

Cystic Fibrosis all about nutrition

Pancreatic sufficiency and nutrition in cystic fibrosis (babies)

With thanks to members of the Cystic Fibrosis Dietitians Group UK (CFDGUK)
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Introduction

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.

Feeding your baby

Good nutrition is very important for ensuring babies grow to their full potential. Babies with cystic fibrosis (CF) can be pancreatic sufficient or pancreatic insufficient. After diagnosis, your baby's stool will be tested to see if he/she is producing the pancreatic enzymes required to digest food. This is called a faecal elastase test.

If your baby is producing enough enzymes, they are said to be pancreatic sufficient. Feeding a baby who is pancreatic sufficient is similar to feeding any other baby.

- They don't usually need any additional calories to gain weight and grow, unless recommended by a dietitian.
- They don't usually need extra salt (sodium chloride). If salt is needed, your baby's doctor will prescribe this.
- They need only the normal Department of Health recommendations for vitamins A, C and D.
 - Babies from birth to one year of age who are being exclusively breastfed should be given a daily supplement of vitamin D.
 - Babies fed infant formula should be given a vitamin A, C and D supplement if they're having less than 500ml of infant formula a day.
 - Children aged one to four years who drink cow's milk should be given a daily supplement of vitamins containing A, C and D.

The faecal elastase test mentioned above is usually repeated every year in childhood and may be repeated more often if your child has slow weight gain, abdominal pain or very smelly, loose or oily stools. Some children stop making pancreatic enzymes and become pancreatic insufficient. If this happens, your baby's CF team will provide you with advice about giving enzyme supplements by mouth.



Which milk should I feed my baby, and how much?

Breast milk

Breast milk is the best milk for all babies, including those with CF (unless indicated by a dietitian or another member of your CF team). Breast milk contains everything needed for growth and development during the first six months of life, and the nutrients it contains are easily digested and absorbed. In addition, it contains antibodies that offer some protection against certain infections, such as coughs and colds, ear infections and tummy upsets.

Infant formula milks

If you are unable to breastfeed your baby, or choose not to, there are a large number of infant formula milks available to buy that are designed for babies from 0–12 months of age. Whey-dominant milks are suitable for use from birth for babies with CF, providing the nutrition for satisfactory weight gain.

How much milk should babies take?

There are no set rules on this. It is best to feed babies on demand, and they will usually take adequate milk. Starting at six months, try to give at least 600ml (20floz) a day, or two to three breastfeeds per day.

Reflux

Some babies may suffer from reflux. Reflux occurs when milk from the stomach moves into the oesophagus and mouth, this can cause vomiting and aggravate wheezy symptoms. Giving smaller more frequent feeds can help reduce reflux. If the symptoms persist, talk to your baby's CF team.

Weaning

Top tips for weaning

- 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 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?

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. It is unusual for these signs to appear together before six months of age

- 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 around their face than they put in their mouth.

Getting started

- 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 only at the end of the meal, rather than after every mouthful. 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 relaxed you are, the more relaxed your baby will be, and the more they will eat.

How much food should I give?

Babies are just learning how to eat, and will be getting most of their nutrition from their infant formula or breast milk. They will only eat small amounts, and plenty of food will end up on their face, 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. At eight to nine months, your baby will move to three meals per day; some babies may do this earlier.

Your baby's milk intake will decrease 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?

Starting steps

- Pureed or very soft cooked (so they mash in the mouth) fruit and vegetables (eg apple, pear, parsnip, sweet potato and carrot).
- When starting out, introduce a new food every couple of days.
- Use pureed foods if you are introducing food before six months of age, and avoid eggs, nuts, fish, shellfish and foods containing gluten (eg bread, rusks and some breakfast cereals).

Next steps

- Offer soft-cooked meats at around six months of age, 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.
- 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.

Drinks

At around six months of age, offer cups of water 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. At around 12 months, most drinks should be given from a cup or a beaker.

Further information on infant feeding

www.infantandtoddlerforum.org

www.nhs.uk/start4life/baby

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. 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.