

Cystic Fibrosis all about nutrition

Eating well for children with cystic fibrosis.

With thanks to members of the Cystic Fibrosis Dietitians Group UK (CFDGUK)
for preparing the information in this leaflet.

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Introduction

This leaflet has been developed as a general guide on the nutritional needs of a child with cystic fibrosis (CF). Your child will have individual nutritional needs based on many factors including age, weight, height, symptoms and activity levels. If you have any concerns or questions about specific aspects of your child's diet and nutrition you should contact their dietitian.

Why eating well is important

Eating well is important for everyone, but it is especially important for people with cystic fibrosis. Having a healthy weight is linked to having better lung function, reduced frequency of chest infections and can help people feel better. If you have any questions about your child's growth and weight ask their dietitian.

What should my child be eating?

Nutrition in children with pancreatic insufficiency

Most people with CF are pancreatic insufficient, meaning that their pancreas doesn't produce enough digestive enzymes to break down, absorb and use the food they eat. Pancreatic enzyme supplements do the job of digestive enzymes. The most commonly-used supplement in the UK is Creon®.

If your child doesn't need to take pancreatic enzymes (ie they are pancreatic sufficient), they can usually follow a normal balanced diet without any extras. However, you should check with your child's CF team if you have any concerns.

Children who are pancreatic insufficient should also follow a balanced diet. However, most will also need to eat extra energy (calories) to help them grow and gain weight. Calories are a way of measuring energy, like centimetres are a way of measuring height. For most people, counting calories often isn't useful and it can be time-consuming. If your child needs extra calories, it can be more useful to know what options are higher in energy, and also how to boost energy in the foods already eaten.

The amount of extra energy people with CF need is very individual. Some people will need to eat lots of extra food for energy and some very little. It can also be different at different times of life, due to growth spurts, compensation for malabsorption or because the body is working harder to fight infections.

Some children can achieve their additional nutritional needs by eating larger portions of family foods, by adding extra calories to family foods or having extra snacks. Some children may need supplemental oral or tube feeds. A dietitian will guide you on your child's nutritional needs. If you need to boost the energy in your child's food you can find some ideas on page 8.

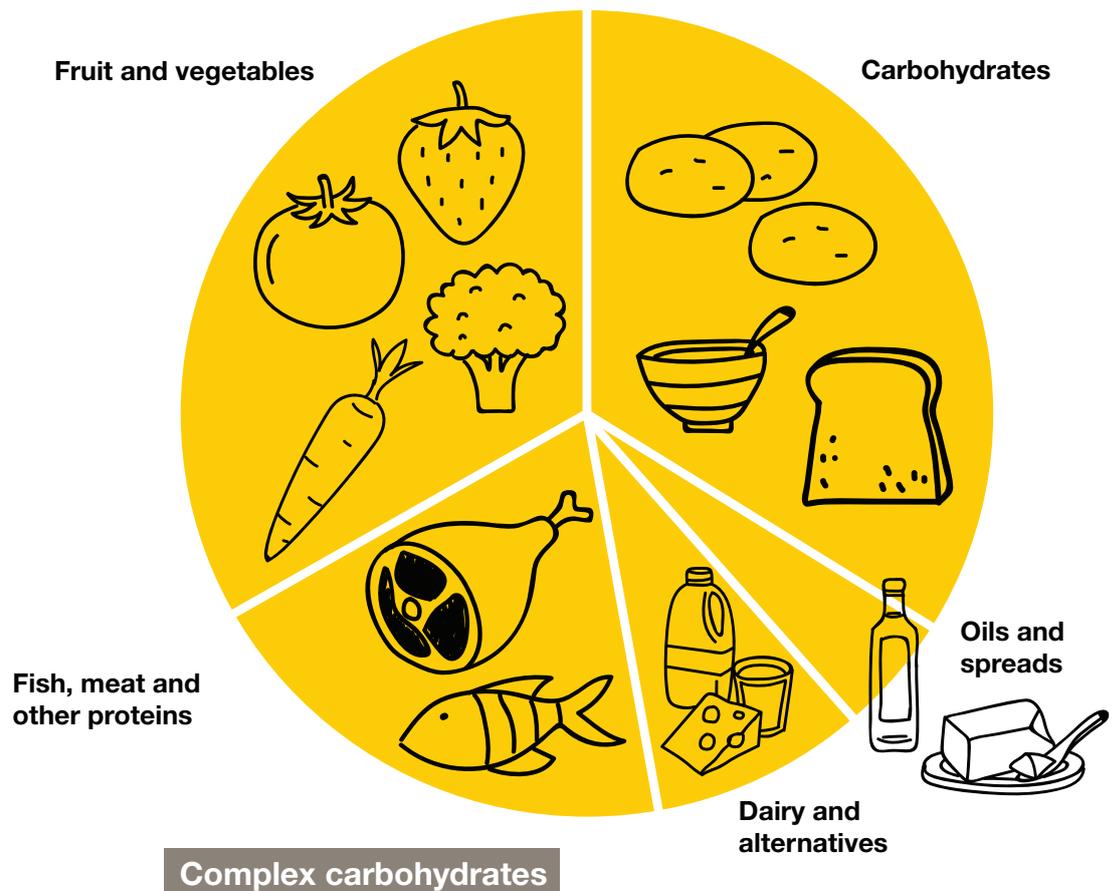
People with CF often lose more salt in their sweat, especially during hot weather or during exercise. As a result, they may need more salt – either added to foods, or as salt solution or tablets. Discuss this with your child's CF team. Our leaflet 'Salt in the cystic fibrosis diet' cysticfibrosis.org.uk/nutritionleaflets may be helpful though please be aware it was written for adults with CF.

Getting the balance right

In the UK, the Eatwell Guide is recommended for the general population as an example of a balanced diet, and your child should have some of each food group every day. The proportions of each food group may be different for people with CF, as they may need a higher energy intake.

The basis of everyone's diet should be the three main macronutrients: protein, carbohydrates and fat. Diets that recommend the removal of any of these are unbalanced and are not suitable for children. Such diets are especially concerning for a child with cystic fibrosis.

In addition, there are micronutrients, which are vitamins and minerals. These mostly come from fruit, vegetables, dairy and fortified dairy alternatives.



Complex carbohydrates

Complex (starchy) carbohydrates are digested and absorbed slowly, and so the energy they provide is released steadily. Foods in this group include bread, potatoes, pasta and rice. You should aim to include a starchy food at every main meal.

Some complex carbohydrates contain fibre, a nutrient that is not digested by the body and remains intact as it passes through the gut. Fibre helps to form and move stool through the gut and reduces the risk of constipation and distal intestinal obstructive syndrome (DIOS). Fibre is also a prebiotic, which means that it feeds the good bacteria in the gut. This can be helpful when taking antibiotics.

It is a good idea for everyone's diet to regularly include foods that are high in fibre. These foods include whole grain foods such as wholemeal, granary and seeded breads, brown rice, wholegrain pasta, fruit and vegetables, lentils and seeds. Nuts are also a good source of fibre, although you should avoid giving whole nuts to children under five years of age due to a risk of choking.

Protein

Protein is needed to help build and repair the body's tissues. Muscles, skin, hair and nails are all made up of protein. Good sources of protein include:

- Meat, poultry and fish
- Beans, pulses and lentils
- Eggs
- Nuts and seeds (avoid giving whole nuts to children under five years of age due to a risk of choking).
- Soya
- Textured vegetable protein (eg Quorn™)

You should offer at least two to three portions of foods high in protein every day.

Many protein-containing foods are also a good source of iron and zinc. Iron is essential for healthy red blood cells, whilst zinc helps with making new cells and enzymes.

Meat, fish and eggs also contain vitamin B12, which is involved in making red blood cells and keeping the nervous system healthy. Oily fish such as salmon (fresh, tinned or smoked), fresh tuna (not tinned), mackerel, trout, pilchards and sardines also contain omega-3 and omega-6. These are good for heart health, so it is recommended that everyone aims for one portion of oily fish per week.

Fats

Fats contain essential fatty acids and fat-soluble vitamins (vitamins A, D, E and K). They are also a good source of energy. There are lots of different messages around dietary fat that can get very confusing and are not always helpful. The three common types of dietary fat are monounsaturated, polyunsaturated and saturated fats.

In the general population, eating too much saturated fat is associated with increased risk of heart disease, although this has not been found currently in people with cystic fibrosis. Polyunsaturated and monounsaturated fats are not associated with an increased risk of heart disease. Fats are a good source of energy, so if extra energy is needed, foods high in fat are good to include in the diet to help achieve good growth.

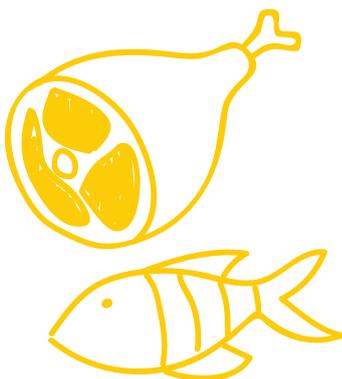
All fats contain the same amount of energy, so use monounsaturated and polyunsaturated fats where possible when catering for the whole family. Different sources of dietary fat include:

Polyunsaturated fats

- Oily fish such as salmon, tuna and sardines
- Vegetable and sunflower oils
- Nuts such as walnuts and peanuts

Monounsaturated fats

- Olive and rapeseed oils
- Avocado
- Seeds
- Nuts such as hazelnuts, almonds and pecans



Saturated fats

- Visible fat on meat
- Milk, butter and cream
- Coconut oil

Trans fats are mentioned a lot in the media as a high intake of these are associated with increased risk of heart disease in the general population. Trans fats aren't common in the UK, as many manufacturers have reduced the amount of trans fats in their products. The main source of trans fats in the UK is deep-fried foods, as they are formed during deep fat frying. It is best to keep deep-fried foods as an occasional treat.

Dairy and dairy-free alternatives

Milk and dairy foods (eg cheese, yogurt) contain calcium, protein and vitamins A and D, all of which are important for bone development.

If you choose not to use dairy, your calcium can come from non-dairy sources. Dairy-free alternatives include soya milk, soya yogurts, nut milks and coconut yogurts. If you are using these dairy-free alternatives to meet your child's calcium needs, check that they are fortified with calcium because not all of them are. Our leaflet 'Calcium and bone health in cystic fibrosis' cysticfibrosis.org.uk/nutritionleaflets may be helpful though please be aware it was written for adults with CF.

Fruit and vegetables

Fruit and vegetables are an excellent source of vitamins and minerals, and also contain fibre (especially if you leave the skins on). In the UK, it is recommended that everyone aims for five portions per day. For a child, one portion of fruit or vegetables is approximately the size of the palm of their hand or one small (150ml) glass of fruit juice.

Here are some ideas for different things to try:

- Add fruit (eg chopped bananas, berries or dried fruit) to cereal, porridge or yogurt.
- Add grated carrot, kidney beans, finely chopped mushrooms or peppers to spaghetti bolognese, chilli or shepherd's pie.
- Add finely-chopped red, yellow or orange peppers to a pasta sauce.
- Mash carrot or sweet potato into mashed potato for orange mash.
- Grate beetroot into a white sauce for a pink pasta sauce.
- Add extra toppings to a pizza, such as finely-chopped pepper, onion and mushroom, sweetcorn or pineapple chunks.
- Add lentils, beans, sweetcorn and peas to stews, bakes and salads.
- Serve peppers, carrot sticks and cherry tomatoes on small plates or bowls next to a main meal.
- Make homemade smoothies with fruit. You can chop and freeze individual packets of fruit to use when needed.
- Blend vegetables into a 'hidden vegetable' sauce for pasta, noodles or rice.
- Add fruit to jelly or yogurt.
- Carry around dried-fruit as a handy snack.



Fatty and sugary foods

Foods such as crisps, chocolate, sweets, biscuits and cakes provide energy (calories) but not many other nutrients. They are usually quite transportable, easy to eat and appetising.

If your child is having a balance of foods from the other food groups but needs extra calories to help weight gain and growth, fatty and sugary foods can be incorporated into the diet to boost their energy intake. Offer sensible portions, either between or after meals. Do not offer them before meals, to ensure that they aren't full on these and then don't eat their meals.

Family Meals

Mealtimes can be stressful when growth and weight are monitored so regularly. To maximise what your child eats you should aim to make meals a positive experience that they enjoy. Here are some tips for happier mealtimes.

- Have a good eating routine. Offer three meals and two to three snacks per day at regular times, so your child knows when they are expected to eat.
- Don't panic if your child has days when they eat less and days when they eat more. This is very normal. Talk to your child's dietitian if you are concerned.
- Try to eat together as a family as often as possible and make meal times a pleasant and social experience.
- Don't drag out meals. Set time limits of a maximum of 20-30 minutes, as very little food is usually eaten after 30 minutes.
- If your child refuses to eat the first meal option, don't make a different meal or offer a preferred snack.
- It's not always easy, but try to hide your worry about how much is eaten. Children are very good at knowing how you are feeling.
- Be positive about any food eaten, even if it is just a spoonful.
- Ignore when food isn't eaten. Although it's difficult not to comment, negative comments can lead to negative feelings towards meal times and eating.
- Don't use bribery to encourage a child to eat more, as it doesn't work in the long term and can make selective eating worse.
- Remember that children won't always do everything asked of them. You can usually stop them doing what you don't want them to do, but you can't always make them do what you want them to do.

As frustrating as mealtimes can be, following these tips consistently can help mealtimes be a positive experience, which helps improve dietary intake in the long term. It is normal for all children to go through phases of selective eating. If your child is being selective you can find more tips on how to manage this with our leaflet called 'Food refusal in children with cystic fibrosis' [cysticfibrosis.org.uk/nutritionleaflets](https://www.cysticfibrosis.org.uk/nutritionleaflets).

Catering for the whole family

Catering for the whole family can be more difficult if your child needs a higher energy diet. However, the happier you are at meal times, the happier your family will be. Here are some tips to keep it simple to cater for different needs without having to cook different meals for everyone.

- Offer high energy snacks between meals, such as:
 - Nuts and seeds (avoid giving whole nuts to children under five years of age due to the risk of choking)
 - Full-fat yogurt with fruit
 - Vegetable sticks with hummus or soft cheese
 - Crackers with avocado, soft cheese, hummus or nut butters
 - Hard-boiled eggs
 - Dried-fruit
 - Cereal
- Keep low and high energy versions of products so that everyone can easily have the same meals and snacks but with different energy content (eg yogurts, milk, salad dressings, crisps, cheese, soured cream, cream cheese).

Energy Boosts

If you need them, below are some ideas to boost the energy content of your child's food. These can be added to an individual portion of food, usually just before serving. If you're adding fat to a meal, remember to adjust the enzymes given to your child. Discuss this with your child's CF team if you have any questions.

When adding extras to boost energy in foods, make sure you taste it before serving to ensure it is still tasty.

High-energy meals:

- Add one to two teaspoons of oil to individual portions of meat when cooking (see the Fats section on page 5 for advice on healthier oils).
- Add avocado and be generous with vegetable oil spreads on toast or in sandwiches or wraps.
- Add cheese sauce, grated cheese or one to two teaspoons of vegetable oil spreads to vegetables, pasta dishes, mince, mashed potato, jacket potatoes or new potatoes.
- Use higher energy dressings in salads (eg mayonnaise, salad cream or Caesar dressing).
- Add avocado, chopped nuts, lentils, beans, chickpeas or hummus to salads.
- Choose higher energy toppings for toast such as nut butters (eg peanut, hazelnut or cashew nut butter) or full-fat cream cheese (e.g. Philadelphia®).
- Choose creamy sauces for pasta instead of tomato sauces, as creamy sauces are higher in energy.
- Add lentils, beans, or ground nuts to soups and stews.



High-energy snacks:

- Dip cucumber, pepper, carrot or breadsticks in high-energy dips (eg hummus, full-fat soft cheese, guacamole or nut butters).
- Add ice cream, nut butters, ground nuts or full-fat Greek yogurt to fruit smoothies.
- Make fortified milk by adding four heaped tablespoons of dried-skimmed milk powder to full-fat milk and use in drinks or on cereal throughout the day.

High-energy puddings:

- Serve fresh or tinned fruit with custard, ice cream, cream or full-fat Greek yogurt and honey.
- Encourage milk-based puddings (eg rice pudding, semolina, custard, mousses and full-fat yogurts).

Meal ideas

Here are some balanced meal ideas for the whole family. In bold is where you can choose a higher energy option or include an energy boost.

Breakfast ideas:

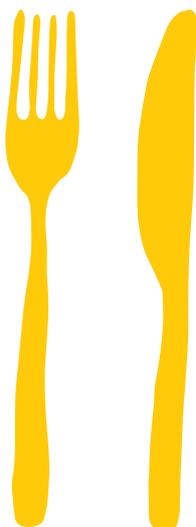
- Toast with **nut butter** and a glass of **fortified milk**
- Cereal or porridge made with **fortified milk**, topped with fruit or **chopped nuts**
- Vegetable and **cheese** omelette
- Scrambled eggs on toast with extra **cheese** or **smoked salmon**
- Bagel with **cream cheese** and dried apricot or **smoked salmon**
- Beans and **cheese** or **avocado** and egg on toast with **olive oil spread**
- Crumpets with a generous serving of **vegetable oil spread**

Lunch ideas:

- Jacket potato with **vegetable oil spread**, beans and extra **cheese**
- Sandwich with generous **vegetable oil spread**, with tinned salmon or tuna with **mayonnaise** or **salad cream**
- Pasta, potato or rice salad with grated carrot, sweetcorn or finely-chopped peppers with **mayonnaise** or pesto and **cheese**
- **Cheese** and crackers with **vegetable oil spread**

Evening meal ideas:

- Chilli served with rice or a jacket potato with **cheese** or **soured cream**, with one to two teaspoons of **vegetable oil spread** mixed in
- Spaghetti bolognese with **cheese** with one to two teaspoons of **vegetable oil spread** mixed in
- Pasta with a hidden vegetable sauce with one to two tea spoons of **vegetable oil** with extra **cheese**
- Chicken and pepper fajitas served with **cheese**, **avocado** and **soured cream**
- Burrito with sweet corn and **avocado**



Following a high energy diet in school

If your child needs a high energy diet, talk to your child's school. They are usually happy for your child to bring in foods that are higher in energy, even if they have a healthy eating policy. If you have any concerns, contact your child's CF team who can talk to your child's school.

Alternative nutritional advice

There is a lot of information on the internet and other forms of social media about nutrition and health. Some of these are lifestyle changes that you may be thinking about for your whole family, such as clean eating or avoidance of certain foods or food groups. Others are about the use of specific food-based supplements such as turmeric, ginger or garlic. If you are considering making changes or using supplements, please do speak to your child's dietitian. They can discuss the science behind some of these ideas with you and help ensure that any changes do not compromise your child's nutrition.

Further information

CF Chef – recipes and meal tips for the cystic fibrosis community
www.chef4cf.com/

Cystic Fibrosis Western Australia cookbook
www.cfw.org.au/wp-content/uploads/2017/12/CF-Bites.pdf

Ellyn Satter Institute
A website which provides information on creating good eating habits and attitudes in children www.ellynsatterinstitute.org/



Cystic Fibrosis Trust

The information in this leaflet is general, please discuss it with your child's 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.