

# Cystic Fibrosis all about nutrition

## Weaning information for babies 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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# Weaning information for babies with cystic fibrosis.

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## Introduction

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This leaflet has been developed as a general guide on the nutritional needs of a baby with cystic fibrosis (CF). Your baby 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.

## Weaning your baby with pancreatic insufficiency

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Weaning your baby with pancreatic insufficiency will be similar to weaning any other baby. The only difference is they will need enzymes with most foods (see page 6).

### Top tips for weaning

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- Allow plenty of time for feeding. Rushing can make it less enjoyable.
- Give your baby a range of foods and textures to expose him/her to a variety of different tastes.
- Don't worry if your baby doesn't like a new food. Leave it and try them again soon. Babies like foods that are familiar, and it can take many tries before they know if they like a food.
- Offer foods the rest of the family eat, either mashed or chopped up, as soon as your baby can manage these textures. Give your baby a range of foods and textures so they get used to lots of different tastes, this should help your baby accept a bigger selection of foods when they are older.
- Eat together as a family as often as possible, as babies learn from watching.

### When should I start weaning my child?

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Weaning a baby with CF starts at the same time as for any other baby, typically around six months. While some parents may find their child is ready earlier, weaning should not be started before 17 weeks of age.

#### **It is important to look for the following signs that your baby is ready for weaning.**

- They can stay in a sitting position and hold their head steady
- They can coordinate their eyes, hands and mouth so that they can look at the food, pick it up and put it in their mouth.
- They can swallow food. Babies who are not ready will push their food back out, so they spread more round their face than they put in their mouth.

It is unusual for these signs to appear together before they are six months old. Weaning earlier than recommended is not better for your baby and is associated with an increased risk of infections and allergies.

## Getting started

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- Sit your baby in a high chair or baby seat.
- Always stay with your baby while they are eating.
- Allow plenty of time for meals. Rushing your baby can make it more stressful for both of you!
- Let your baby enjoy touching and holding the food. Touching food and using their hands to feed themselves (including puree!) helps them understand what the food will feel like in their mouth.
- Things can get very messy! Place a plastic tablecloth, old sheet or towel on the floor to make cleaning easier.
- Wipe their face and hands at the end of the meal only. Too much wiping can put babies off eating.
- When using a spoon, wait for your baby to open their mouth before you offer the food. Your baby may like to hold a spoon too.
- Never force your baby to eat. Wait until the next time if they are not interested this time.
- Enjoy it! The more you are relaxed, the more relaxed your baby is and the more they will eat.

## How much food should I give?

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At first, babies are just learning how to eat, and they will be getting most of their nutrition from their infant milk/breast milk. They will only eat small amounts, and plenty of food will end up on their face, the highchair and/or the floor. This is normal, and all part of learning.

- Start by offering a few pieces or teaspoons of food once or twice a day at times that suit you.
- Don't force your baby to eat more than they want. Stop when they are showing these signs of being full:
  - Refusing to open their mouth
  - Pushing the food or spoon away
  - Turning their head away
  - Crying

The amount your baby will want to eat will gradually increase, and your baby is the best guide for how much to give. If your baby still appears hungry, offer a little more food. By eight to nine months, you should aim to move your baby to three meals per day. Some babies may do this earlier.

Your baby's milk intake will reduce as their solid intake increases. Even when your baby is eating plenty of solids, continue some breastfeeds or give 500–600ml infant formula per day.



## What food should I give?

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### Starting steps

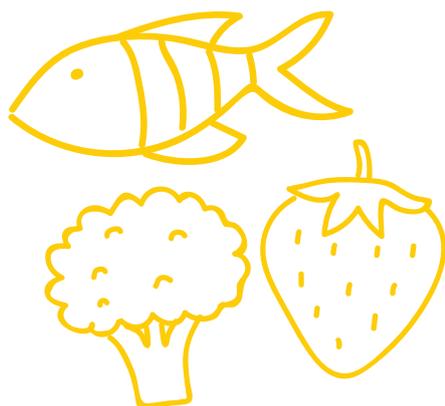
- Pureed or very soft cooked (so they mash in the mouth) fruit and vegetables. (eg apple, pear, parsnip, sweet potato, carrot).
- Fruit and vegetables (apart from avocado and coconut) don't contain fat so will not need enzymes. This helps your child get used to eating without needing to give enzymes.
- When starting out, introduce a new food every couple of days.
- Use pureed foods if you are introducing solids before six months of age, and avoid eggs, nuts, fish, shellfish and foods containing gluten (eg bread, rusks, some breakfast cereals).

### Next steps

- After two to three weeks (or around six months of age) offer soft cooked meats such as chicken, mince and mashed fish (checking carefully for bones).
- You can also offer toast, small pieces of chapatti, lentils, mashed hard-boiled eggs, yogurt, fromage frais, custard, small pasta shapes and rice in sauces.
- At around six months of age, it is important to include foods containing iron, as babies' natural stores run low around this time. Iron-containing foods include:
  - Meat (eg beef, lamb, dark meat from poultry).
  - Fish (eg tuna, salmon).
  - Eggs.
  - Beans, lentils, chick peas (eg hummus, dhal).
- Most of these foods contain fat, protein and starch and will need enzymes.
- Offer some soft finger foods. Even without teeth, babies' gums are very hard and they can chew!
- Make foods lumpier and more formed as your baby develops, from six to seven months aim to move off puree and onto a mixture of soft finger foods, chopped and mashed foods.

### By 12 months

- Aim for your baby to be eating family foods, which can be chopped if required.
- Introduce small snacks.
- Incorporate whole cow's milk (full fat) as a main drink, instead of infant formula or breast milk.



## Pancreatic enzymes

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### How much should I give?

Your baby's dietitian will advise you on enzyme doses depending on what suits you and your baby best. They may suggest a dose per portion of food or a ratio of enzyme to grams of fat.

Pancreatic enzymes should be taken with all fat and protein-containing food and drinks. The most common enzyme replacement used in babies in the UK is Creon® Micro.

You don't usually need to give any additional Creon® with foods that are fat-free or contain very little fat, such as fruit and vegetables (apart from avocado and coconut).

Everyone needs different amounts of enzymes, and this dose will change as your baby grows and the foods they eat change.

### When should I change the dose?

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While you are introducing solids, your baby's stools (poos) will change with different foods. However, if your baby begins to poo a lot more, or your baby's stools become more offensive smelling, looser (not related to teething, illness or antibiotics treatment), yellow/pale, greasy or have orange streaks, you should contact your child's dietitian to see if you need to adjust their enzyme doses. Slower than expected weight gain may also suggest the enzyme dose needs to change.

**“We were told by our son's dietitian that getting the Creon dose right was more of an art form than a science. That really helped us to feel more comfortable about it because sometimes, even with some careful calculations of fat content we didn't always appear to get it right. We also found eating out really difficult as I could never quite guess all the fat that was in something our son ate. When we relaxed and looked more at his overall growth and thought most of the time the dose seemed ok we felt happier that we were learning the art of Creon. We also learnt a few things to tweak along the way which helped.”**  
– Juliette, mum of Sammy (aged 14 months).



Please use the space below to record notes about your child's enzyme dose if you want to.

<b>Date</b>
<b>Enzyme Doses</b>

## Frequently Asked Questions

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### **My baby often refuses foods he ate the day before. What do I do?**

This is very common. Don't force them to eat it on this occasion, but offer it again soon. Babies like foods that are familiar, and it can take many tries before they know if they like a food!

### **Is it normal for babies to gag when feeding?**

Yes! Babies do gag, cough and regurgitate, which is a very normal part of learning how to eat. Real choking that causes harm is very rare. Most babies cough up and regurgitate a lot of food while they are weaning, and some will even put spat out food back in their mouth! This is all normal, but it can look very scary.

### **When can I give cow's milk as a main drink?**

You can use cow's milk in foods from six months. However, their main drink should be breast milk or infant formula to ensure they get all the vitamins and minerals they need. Once they are 12 months old you can move them on to whole (full fat) cow's milk as a main drink.

### **When should I offer cups?**

Offer cups with water from around six months with meals. An open or free-flow cup without a valve will help your baby learn to sip and is better for your baby's teeth. Babies do not need juice. Giving juice is not good for your baby's teeth and may reduce their appetite for food.

### **Should I add fats?**

Some babies with CF need extra calories to help them grow and gain weight normally. Fats such as margarine or oil are high in energy (calories) and also provide essential fatty acids and fat-soluble vitamins for good health. The healthiest choices are high in mono or poly-unsaturated fats such as olive, rapeseed or sunflower-based oils or spreads. Your dietitian will advise you if it is necessary to add fats to your baby's solids and how to adjust enzyme doses with extra fat.

### **Should I add sugar?**

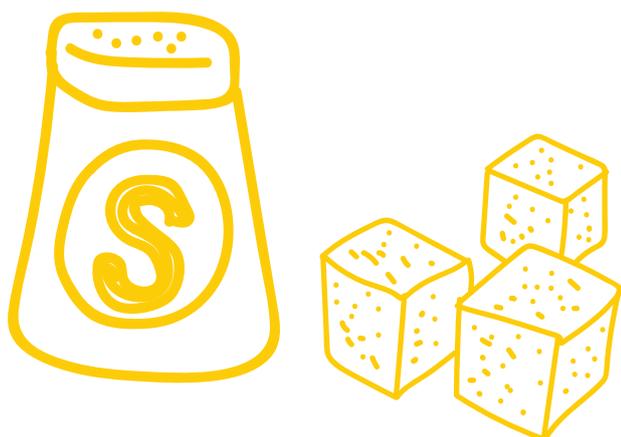
There is usually no need to add sugar to your baby's foods, although small amounts of sugar can be added to homemade puddings or to fruit to improve taste or to add energy (calories).

### **Should I add extra salt?**

We wouldn't advise adding extra salt to weaning foods because it is difficult to keep the amounts the same on a daily basis. For this reason, if extra salt is required, salt supplements are better in the first year. However, you don't need to separate your baby's food out or cook it separately because of salty stocks or gravies. If you've made something for everyone else that you think your baby will enjoy, mash some down and see if they like it! In this respect, it's easier to wean a baby with cystic fibrosis.

### **My baby makes such a mess! They keep grabbing the spoon and more ends up on the floor than in their mouth. I'm finding weaning really stressful!**

Weaning can be a tricky time, particularly if you are used to things being neat and tidy. Try to relax and put a wipe-clean mat under the high chair. Grabbing the spoon from you is actually a good sign – even if it is annoying! It means that your baby is enjoying the food and wants to join in. Give your baby their own spoon so that you can both take part in feeding at the same time.



# Cystic Fibrosis Trust

**The information in this leaflet is general, please discuss it with your baby'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](https://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](https://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](mailto: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](https://cysticfibrosis.org.uk/publications).