

Cystic Fibrosis all about nutrition

Achieving a healthy weight in cystic fibrosis

With thanks to members of the Cystic Fibrosis Dietitians Group UK (CFDGUK)
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What weight should I be?

A healthy weight is important to help you maintain good lung function. Weight and lung function are linked, and better nutrition is associated with higher lung functions. If you are under 18 years of age, your appropriate weight is determined by your growth. This can be calculated for you by your dietitian. If you are over 18 years of age, your optimal weight is calculated by your body mass index score (BMI).

BMI is a measurement of weight vs height. Research has shown that adults with cystic fibrosis (CF) have the best outcomes if they achieve the following BMI:

Male BMI: 23kg/m²

Female BMI: 22kg/m²

Taken from the Consensus Document on the Nutritional Management of Cystic Fibrosis (2016) and Stallings et al. (2008).

Calculate your BMI

You can calculate your BMI by using online calculators, graphs or a calculator. Your dietitian can also help with this if you are unsure.

To calculate your BMI using a calculator you need:

- your height in metres
- your weight in kilograms

Enter your weight on the calculator and then divide this by your height. Then, divide the answer from the first calculation by your height again. The answer will be your BMI.

Example

If you weigh 54kg and are 1.6m tall you can calculate your BMI as follows:

$$54 \div 1.6 = 33.75$$

$$33.75 \div 1.6 = 21$$

Your BMI in this case would be 21kg/m²

BMI can be misinterpreted or can be incorrect for people with a large muscle mass or who are still actively gaining height. This calculation is designed to give you an estimate of your nutritional status. You should discuss your BMI and your targets with your dietitian.

Why is gaining weight hard work?

Most people with CF need more energy than people without the condition. Having CF can increase your energy needs by 100-200%.

The amount of energy you need also increases again as your lung function drops. This can increase further if you are unwell and fighting an infection. This means that when you are unwell or have a lower lung function, you need to take in more energy to keep your weight stable, and this can be difficult to do when your appetite is lower or you feel tired.

Why is my weight important?

If your weight is lower than recommended, it is harder for your body to fight infection or to support your lung function. There is a direct link between nutritional status and living a longer and healthier life. Improving your body weight will also help to protect you if you do have an exacerbation (sudden worsening) of your lung health.

What can I do to gain weight?

If your weight is lower than the recommended BMI, your dietitian can discuss ways to improve this with you. This leaflet provides advice and ideas to help you gain weight and achieve a healthy BMI. Energy is usually displayed on food packaging as kcal, but referred to as calories, and the number of extra calories you need to eat to gain weight will vary depending on how well you are at the time, your lung function, your age and gender. To gain weight start by remembering that people usually need to eat at least 500–600 kcals more than they are currently eating on a daily basis. This additional calorie intake can be 1,000 kcals or much more for some people. Your dietitian will be able to help you examine your current energy intake and advise you how much you should increase this by.

What should I eat?

It can be difficult to add extra calories into your day, especially if you are already eating regularly.

You can increase the energy in the foods you are already eating by making some swaps or by ‘fortifying’. The quickest way to do this is to add fat to food. Fat is the most energy-dense food we can eat, so gram for gram it is a good way to add calories to your diet. Adding fat is a good short-term way of gaining weight. You can also increase carbohydrate and protein to increase overall calories, although you will need to eat more of these items to have the same effect. It is important that your overall diet is balanced. Your dietitian can help you to examine your diet and make sure you have adequate protein, carbohydrate and vitamins and minerals to help your longer-term health.

When trying to gain or maintain your weight, look at your day: are you eating breakfast, lunch and dinner? Are you sleeping late and missing meals? Can you add in extra meals or move your meals to different times in the day so that you don’t miss them?

Aim to eat three meals per day and at least one or two snacks per day. If you cannot manage this, try eating smaller, more regular meals and snacks, and try not to skip meals. Sometimes, a small change to your routine can make a big difference.

Don’t forget about drinks. Milk or milkshakes can have higher calories than some soft drinks or squashes, which can help you gain weight quicker. Coffees made with milk at home or full fat coffee shop products such as a latte or hot chocolate can quickly increase your daily intake of energy.

Fortifying foods

Adding certain high-calorie items like fat or sugar to your food can help to increase your energy intake. If you have diabetes and are concerned about increasing your sugar intake, or if you have concerns over how to take your pancreatic enzymes now that you are consuming more fat, please speak to your dietitian.

Here are some things you can add to your food to achieve a healthy weight:

- Dairy products such as cream, butter, full-fat milk and cheese
- Eggs
- Sugary products such as syrup, honey and sugar
- Other fats such as olive oil, mayonnaise, salad cream, dressings, nuts and nut butters/spreads

Practical ways to do this might include:

- Adding milk, butter, cheese and cream to mashed potatoes or scrambled eggs
- Adding butter to vegetables and buttering bread for sandwiches or toast
- Adding oils, mayonnaise, dressings, seafood sauce, salad cream or avocado to salads or sandwiches
- Adding cream, sugar, syrup or honey to desserts, porridge, custard, rice puddings, yoghurt and ice cream
- Adding nuts to desserts, spreading peanut butter on bread or adding nuts to salads or eating them as a snack

Examples

Here are some examples of how adding these things to your food could help to add extra energy to your diet:

- A small portion of mashed potato with butter could be around 120 kcals
- Adding full-fat milk and full-fat soft cheese could increase this to 230 kcals
- A glass of full-fat milk could be around 130 kcals
- Adding milkshake powder and a scoop of ice cream could increase this to 235 kcals



Ways to quickly add 100 kcals

Here are some ways to quickly add 100 kcals to your diet:

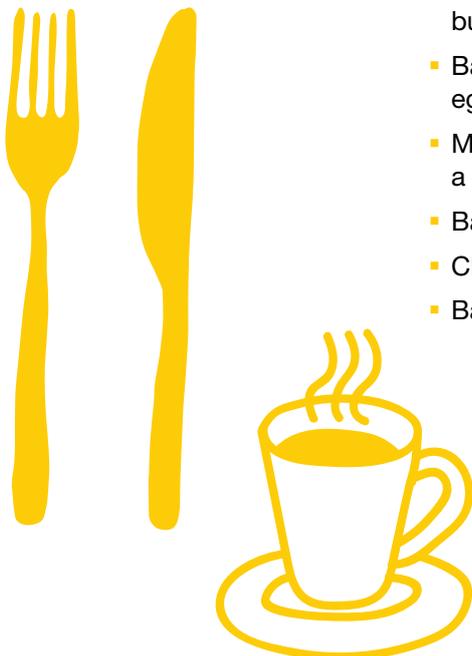
- Avocado: half an avocado. Add to sandwiches and salads or make guacamole.
- Bacon: two fried slices. Add to sandwiches, burgers, macaroni cheese or crumble into salads.
- Margarine or butter: one tablespoon. Add to sandwiches, crackers, pancakes and breads or melt on hot foods such as potatoes and vegetables.
- Mayonnaise: one tablespoon. Use in sandwiches and salads or make a dip for raw vegetables, chicken strips, chips and seafood.
- Cheese: 30g or two tablespoons of grated cheese. Add to sandwiches and salad or melt into foods like scrambled eggs, potatoes, soups and chilli.
- Chopped nuts: two tablespoons. Add to cereals, ice cream, fruit salads, and puddings.
- Cream cheese: two tablespoons. Spread on breads, bagels and crackers or mix in food such as mashed potato, pasta and macaroni cheese.
- Double cream: one and a half tablespoons. Add to full-fat milk, hot/cold cereals, fruit smoothies, creamed soups and any recipe that uses milk.
- Chocolate spread or peanut butter: one tablespoon. Spread on toast, crackers, bagels and fruit slices.
- Syrup or honey: two tablespoons. Add to hot cereals/porridges, drizzle on pancakes or pour over ice cream.

What types of snacks and meals should I eat?

Here are some examples of foods that you could try for meals and snacks.

Breakfast

- Toast with jam and butter, chocolate spread, peanut butter or pâté.
- Cereal with full-fat milk and added fruit and nuts.
- Croissant, Danish pastry, muffin or crumpets with butter, jam, peanut butter or syrup.
- Bagel with cream cheese, chocolate spread or salmon or scrambled eggs with cheese.
- Milky coffee, latte, cappuccino made with full-fat milk, a glass of milk or a milkshake.
- Bacon, sausage or egg sandwich.
- Cheese and beans on toast with butter.
- Bacon, sausage, egg, beans, toast and hash browns.



Lunch

- Sandwich made from thickly-sliced bread with butter, a full-size bagel or large tortilla wrap. Fillings could include tinned fish, egg, meat, cheese and sauce such as mayonnaise, seafood sauce, potato salad or coleslaw.
- Jacket potato with butter or olive oil and fillings such as cheese, beans, tuna with mayonnaise or chilli.
- Ready meal such as lasagne, curry or macaroni cheese, served with naan bread, poppadoms or garlic bread.
- Scrambled, poached or fried eggs with beans and/or cheese.
- Pâté, peanut butter or chocolate spread on buttered toast, English muffin or tortilla wrap.
- Additions to lunch could include sausage rolls, Scotch eggs, full-fat yoghurt, chocolate bars, crisps, nuts or a piece of cake.

Evening meal

- Fried, grilled or roasted meat, fish or vegetarian meat substitute with vegetables and potatoes (add fortified mashed potatoes for more calories).
- Lasagne, curry or chilli with rice and garlic bread, naan bread or nachos.
- Pastry pie (crust top and bottom) with buttered vegetables and fortified mashed potatoes.
- Pasta with creamy sauce and additional cheese on top.
- Tortilla wraps with meat, vegetables or meat substitute with avocado, sour cream and cheese.

Dessert

- Full-fat yoghurt or chocolate dessert pot.
- Cheese and biscuits.
- Individual crème caramel, trifle or milk pudding.
- Ice cream, cheesecake, gateaux, fresh cream cake or a slice of cake.
- Sponge pudding with ice cream or custard.
- Biscuits or cookies and a glass of full-fat milk.
- Pancakes or waffles with syrup, chocolate spread and cream.

Snacks

- Chocolate bars, crisps, nuts, individual pizzas, chips, toast, biscuits, cake or individual trifles.
- Chocolate pots, individual fruit pies, cheese and biscuits, yoghurt, scones or scotch eggs.
- Sausage rolls, mixed cured meats and cheese, sushi, doughnuts, Danish pastries, waffles or quiches.



Labelling

Spending a little time checking the label of your food can help you to choose higher-calorie options and make sure you are buying the best products for maintaining or gaining weight.

All food packages are required to have nutritional information in 100g. You may not eat 100g of the food, but this allows you to directly compare foods against each other.

For example, if you compare two brands of cream cheese, they can contain a different numbers of calories. You will take in more energy if you chose the one that has more calories (kcal) per 100g.

Label 1: Cream cheese		
Nutrition		
Typical values	100g contains	per portion (30g)
Energy	690kj	207kj
	166kcal	50kcal

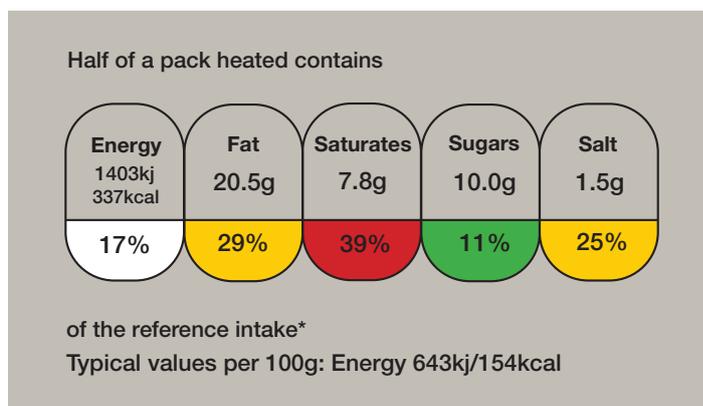
Label 2: Alternative brand of cream cheese		
Nutrition		
Typical values	100g contains	per portion (30g)
Energy	964kj	289kj
	235kcal	70kcal

Label 2 has 235 kcals per 100g compared to only 166 kcals per 100g in Label 1. If you choose the cream cheese with the higher energy content per 100g you will consume more energy overall every time you use it.

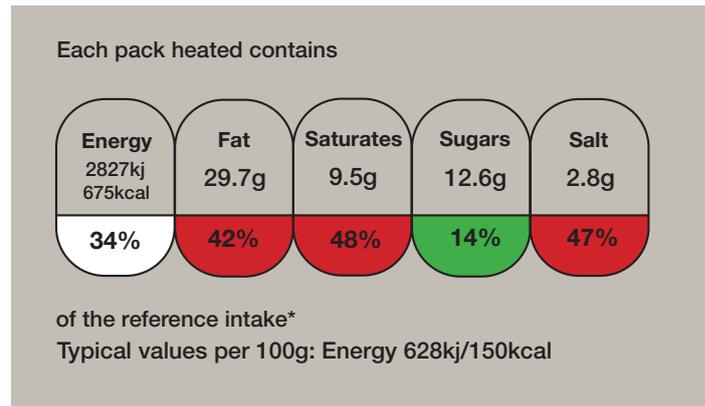
Many products now also have a handy reference on the packet, which tells you how much is in the portion you plan to eat. It is important to check what portion the reference is referring to. For example, is it a full pack or a half pack? For energy contents, you should look for kcals on labels.

Foods can vary in their energy content. 'Diet', 'healthy' and 'low fat' versions are usually lower in calories than some of the standard items, but it is important to check the label and the size of the pack.

Label 1: ready-made chicken tikka masala



Label 2: alternative brand ready-made chicken tikka masala



As you can see in this example, if you glance quickly at a packet, it can be misleading. The two labels above are from two different chicken tikka masala ready meals.

Label 2 at first glance suggests it has 675kcal, whereas Label 1 only has 337kcal. This may tempt you to buy the second packet as it has more calories. However, the pack size is different. Label 1 refers to 'half a pack', whereas Label 2 refers to 'each pack'.

If you look at the calorie content per 100g, there is a difference of only four kcal between the two products (150kcal vs 154kcal).

Checking the label and making sure you are getting the most calories in the products you are eating will help you to consume more energy.

What else can I do?

Sometimes, despite all these additions, it is difficult to eat as much as you might want or need. Your dietitian can speak to you about other ways to increase your energy intake but can also offer nutritional supplements or enteral tube feeding as options to increase your weight further.

It is important to recognise that using nutritional supplement drinks or tube feeding is not a failure or necessarily a sign of you becoming more unwell. The earlier you can achieve and maintain the correct BMI, the better outcomes there will be for your overall health and wellbeing. The more tools you have to help you achieve this, the easier it will be.

Nutritional supplements

Sometimes it can be easier to drink than eat when your appetite is poor. This is where nutritional supplement drinks can be helpful to boost your intake. These additions may be needed as a temporary measure during episodes of infection or longer term to help you maintain or gain weight.

Nutritional supplements can come in many forms such as milkshakes, juices, powders or small shots and are available on prescription. There are some products such as Complan® and Meritene® that can be bought in supermarkets. Your dietitian will be able to advise you about the type and amount of supplement drinks you may need and the number of pancreatic enzymes needed if appropriate.

Nutritional supplements can be used as a drink or added to other foods or drinks to increase energy. These should ideally be used in addition to food to improve your nutrition rather than as a meal replacement.

Nutritional supplement drinks can also be different in flavour, texture, content and volume. You may try several types before you find one that works for you. If you do not like a particular supplement, talk to your dietitian about different options and ways to use these practically.

Tube feeding

What is tube feeding?

Tube feeding, sometimes referred to as enteral feeding, can provide you with additional nutrition to help you to meet your energy requirements. This comes in the form of a liquid feed that is taken in directly to your stomach, or another part of your gastrointestinal tract, via a tube. The tube can be placed in different ways which can make tube feeding suitable for short-term or long-term feeding.

Why tube feed?

Tube feeding can help you gain or maintain your weight when you are unable to manage sufficient food or oral supplements. Tube feeding will only help if you use the tube on a regular basis. It is important that you are fully informed and involved in the decision-making process when choosing tube feeding. Often, it takes people time to think about tube feeding and whether it is right for them. It is important, therefore, that where possible, your dietitian discusses tube feeding early so that you have time to consider your options. Your dietitian needs to also ensure that you are well enough for any possible procedure that may take place. Tube feeding should not be seen as a last resort. It is another option that can help you to improve your nutrition either in the short-term or the long-term and can relieve some of the pressure when you are struggling to eat the required amount of food.



What are the benefits for me?

Many people who use tube feeding to 'top-up' their dietary intake comment that it takes the pressure off trying to eat enough and can enable them to start enjoying food again. When you are trying to gain weight or when eating is difficult due to nausea or other problems, food can become a chore. Tube feeding allows you to take on extra calories without having to force yourself to eat, or it can help you meet your goal when you just cannot eat or drink enough.

How does tube feeding work?

A specially prepared liquid feed is used to give you a specific number of calories. Your dietitian will choose the correct feed for your nutritional needs and discuss the options with you. You will have a feeding tube that allows the feed to go into your stomach, and this is usually given by a pump but can also be given by a syringe, depending on your individual needs. The feed works in the same way as eating, except you do not need to swallow the feed and you can receive a larger amount of energy in a shorter period of time. It is also useful if your appetite is poor or you struggle to complete meals due to breathlessness. Tube feeding can occur at any time of day and many people choose to have these extra calories overnight while they sleep. This may not work for everyone so it is important to discuss your individual needs with your dietitian.

What type of tube would I have?

The type of tube will depend on your health and how long the tube feeding is needed for. Some tubes are more suited for temporary feeding when you are unwell for short periods of time. Other tubes are more suited for regular feeding. Your dietitian can discuss all the tube-feeding options that are available to you and how these may be used.

If you are wondering whether tube feeding may be right for you or would like further information, please speak to your dietitian.

References

Cystic Fibrosis Trust, Members of the Nutrition Working Group and all contributors. 'Consensus document on nutritional management of cystic fibrosis', published September 2016 – [cysticfibrosis.org.uk/publications](https://www.cysticfibrosis.org.uk/publications)

Stallings VA, Stark LJ, Robinson KA, Feranchak AP, Quinton H. Evidence-based practice recommendations for nutrition-related management of children and adults with cystic fibrosis and pancreatic insufficiency: results of a systematic review. *J Am Diet Assoc.* 2008;108(5):832–9.

Cystic Fibrosis Trust

The information in this leaflet is general, please discuss it with your dietitian for a more personalised look at the topic.

This leaflet is part of a broad series on nutrition. Leaflets are available as online downloads and printed copies and can be found here: cysticfibrosis.org.uk/nutritionleaflets. You can also order the leaflets and our other publications from our helpline or download them here: cysticfibrosis.org.uk/publications.

Our helpline is open Monday to Friday, 9am–5pm, and can be contacted on 0300 373 1000 or by emailing helpline@cysticfibrosis.org.uk. Trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support.

The information in this leaflet is based on clinical best practice, a consensus of opinion by dietitians within the CFDGUK and a consensus document on nutrition management of cystic fibrosis, which you can read here: cysticfibrosis.org.uk/publications.