, celery, sweet potato or butternut to spread out the energy involved in preparation. Soups are fine to batch cook and freeze for later.

■ **Eat the rainbow:** Include lots of colour. Eat five or more different fruits and vegetables each day, across the spectrum from red, orange, yellow, purple/blue, green, beige/brown.

■ **Plan ahead:** Prepare several days of fresh fruit and veg at the same time and keep them in a sealed container in the fridge. This will cut down on daily prep. Frozen fruit and veg is great for total convenience.

■ **Pre-prepared:** Look online to explore what you can get through your supermarket or internet shopping. You may be surprised how much time and energy you save by buying pre-prepared ingredients.

■ **Variety:** The bigger your range of foods, the greater will be your intake of different vitamin and minerals.

■ **Include plant-based options:** Plenty of plant-food variety helps the gut microbiome which is increasingly being recognised as important for our immune system. Aim for many different plant foods, such as veg, fruit, pulses, beans, nuts, and seeds within your week.

■ **Try before you fry:** Before getting out the deep-fat fryer, try cooking your vegetables in healthier ways, such as boiled, steamed, roasted or stir-fried. You'll feel so much better for doing it.

■ **Texture and taste:** Salads and sides are a great way of getting in lots of different tastes, textures, colours, vitamins, and fibre to feed your gut microbiome. Savour the flavour of some delicious new recipes.

■ **Sweet stuff:** Your body's readiest source of energy is from glucose, (a type of sugar), in your blood, liver and muscles. The glucose in your blood comes from the breakdown of any starchy, including healthy wholegrains, or sugary food, including fruit and processed table sugar. Most people who occasionally eat small amounts of processed sugary foods are unlikely to compromise their health. Healthy eating is all about balance.



*Veggie Stir Fry.
Recipe on page 32.*



Root vegetables can be prepared ahead and frozen, or bought ready-prepared.

HOW TO IMPROVE YOUR DIET

Tips for easy food preparation

■ **Onions:** Use ready-chopped onions. They can be bought either fresh or frozen or maybe ask a friend or family member to chop in advance and freeze, if you are unable to do this yourself.

Two heaped tablespoons of chopped onion = 1 medium onion, approximately 130g

■ **Root Vegetables and Sweet or Chilli Peppers:** Carrots, butternut squash, sweet potato, red, yellow, green or orange peppers. These also can be prepared ahead and frozen, or bought ready-prepared, often fresh or frozen. Frozen can be better, as they keep for longer and retain more vitamins.

■ **Tinned Vegetables and Pulses:** Tinned tomatoes, peas, sweetcorn, beans, chickpeas and pulses have a long shelf life and are good store cupboard items to have. Not only do these keep for a long time and are good value, they are packed full of nutrition and fibre and an excellent option.

■ **Nuts and Seeds:** These are excellent sources of fibre, protein and minerals, which keep a long time in an airtight container. Keep some of these handy too, for recipes and healthy snacks.

■ **Salad Vegetables:** Have bags of ready salad, or keep a whole lettuce in a bowl with a little water and in a bag, where it can last for up to a week. Peppers, radish, cucumber and tomato last longer if kept separately whole, rather than chopped together in a ready bag of mixed salad.

■ **Frozen Vegetables and Fruit:** Frozen peas, beans and sweetcorn are nutritionally excellent and a useful energy saver for meals. Using frozen berries, cherries, and apples also works well in recipes.

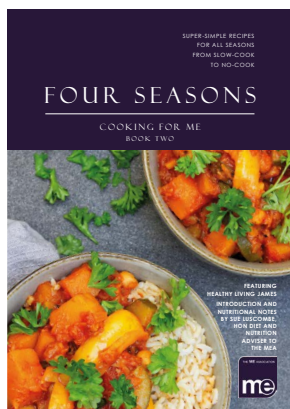
■ **Garlic, Chilli, Ginger:** Use ready-made, available in jars or as pastes in tubes. If you do buy fresh ginger, no need to peel, grate the lot.

1 level teaspoon garlic paste = 1 crushed garlic clove

1-2 teaspoons chilli paste = 1 medium chilli (depending how hot you like it!)

1 dessert spoon ready ginger = golf-ball sized knob of ginger

■ **Herbs and Spices:** Keep a range of your favourite herbs and spices dried in jars.



“I have had ME for 20 years and am now living on my own at the age of 70. I find cooking and all the prep daunting although, before becoming ill, my friends considered me to be a good cook and I loved to entertain.

“My good friend Ann gave me the ME Cookbook as a gift. It’s a fantastic book and I’ve really enjoyed trying some of the recipes. They are simple to follow with few ingredients and I look forward to cooking my way through the book!”

SM

HOW TO IMPROVE YOUR DIET

- **Cheese:** Ready-grated cheese keeps for ages in the freezer. Always good to have a bag rather than grating your own cheese. Tasty and nutritious addition to soups and other recipes.
- **Easy-clean Baking Trays:** If you lay some baking paper on your baking trays, before spraying them with oil, or putting any food on them, nothing much will stick, the paper goes straight in the bin and the trays are super easy to clean.

Four Seasons Cookbook

The ME Association’s **Four Seasons** book has a wealth of recipes with different flavours and tastes. Adding this to your bookshelf could tempt you to expand the range of foods you enjoy, and be inspired to try something new and different.

[Purchase the Four Seasons recipe book here](#)



NUTRITIOUS RECIPES



Vegan Beetroot Soup

PREP: 10 min

READY: 30 min

SERVES: 2

INSTRUCTIONS:

Heat the oil in a large pan and add the onion, beetroot and sweet potato. Cook for about 10 minutes, until the onion has softened slightly. Add the ginger, chilli and garlic, and cook for a couple more minutes, then add the tomatoes and vegetable stock. Bring to the boil and simmer for 20 minutes.

Season, stir in the peanut butter, then blend until smooth using a hand blender or food processor.

Alternative cooking method: If you have a soup maker, follow the instructions in the same way, adding the peanut butter when it's time to blend.

*Gluten-free option: Use gluten-free peanut butter.

This recipe is from The ME Association's Four Seasons cookery book.

[Purchase the Four Seasons recipe book here](#)

INGREDIENTS:

- 2 tsp groundnut oil
- 1 onion, finely diced
- 2 beetroot bulbs, peeled and finely diced
- 2 medium sweet potatoes, cut into 2cm pieces
- A 2-inch piece of grated ginger, or 2 tsp of Ginger Paste
- 1 red chilli, finely chopped, or a small amount of Lazy Chilli according to taste
- 2 garlic cloves, sliced, or 1 tsp of Lazy Garlic
- 3 ripe tomatoes, chopped
- 1 pint vegetable stock
- 2 tbsp smooth peanut butter*

NUTRITIOUS RECIPES



Veggie Stir Fry

PREP: 5 min

READY: 15 min

SERVES: 2+

INSTRUCTIONS:

Fry the veg with a little oil over a hot heat for about 5-7 minutes. Just before serving add the juice of a lime, a little soy sauce and a handful of mixed seeds or nuts.

Variation: If you're really hungry, add some rice noodles for a more satisfying dish!

Tip: Use ready-prepared or frozen vegetables to save on prep time.

This recipe is from The ME Association's Four Seasons cookery book.

[Purchase the Four Seasons recipe book here](#)

INGREDIENTS:

Broccoli florets, mangetout or sugar snaps, peppers, onions, beansprouts, mushrooms, water chestnuts and garlic

Juice of a lime

Gluten-free Soy sauce

Mixed seeds or nuts

You can use any quantity of each veg for this yummy stir fry - and eat as much as you like!



Sue says...

"Aim for many different plant foods, such as veg, fruit, pulses, beans, nuts, and seeds within your week. Eat five or more different plant foods each day, across the spectrum from red, orange, yellow, purple/blue, green, beige/brown. Variety helps the gut microbiome, which is increasingly recognised as important for our immune system."

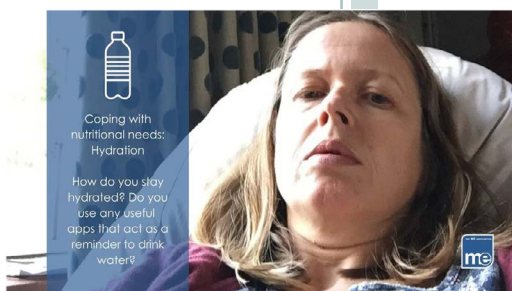
COMMUNITY FEEDBACK

Coping with nutritional needs: Hydration

We asked the ME/CFS community:

How do you stay hydrated? Do you use any useful apps that act as a reminder to drink water or other fluids?

Do you know that the NHS Eatwell Guide recommends that people should aim to drink 6 to 8 cups or glasses of fluid a day?



One of my symptoms is having a dry mouth so I actually drink more than before. I do take rehydration tablets if I sleep for a very long period of time in one go, usually 12+ hours. I also mix it with squash to make it taste a bit better and encourage me to get through it.

Lowri



Debra: I have water bottles everywhere: next to my bed, my chair, at my desk, in my car. That definitely helps me stay hydrated. Also take a water bottle with me everywhere. You can also tweak a plain glass of water, by adding lemon or other fruit, or ice, or fizz it up. It's quite easy for me because I absolutely love water.

Caroline: My young person has two clear bottles with measures on the side, so they (and I) can see how much has been drunk.

The bottles go about with my young person. Ideally both are empty at the end of each day. They have one as water and choose a flavouring for the second to relieve the boredom factor. Mainly it works.

Vicki: I have a 5-litre drinks dispenser next to my sofa. I have water bottles (and snacks) next to bed. If it's there and easy to get to, I remember to drink. If not, I don't.

Sarah: I mix water with a dash of milk or coconut water and use electrolyte tablets. If I'm being bad, I buy mineral water.

Stephanie: I struggle. When I sleep, I don't wake up and I'm stuck in vivid dreams and nightmares. I often wake up drenched from night sweats. I am always low on hydration and do not eat in a well managed way. I have asked for IV fluids but have been denied. But when you sleep for 18-36 hours because of the fatigue, how in the world can I otherwise?

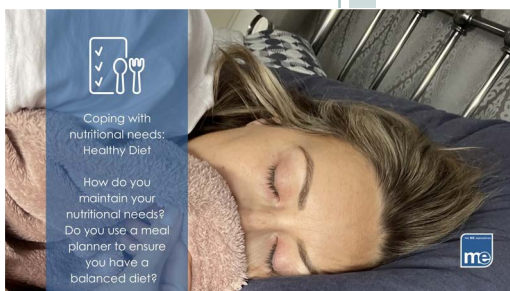
Jo: I'm lucky as my husband/carer always makes sure I've got water with me. I've got a handy opener so I can get to it easily without hurting my hands too much. He's always got the kettle on for me as well in-between times.

Kate: I always have a jug of fresh water and a glass on a table next to my chair. When attending appointments, I carry a bottle of water with me. On the bedside table I have glass of water for through the night. Essential: If you feel thirsty... You are dehydrated!

COMMUNITY FEEDBACK

Coping with nutritional needs: Healthy Diet

How do you maintain your nutritional needs? Do you use a meal planner to ensure you have a balanced diet? Do you have any tips for people struggling to prepare meals?



“It’s very hit and miss. Most days I find it hard to decide what to eat and can’t guarantee I’ll want to eat it when it’s time. Today’s roast turned into cheese and biscuits. I wouldn’t bother at all with proper meals if I was on my own.”

Carolyn

Sally: When there is the energy to cook, it’s a triple or double batch so one to eat and the other to the freezer for days when putting something in the microwave is the only option.

Emma: I have found eating Weetabix or wholemeal bread evens out my blood-sugars as whole-grain doesn’t cause the crashes that white bread and white pasta does. I can’t eat wholemeal rice or pasta with my IBS but I seem to tolerate whole grain. Not everyone with IBS can but, if you can, it’s worth a try.

Lex: I have tried a few things. A frozen meal delivery service was really useful for a time but was expensive. At the moment I have a set menu for the week and have meals that I can usually make. It takes the effort out of thinking about it at least, if not the effort of actually making it.

Virginie: I use a crockpot on good days and plan prep for simple food with ingredients like black beans (contain iron), cauliflower florets (anti-inflammatory), etc... It can be made tasty with a pinch of spices, herbs, and whatever agrees with your diet. Couscous is made with absorbing some boiling water and I use this as an accompaniment.

Hjay: I use an electric soup maker: Add chopped/small veg. Then add protein. Press the button for smooth or chunky. Go away and come back when it’s done. So easy. Dip bread in it! You can use tinned or frozen foods - you can get ready-chopped veg from a supermarket, or I chop veg earlier so that I spread out the energy required. Rice vermicelli is another good option as it just needs three minutes soaking in water from a boiled kettle. Otherwise I use tinned food and the microwave.

Fi: My husband prepares any veg in advance for me to throw into a pan. I plan quick meals and have easy-access staples such as frozen garlic and ginger. When my husband is home he can cook double portions to freeze in preparation for my bad days. I try to cook as much as possible as it’s something that gives me pleasure so I use devices such as chopping and grating/slicing machines.



COMMUNITY FEEDBACK

Mike: I start off with nutritional requirements and then work backwards to low-cost ingredients that tick the boxes to fulfill those nutritional requirements. Consequently, my diet is uninspiring but (nutritionally) adequate. If you limit ingredients-wise the amount of crap (to use the technical term) you buy, then that limits how poor your diet can be. Device-wise, microwaves are brilliant and a lot of things can be bodged, culinarily speaking, in them. As is the electric kettle. It helps enormously if temperamentally speaking you are an eat-to-live, rather than a live-to-eat person.

Alison: Meals that can have most prep done earlier in the day means I can spread prep tasks out with lots of breaks. I usually cook them earlier in the day too, so it is just plate-up and microwave at teatime. A slow cooker is also good. Cook large batches and freeze portions. And I always have a default no effort dinner (mine is beans) for days when it's needed. I even cook lots of rice in one go to eat over three days, just to save energy.



I have found a local woman who makes home-made meals and delivers them frozen/chilled at reasonable prices. But in the early days I couldn't even heat food up (let alone order it).

Joanne

Symptoms of Postural Orthostatic Tachycardia Syndrome (PoTS) include dizziness on standing, sweating, nausea, fainting and it can be very debilitating.



MORE INFORMATION

FURTHER HELP

Further reading

The ME Association has a **full range of free booklets** that you can download from the website. Topics relevant to Diet and Nutrition include:

- **Nutrition Assessment & Malnutrition**
- **Orthostatic intolerance**
- **Postural orthostatic intolerance syndrome (PoTS)**
- **Stomach and irritable bowel symptoms**
- **Vitamins and supplements**
- **Vitamin B12 and deficiency**
- **Vitamin D and deficiency**

The British Dietetic Association

The BDA has a **range of food facts leaflets** that can be downloaded for free from their website. These include:

- ME/CFS
- Long Covid
- Allergy testing
- Fluid and hydration
- Food allergy and intolerance
- Irritable Bowel Syndrome
- Menopause
- Omega 3
- Probiotics
- Probiotics and gut health
- Spotting malnutrition
- Weight loss.

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“Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful.”



THE ME ASSOCIATION

Changing attitudes and improving lives...

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today!**

■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. We provide a personalised service and we're here when you need us most. Most of us have personal experience of these medical conditions, or care for a loved one who does. To view the ME Connect telephone helpline opening hours please visit: <https://www.meassociation.org.uk/me-connect>

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, to get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations from the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

“The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research.”



THE ME ASSOCIATION

Changing attitudes and improving lives...

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guidelines reproduced in full in an easy to use **database**.

MEDICAL MATTERS

Medical Matters is an easy to use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy to use **database**.



ME CONNECT

The Support and
Information Service for
people affected by
ME/CFS/PVFS
and Long Covid



Freephone
0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect

Contact ME Connect
3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.



VITAL SUPPORT

We are here to help you reach an informed decision.



SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!



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