



The Young ME Sufferers Trust

Diet in ME - is it such a big deal?

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Some years ago I produced a leaflet on diet in ME. I wrote it because unnecessary mystique had built up around the subject. I used personal experience coupled with information and advice from the late Dr Alan Franklin, Consultant Paediatrician, ME and allergy specialist, and Dr Elizabeth Dowsett, then Honorary Consultant Microbiologist for South Essex Health Trust, the UK's foremost expert on the virology of ME.

What emerged was a commonsense leaflet which punctured numerous food myths. It is packed full of simple information you're not usually told.

Dr Elizabeth Dowsett's especial concern is that malnutrition can occur in people with ME who restrict their diet too much. She advises against sugar-free diets for this reason.

Two key recommendations are:

Don't restrict what you eat more than you really need to because you will end up malnourished and this is bad for your healing processes.

Do use your common sense about what agrees with your own body, rather than following some standard recommended diet.

One particular point Dr Dowsett makes, which is especially relevant to young people, is that going without breakfast is not only generally bad for you, as people with ME often suffer from periods of low blood sugar, but intellectual performance has been found to drop because of going without breakfast.

Introduction

We hear many conflicting things about food in ME. Some say it is better to eat organic food, others say that additives are a problem, and yet others claim that they have been made dramatically better or worse by sudden and dramatically big changes in their diet such as completely cutting out bread, for example.

The problem with all these ideas is that ME naturally fluctuates so much that it is often impossible to say that you would not have felt worse or better anyway. You would need to keep very careful records over a long period of

time to have enough evidence to judge from, and during this time you may have been improving or going through a down period which is nothing to do with what you are eating. The way you feel may, indeed, have more to do with how you have been managing your energy, whether you have had to cope with periods of extra effort or upset, or whether you have had extra support from friends. There are so many variables in life.

Therefore you need a common sense approach to food if you are not to become too worried about what you are eating in case it makes you worse. We hope that this leaflet will help you in this common-sense approach.

Nutrition

It is of course quite true that diet can produce some problems in ME because people with ME typically develop sensitivities (rather than true allergies) to various foods. For the moment, their bodies may overreact to certain food substances. This can lead people to adopt such restrictive diets that they do not get enough nourishment

for a healthy person, let alone a sick one whose body needs all the nourishment it can get.

The two key tenets to keep in mind:

Don't restrict what you eat more than you really need to because you will end up malnourished and this is bad for your healing processes.

Do use your common sense about what agrees with your own body, rather than following some standard recommended diet.

Bloating and pain

These are common problems. Following the general principles below should help you minimise them.

Root vegetables like potato, carrots, turnip and parsnip are easier on the gut than green-leaf vegetables and things with skins.

Potatoes are easier to digest than bread and are therefore a very good source of slow-release carbohydrate, avoiding too many highs and lows in blood sugar.

Bananas are also good for slow-release carbohydrate and are rich in potassium. They do not appear to cause problems in many people with ME although almost anything can be a problem if you are really ill at the time.

Don't eat the skins of baked potatoes if they irritate your gut; take the skins off tomatoes (remove the pips too) and fruit etc. if you need to. You'll probably - eventually - be able to eat them again, but it can take several years for your gut to steady down enough to manage them with ease. An in-between phase may be necessary, when you re-introduce them to your diet in small stages.

Fruit which may cause various problems are oranges (including orange juice) and apples. If you can't eat raw apples without getting pain,

you'll most likely be OK to eat them cooked, due to a chemical change caused by the cooking.

Wholemeal or granary bread may also cause bloating and pain. Use white bread if so - it may be fashionable to eat fibre but it's no good if it causes you trouble. Bran-type bread may be much more easily tolerated if it's made from oat bran - good as toast spread with an olive-oil based margarine.

Likewise it's fashionable to eat al dente (half-raw) vegetables, but cooking them thoroughly is easier on the gut. We have known people with ME who have no problem with raw vegetables, but if you are having trouble with bloating and wind, try making sure your vegetables are all well cooked and this may help to alleviate the problem.

If you find that reducing your fibre produces a problem with constipation, the most gentle remedy we have found is prunes. They don't seem to give the same problems as some other fruit. You can buy them tinned (avoid the ones in apple juice for the reasons above) or nibble them as a tasty snack out of a ready-to-eat packet. For ease, buy the ones that have been de-stoned (they may be referred to as pitted prunes). Dried apricots may be OK for you too. Drinking plenty of fluid will also help with constipation, especially if you are not eating much.

Keep away from fizzy drinks because of the gas problem.

Too much pepper or other spice can also irritate your stomach.

Wheat can produce problems. People who have this problem are better with bread made from other grains.

Other useful pointers

Some people find that goat's milk or soya milk suits them better than cow's milk. The Countess of Mar, one of the Trust's patrons, whose

farm produces award-winning goat's cheese, tells us that the goat is the 'universal mother' and goat's milk can be tolerated by all animals.

Alcohol is generally not tolerated by people with ME and makes them feel ill or sets them back in some other way. It may also interfere with heart rhythm. Check if you are in a restaurant (or eating packet mince pies!) that there is no alcohol in the food. Generally, if the wine, beer, cider etc. was cooked in with the food, all that will be left is the taste. Most of the alcohol will have been lost in the cooking process. But if the chef has put in some neat alcohol at the last minute, this can be bad news for someone with ME. I was once having French onion soup in a pub and I asked (feeling very foolish because it seemed so unlikely) 'Is there any alcohol in the soup?' Not only was there alcohol in it, but it had been added at the last minute. No soup for me, thank you very much.

Caffeine can also interfere with heart rhythm and make you 'high', which will exhaust you. Try decaffeinated coffee and weak or decaffeinated tea. (Sometimes even the coffee itself can be a problem.)

You will want to avoid things which bring on really bad headache or migraine. These are typically cheese and chocolate, but may include other things too, such as the spices found in Chinese or Indian meals. Keep a record of what you ate/drank before each headache or migraine and you may be able to see a pattern, though migraine can be triggered by many other things. If you have a real problem, consult your GP and make contact with the Migraine Trust.

If all this advice sounds complicated, remember the the simple principles behind it:

Not too much fibre or gassy stuff to avoid pain and bloating.

Nothing that gives you headaches, migraine, or makes you very unwell.

Don't get constipated.

If it all sounds like too many don'ts then remember the do's:

Do try eating a little and often. Many people find that 'grazing' is better than eating three meals a day with nothing in between. It stops the highs and lows in blood sugar and it is gentler on the stomach.

Do find lots of foods you can enjoy and get plenty of them.

Do carry a snack with you when you go out. If you start to feel panicky, weepy or just 'weird', eat something. It often works like magic.

What's the safest bet?

Traditional meat and two veg, especially potatoes, is excellent. You won't go far wrong with that. Vegetarians with ME need to be very careful to get enough protein. Most people find that lots of protein, ideally in the form of meat, really does help, and this has recently been underlined by work in America headed by Professor Richard Bruno. My own finding was that a helping of meat twice a day may be better than just one large meal.

Hints and Tips

Contrary to popular myth, if you are too tired to prepare and cook fresh vegetables without suffering ill-effects from the sheer effort of the task, frozen vegetables are every bit as good with regard to getting the vitamins you need. If microwaved, they take even less time to cook than in a saucepan, and may retain more goodness too. Tinned vegetables, on the other hand, have lost much of their vitamin content because of the high heat they undergo in the processing.

Dr Dowsett is a great advocate for ice-cream because it's nice and it's full of nourishment and easy on a sensitive tum. Custard's good too. My own favourite for a painful tum with trapped wind was a tin or carton of creamed rice, heated up. YUM.

As an alternative to proprietary tablets or mixtures, peppermint sweets or ginger biscuits are both effective if you have trapped wind. Keep some by the bed - extra strong mints may be particularly effective. A hot drink may help - not tea at this point though, or it may aggravate the wind pains rather than help.

Caution

If you are taking an MAOI antidepressant, or St John's Wort, AVOID Bovril, gravy mixes, cheese and Chantilly wine - chance'd be a fine thing! There is a potentially serious interaction.

And finally...

If you were able to eat things before your ME which are causing trouble now, you'll probably be able to eat them again one day without trouble. But you may need to be a bit patient.

Food ought to be a source of pleasure. Sadly, because of the problems in ME, some of the pleasure may be lost. At times you may even get too exhausted to chew properly (meat should be tender, eaten in small mouthfuls, perhaps casseroled rather than roasted or grilled) and things may taste different from the way they did before you were ill.

So try to find seven special snacks that you really like and which make you feel good. Then give yourself a treat with one of them every day. (Work them into your daily food plan if you have one, so as not to put on too much weight; some people with ME lose weight alarmingly and extra treats help to alleviate this, but some go the other way.)

Buy (or ask for) a matching mug and plate with a picture that you really like. My favourite for the winter months is the Winter design from the Brambly Hedge series - mice sitting in a warm kitchen toasting themselves by the fire, nibbling hot crumpets - outside the snow is coming down...

There's probably nothing quite so comforting when you're ill as curling up under a rug by the fire, like the mice, with a steaming hot mug of something soothing and a small plate of chocolate covered raisins, or if you can't take chocolate, try crisps, pieces of crunchy toast and jam, dried fruit pieces - anything you can nibble slowly while you uncover the picture bit by bit. All in moderation of course! Dark chocolate is thought to be good for you as it contains more flavanoids than milk chocolate.

The subliminal (secret) message you're giving your body when you take care of it like this is, 'I love you, I know you're going through a bad patch but I'll make it as painless as possible.' Loving and caring for your own sick body is one of the best ways to help it heal you.

If you are reading this in Spring, you'll want a different picture of course, and in Summer you can sit outside for your treat - be careful of direct sunlight though - shades, a hat and plenty to drink are in order. We people with ME may need Vitamin D from sunlight but we often react badly against too much heat. But that's another story.

Happy eating.

Note : If you have diabetes or gluten-sensitivity or another medical condition as well as ME, you'll need to seek specialist guidance on your diet.