

EATING WELL WITH CYSTIC FIBROSIS

A guide for Children and Parents

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This factsheet has been written to assist you and your medical advisers. It is not intended to replace any advice you may receive from your Specialist CF Centre or CF Clinic.

Introduction

All children need to eat a variety of foods to achieve the balanced, high quality diet, which is essential for growth. Good nutrition is vital for children with CF to reduce the risk of them developing a chest infection and to enable them to grow and gain weight normally.

Many children with Cystic Fibrosis (CF) need a diet higher in calories and protein than children without CF.

This is because:

1) The majority of children with CF do not produce sufficient pancreatic enzymes to digest their food. Pancreatic enzyme replacement is given, but even with these, there will be some loss of energy and protein in the stools. A higher calorie diet is needed to compensate for this.

2) Some children with CF have an increased need for energy and will need to eat more calories.

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The diet

Your child should be encouraged to eat a variety of foods including eggs, meat, fish, pulses, cereals, vegetables, fruits and dairy products.

By encouraging plenty of fatty and sugary foods, a good energy intake can be achieved. This may be slightly higher than is normally recommended for children, but is important for children with CF to enable them to grow properly.

Three meals a day plus small mid meal snacks are recommended to achieve the best intake.

High calorie foods

Fatty foods

Fat is the richest source of calories in our diet and is a good source of essential fatty acids and fat-soluble vitamins. Essential fatty acids and some fat soluble vitamins may help the body to fight infection.

- Use ordinary margarine or butter rather than low fat spread. Choose spreads high in polyunsaturates or monosaturates e.g. sunflower or olive oil spreads. These are as high in calories as butter, but contain healthier fats. Spread generously on bread and toast. Add to potatoes and vegetables.
- Frying foods rather than grilling will increase their calorie value. Choose polyunsaturated oils or nut oils in preference to lard or butter. Alternatively foods can be drizzled with oil before grilling.
- Chocolate, crisps, cream cakes, éclairs, doughnuts, cream buns are popular snack foods, but should not replace meals.
- Cream, single, double or whipped can be added to puddings, drinks, cereals, sauces and soups.
- Ice cream, sweet pastry dishes, trifle, crumbles and mousses are high calorie puddings.
- Add generous quantities of salad dressings, salad cream, mayonnaise and dips to salads and vegetables.

Starchy foods

- At least one portion of starchy food should be offered with every meal. Examples of starchy food include potatoes, bread, cereals, rice and pasta
- Breakfast cereal, toast, biscuits and sandwiches are useful bedtime snacks.

- Encourage plenty of pasta dishes using meat and cheese sauces. A variety of pasta shapes can be used. These are popular with children.
- Try adding pasta, potato, rice or noodles to soups and casseroles.
- Offer jacket potatoes with a variety of fillings or just add butter or margarine or mayonnaise as a snack meal.
- Always offer bread or potatoes with salad dishes. Potatoes, pasta or rice added to salads will provide extra calories.
- Fried rice, potatoes such as chips and roast are good sources of fat and calories. Fry in polyunsaturated or monounsaturated oil rather than lard
- Potato shapes e.g. 'Alphabites', 'Hungry Joe's', potato fritters, and mini potato waffles are helpful when feeding toddlers.
- Savoury biscuits and bread e.g. herb or garlic bread, cheese sandwich, biscuits, cheese bites or fingers, cheddar cheese, bread sticks served with dips are popular.
- Toasted buttered crumpets, fruited teacakes or filled pitta bread are useful snacks.

Extra calories

It may be necessary to increase the calories further in your child's diet. This can be done by increasing the sugar content of the diet.

- Sweets may be given, but remember they should not replace meals. Give them after a meal rather than just before.
- Sugar can be used liberally in drinks, cereals and puddings.
- Spread jam, honey, marmalade or chocolate spread thickly on bread or toast.
- Avoid low sugar or low calorie squashes and fizzy drinks.

Snacks

- Children often have small appetites.
- It is often better to offer small frequent meals with 2-3 snacks.
- However, do not give a snack less than 1 hour before a meal, as the meal may not be eaten.

Protein rich foods - encourage two portions daily

Meat

- All types of meat are suitable and can be cooked in any way. Try to cook with added fat, for example by frying and roasting to boost calories.
- Shaped meat in breadcrumbs such as 'Dinosaurs' and chicken nuggets are popular with young children.
- Do not remove the fat from the meat.

Fish

- Oily fish e.g. sardines, pilchards, herring, tuna, mackerel and salmon are a good source of essential fatty acids.
- All types of fish are suitable including fresh or tinned and frying fish rather than poaching or grilling increases the calories
- Choose tinned fish in oil rather than brine.

Beans and Lentils

- Add lentils or red kidney beans to soups and casseroles.
- Baked beans on toast, or baked beans served with jacket potatoes or chips are useful snack meals.
- Nuts and peanuts are high in calories, protein and essential fatty acids. However, due to the risk of severe nut allergy, young children under 3 years of age, with asthma, eczema or hay fever are recommended to avoid nuts and nut products like peanut butter.

Whole nuts should NOT be given before five years of age.

Quorn or Tofu

- These are useful sources of vegetarian protein and can be used to replace meat.

All milk and milk products

See below

Eggs

- Use extra eggs in recipes for cakes and biscuits.
- Chop up hard-boiled eggs and add to salads.
- Eggs should be boiled until the yolk is hard. **Do not give raw eggs.**

High calcium foods for strong bones

The following foods have a high calcium content and will help to build healthy bones. By choosing full fat varieties you can also boost the energy intake. Try to have two-three portions daily of the following foods:

Milk

- Drink plenty of milk – up to one pint of milk daily. Try to use full cream milk for extra calories.
- Do not use low fat milk. It is low in calories.
- Encourage milky drinks e.g. drinking chocolate, home-made milk shakes, Horlicks or Ovaltine.
- Give plenty of milky pudding e.g. instant desserts, custard, rice puddings, mousses, yoghurt and fromage frais desserts.
- Toddler pot size desserts are particularly useful.

Yoghurts/Fromage Frais

- Full cream yoghurts are high in energy e.g. thick and creamy or custard-style yoghurts.
- Avoid low fat/diet yoghurts or fromage frais.
- Yoghurt can be used as a between meal snack. Fruit, crunch or crumble corner yoghurts are particularly popular.
- Fruit yoghurt and fromage frais can be used to put on the top of fruit or added to instant desserts.

Cheese

- Always choose full fat cheese e.g. Cheddar, Cheshire, Philadelphia.
- Give cheese sandwiches, cheese on toast or cheese and biscuits as snacks.
- Cheese triangles, cheese slices and spreads are often popular with young children.
- Add grated cheese to sauces, soups, omelettes, scrambled eggs and mashed potato or extra cheese on pizzas.
- Sprinkle grated cheese over vegetables, potatoes, beef burgers, baked beans or spaghetti.
- 'Cheese Dippers' are a popular lunch box treat.

Fibre rich foods

Children with CF should be encouraged to eat some foods which are rich in fibre to help maintain normal bowel function and prevent constipation. These foods also contain 'phytochemicals' which may help the body to fight infection. Too much fibre is very filling however and may reduce your child's intake of high energy foods. Foods containing fibre include:

- Wholemeal bread or white bread with added fibre.
- High fibre cereals e.g. Weetabix, Fruit & Fibre or Shredded Wheat.
- Oat, flapjacks, digestive biscuits or cereal bars.
- Dried fruit e.g. raisins and sultanas.

Do not give young children bran. If they have problems with constipation, contact your dietitian for advice

What about fruit and vegetables?

These foods are not high in calories, but they are valuable source fibre, vitamins and some minerals

Encourage three to five portions daily.

- Stir frying vegetables will increase their calorie value.
- Adding a knob of butter to vegetables increases the calories.

- Dried fruit such as currants and raisins are useful calorie sources and can be given as a snack or added to breakfast cereals.
- Tinned fruit in syrup is higher in calories than tinned fruit in natural juices.

Vitamin supplements

In CF there is often loss of vitamins in stools, particularly the fat soluble vitamins A, D and E. It is important to take regular supplements of these. Without them the blood level will be low and occasionally deficiency symptoms occur.

The daily supplement should include:

Vitamin A	4000 – 8000 iu
Vitamins D	400 – 800 iu
Vitamin E	50 – 200 mg

The doctor or dietitian will advise the best preparation to use.

Salt supplementation

Salt loss in sweat is generally only a problem in very hot weather or when exercising strenuously for extended times, such as marathon runs. Your doctor may recommend that your child takes routine salt supplements during hot summer or when on holiday abroad in a hot climate.

Please discuss salt supplementation with your child's doctor.

Fluids

It is important that your child drinks enough fluid, especially during the summer or if you are on holiday in a hot country.

Encourage your child to drink six to eight cups of fluid daily.

Pancreatic enzyme supplements

The pancreas is an important digestive organ in the body. It produces enzymes to break down the fat, protein and carbohydrate in food, so that the nutrients can be absorbed into the body. Some children with Cystic Fibrosis produce enough pancreatic enzymes to digest their food normally; however, the majority do not, and need to take Pancreatic Enzyme replacement.

If not controlled, the lack of digestive enzymes will result in loss of energy and protein in the stools. The symptoms of this are loose, pale, offensive stools, abdominal distension and poor weight gain.

The most commonly used pancreatic enzymes in the UK are Creon and Pancrease.

These preparations are made up of microspheres or granules that contain enzymes. Each microsphere is coated to protect the enzyme from being destroyed in the stomach. Lots of microspheres are packed into one capsule.

How should pancreatic enzymes be taken?

- If your child has been prescribed enzyme capsules, they should be opened, and the contents given on a spoon mixed with fruit puree, yoghurt or a little milk for babies who cannot swallow them whole.
- The enzymes should be taken whole, in the capsule as soon as your child is able to swallow tablets. This is normally around five to six years of age, although some children may learn earlier.
- If your child has been prescribed enzyme granules (Creon Micro) they should be given on a spoon with a little fruit puree or yoghurt.
- Do not mix the enzyme with hot food, or with the meal itself as this will reduce the effectiveness.
- Try to give enzymes at the beginning and part way through a meal.
- Do not allow your child to chew the granules.
- If enzymes are forgotten at the start of the meal, it is not too late to take them during or even after the meal, providing it is within five to ten minutes of the meal finishing.

How much enzyme will my child need?

The dosage of enzyme needed varies from one child to another.

You will be advised on the amount to give by your dietitian. Do not adjust the dose without discussion with your CF team.

In general remember:

- Pancreatic enzymes should be taken with all foods containing fat, protein or starch.
- Foods containing sugar and little protein or fat, do not need enzymes.
- Fatty meals will need more enzymes, than low fat meals.
- Although most snacks will require less enzymes than a meal, some snacks are very fatty and may need as much, or even more, enzymes

Foods which do not need enzymes

- Boiled sweets, jelly or chewy sweets
- Fresh or tinned fruit
- Jelly
- Squash, fizzy drinks or fruit juice

How will I know if the amount of enzyme is correct?

There are several signs which may mean that the dose of enzymes is incorrect:

- Pale, floaty stools which are difficult to flush away.
- Increased stool frequency.
- Abdominal pain, bloating, flatulence or wind.
- Poor weight gain.

If your child is suffering from any of the above, contact your CF team who will advise you – **do not change the dose without checking with your CF team.**

How often should I see a dietitian?

Your dietitian will give you practical help and advice on how to achieve the best food intake for your child. They will also carefully assess your child's growth and give advice to ensure that your child is reaching their full growth potential. If your child is on pancreatic enzymes, the dietitian will give advice on any adjustments to the dose as they are needed. It is important to try to see your dietitian regularly, ideally at every clinic visit.

Tooth care

Children with CF have normal teeth, but as for all children, sugary foods may allow tooth decay to occur.

The following tips will help keep teeth healthy:

- Your child should brush their teeth thoroughly every morning and night with a small amount of fluoride toothpaste.
- Children under eight years should be supervised while brushing their teeth.
- Rinse the mouth with water after sugary snacks and drinks.

- Encourage your child to eat sugary foods at the end of a meal rather than in between meals.
- Visit your dentist every 4 months for a check up.
- Tell your dentist about the CF diet and he/she will give you further advice.
- Ask your dentist about fluoride supplements.

My child has feeding problems – what should I do?

Appetites tend to be erratic in childhood. Some days children will eat everything – other days they appear to eat almost nothing. This is quite normal and providing they are growing and gaining weight this is nothing to worry about. The following tips may help you:

- Sit down at the table and eat together as a family so that mealtime becomes a social event. A lack of structure to mealtimes can lead to both poor routine and poor eating habits.
- It is important not to make a fuss or push your child to eat food. If children are forced to eat, they will soon learn how to control the situation by being even more difficult. Mealtimes are then guaranteed to end in tears!
- Avoid discussing your child's eating in front of them.
- Use a microwave oven to prepare small amounts of favourite foods quickly.
- Favourite foods can be stored in the freezer so they are readily available.
- Praise children if they eat anything, even if it is only a small amount.
- Offer small portions of food. Second helpings can easily be given. Desserts served in small containers e.g. Pot Shot desserts are particularly helpful.
- Likes and dislikes may change from day to day and it is important to keep offering foods even if they were previously refused. However, do avoid food for which the child has an obvious strong dislike.
- If a child has difficulty in chewing, concentrate on foods that are easy to eat e.g. fish in sauce, mince with extra gravy or tomato sauce, macaroni cheese.
- Encourage your child when eating – but do not let mealtimes drag on; otherwise, one meal quickly runs into the next. It may be helpful to set a time limit of no more than 20 - 30 minutes.
- Avoid using sweets as a bribe. Keep these out of sight until savoury foods have been eaten at meal times.

- Avoid filling up on lots of drinks. Drinks immediately before a meal may reduce the appetite for food.
- Do not offer a second meal or a snack if the meal is refused, even if pancreatic enzymes have been taken. Take the meal away without comment. Pancreatic enzymes given without food occasionally will not harm your child. If food refusal is a big problem, it may be helpful to give a small amount of enzyme at the start, and if the meal is eaten, give more during the meal.
- Be consistent with your approach to feeding.
- Remember, keep mealtimes a happy experience.

Useful Ideas for packed lunches

A packed school lunch can just be as healthy and high calorie as a cooked meal. The following are useful suggestions:

Sandwich fillings

- Cream cheese and pineapple
- Tuna mayonnaise
- Chocolate spread with raisins
- Ham, cheese and pickle
- Chicken tikka
- Chopped chicken with mayonnaise
- Thick peanut butter and jam
- Beef, tomato and onion.
- Grated apple, honey and raisins
- Turkey and apple sauce.

Lunch box fillers/ High calorie snacks

- Chocolate raisins
- Danish pastries
- Individual packed carrot cakes, Jaffa cakes, chocolate mini rolls or cakes
- Individual fruit pies
- Chocolate muffins
- Doughnuts
- Crisps or savoury snacks

Nutritious additions

- Individual cartons of milk shake
- Yoghurts
- Pre-packaged cheese sticks

- Cold meat and sausage slices
- Grapes/bananas or other fruit
- Chopped cucumber/tomato/celery
- Pork pie or sausage roll
- Babybel cheese

Quick and useful meal ideas

- Filled jacket potatoes
 - savoury mince
 - chilli
 - creamy bacon and mushroom
 - tuna mayonnaise
 - vegetable curry
 - coleslaw
 - creamy cheese sauce
 - cheesy herb
 - sardine and tomato hash
 - ham and cheese
 - bangers 'n' beans
- Spaghetti bolognese served with garlic bread and salad.
- Chilli con carne made with baked beans and served with fried rice.
- Chicken Kiev served with jacket potatoes and vegetables.
- Cheese burgers served with beans and chips.
- Oven-baked chicken in breadcrumbs served with roast potatoes or chips.
- Tuna pasta in tomato sauce with bread and salad.
- Stir fry pork and vegetable and rice.
- Sausage casserole served with sauté potatoes and vegetables.
- Fish in cheese sauce served with potato croquettes and vegetables.

Special dietary supplements

If your child's weight or appetite is poor, your dietitian may recommend a special supplement to boost nutrient intake. These will only be used if ideal growth rates cannot be achieved using normal foods.

There are a wide range of supplements available; your dietitian will advise you on the best type to use.

Tips and guidelines for special dietary supplements

- Use only the quantity recommended by your dietitian, particularly for young children.
- Supplements are quite filling. They are better given immediately after a meal or at bedtime rather than with meals.
- Excessive intake may reduce the appetite for other food. The purpose of supplements is to improve calorie and nutrient intake: not replace normal food.
- Many of the 'milk-shake' and fruit juice supplements taste better after they have been chilled in the fridge.
- Pancreatic enzymes are needed with milk shake supplements.
- Almost all special dietary supplements are available on prescription from your GP.
- Ask your dietitian for samples of any suitable supplements to try.
- If your child has tried supplements before and dislikes them, it is worth trying again as new supplements, flavours and recipes are continually introduced.

Further information

The Cystic Fibrosis Trust Support Service has trained staff on hand to help answer any question not covered in this booklet.

Cystic Fibrosis Helpline

☎ 0300 373 1000

For further general information and literature published by the Cystic Fibrosis Trust please contact:

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