

Cystic Fibrosis *our focus*

**Nutrition: a guide for feeding infants
with cystic fibrosis**

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Fighting for a
Life Unlimited

Nutrition: a guide for feeding infants with cystic fibrosis

Introduction

Feeding a baby with cystic fibrosis (CF) is similar to feeding any other baby. However, babies with CF do have some additional needs. This factsheet describes how you can help ensure good nutritional health in your baby.

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A guide to feeding infants

Feeding a baby with cystic fibrosis is similar to feeding any other baby. However, babies with CF do have some additional needs:

- Most babies need pancreatic enzymes (see below) with feeds. These replace the digestive juices normally produced by the pancreas and help break down the fats found in milk and solid foods. They also help break down protein and carbohydrates.
- Some babies need extra calories to help them gain weight and grow to their full potential.
- Most babies need extra fat-soluble vitamins A, D and E. Some will also need extra vitamin K.
- Some babies will need extra salt (sodium chloride), given as a liquid preparation. If this is needed, it will be prescribed for your child by your doctor.

Which milk should I feed my baby?

Breast milk and infant formula milks are both suitable for most babies with cystic fibrosis. However, occasionally infants will require a special high-protein, high-energy formula, or a pre-digested feed to achieve the required weight gain.

Your dietitian and doctor will discuss with you the best type of milk to give your baby, however, the following information gives some background to the different options available:

Breast milk

Breast milk is the best milk for babies without medical problems and for most babies with cystic fibrosis. It contains everything needed for growth and development during the first six months of life. The nutrients it contains are easily digested and absorbed. In addition, it contains antibodies which offer some protection against certain infections, such as coughs and colds, ear infections and tummy upsets. Many babies with CF grow well on breast milk and it is encouraged wherever possible.

Some babies who have cystic fibrosis have extra energy needs and may have difficulty gaining weight. If this is the case, and your breast feeding technique (attachment and positioning on the breast) is good and frequent feeds are being given, then it may be necessary to give supplementary feeds of infant formula or nutrient-dense infant feeds. If nutrient-dense feeds are needed, these are available on prescription for your baby. Your dietitian will advise you on the best choice of feeds, if you need to supplement your baby's breast feeds.

Infant formula milks

If you are unable to breast-feed your baby, or choose not to, there are a large number of infant formula milks available to buy that are designed for use between 0–12 months old. They are all suitable for babies with cystic fibrosis and most babies will gain weight satisfactorily on these.

Nutrient-dense infant formula milks

If your baby is struggling to gain weight, your dietitian may advise that you give a nutrient-dense infant formula milk. This milk contains extra energy and other nutrients such as protein, vitamins and minerals to help your baby gain weight. There are three brands of nutrient-dense feed on the market in the UK and your dietitian will advise which one to use.

Nutrient-dense feeds are specially produced for babies who are not gaining weight or growing well and they are available on prescription from your GP.

Special milks

Occasionally, your dietitian or doctor may recommend that your baby has a special milk which contains fats, proteins and sugars in a more easily digestible form. This is because some babies with cystic fibrosis have problems digesting standard infant milk or breast milk. This is most commonly seen in babies who have needed surgery on their bowel. Many babies who have had surgery can tolerate breast or infant formula feeds, and special milks will only be used if your baby has had difficulty tolerating their usual feed.

Some babies may suffer from reflux, causing vomiting and aggravating wheezy symptoms. If this is the case, thickening the feed with a thickener such as Thick N Easy (Fresenius), Thixo D (VitaFlo) or Carobel (Cow and Gate) will help. Alternatively an anti-reflux milk, eg Enfamil AR (Mead Johnson) or SMA Staydown (SMA Nutrition), may be used.

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. However, if your baby is only taking small quantities of milk or does not wake for feeds during the day, please discuss this with your dietitian. If you have any concerns about the quantity of feed to offer, or frequency of feeding, your dietitian will be happy to give you specific advice.

When can cows' milk be given as a drink?

Pasteurised cows' milk should not be given as a drink before one year of age as it is low in iron. It is therefore better to continue breast milk, infant formula feeds or nutrient-dense feeds until this time. For some babies, there may be advantages in continuing infant formula milk beyond one year. It contains the same calories as pasteurised cows' milk, and is a good source of many other nutrients including iron and vitamin C. This may be beneficial if a young child is only eating a small quantity of solid food.

Alternatively, from six months, follow-on milk can be given. This contains more iron and other nutrients, but still has the same number of calories as normal baby milk.

Pancreatic enzymes

Pancreatic enzymes are natural chemicals that help the body to break down and digest protein, fat, and carbohydrates in food. The enzymes are contained in the digestive juices produced by the pancreas.

In most people who have cystic fibrosis, the pancreas does not function normally. This is known as pancreatic insufficiency or pancreatic failure. This is seen in around 90% of people with cystic fibrosis.

Pancreatic insufficiency can make it difficult to digest food, which can lead to slow weight gain and growth in children, and abdominal symptoms such as frequent loose stools and bloating.

Most babies with cystic fibrosis will need pancreatic enzyme supplements to replace those not produced by the pancreas.

The most commonly-used pancreatic enzyme supplement for children in the UK is Creon. The enzymes are given in small capsules or granules

called microspheres. They are usually very effective at digesting food.

The dose of pancreatic enzyme supplements will be prescribed at the hospital clinic, and will vary from baby to baby. For both breast- and bottle-fed babies, it is best to mix the microspheres with a little milk when they are very young, or in fruit puree when they are a little older. They should be given from a spoon at the beginning of the feed. Using fruit puree holds the granules into a gel and makes them easier for your baby to swallow. Either homemade fruit puree or any of the commercial baby fruit purees are suitable.

Caution

Do not place the dry granules into your baby's mouth as it may cause your baby to choke.

Weaning

When to start weaning

Weaning is the process of gradually adding solids into a baby's diet. There is no need to start your baby on solid food before six months of age, however some parents find that their baby is ready to start solids sooner. The earliest time to introduce solids is 17 weeks of age.

Three signs your baby is ready for their first food:

Every baby is an individual, but there are three clear signs which, together, show your baby is ready for solid foods alongside breast milk, infant formula or nutrient-dense feeds. It is very rare for these signs to appear together before your baby is six months old.

- 1. They can stay in a sitting position and hold their head steady.
- 2. They can co-ordinate their eyes, hands and mouth so that they can look at the food, pick it up and put it in their mouth, all by themselves.
- 3. They can swallow food. Babies who are not ready will push their food back out, so they get more round their face than they do in their mouths.

Some signs that can be mistaken for a baby being ready for solid foods:

- chewing fists
- waking in the night when they have previously slept through
- wanting extra milk feeds

These are normal behaviours and **not** necessarily a sign of hunger, or a sign of being ready to start solid food. Starting solid foods won't make them any more likely to sleep through the night. Extra feeds are usually enough until they're ready for solid food.

To begin with, how much your baby takes is less important than getting them used to the idea of eating. They will still be getting most of their nutrition from breast milk, infant formula or nutrient-dense feeds. Babies don't need three meals a day to start with, so you can start by offering foods at a time that suits you both.

Gradually you'll be able to increase the amount and variety of food your baby eats until they can eventually eat the same as the rest of the family, in smaller portions.

This gives a baby's digestive system time to develop so that they cope fully with solid foods. This includes solid foods made into purées and cereals mixed with milk.

Getting started

- Always stay with your baby when they are eating in case they start to choke
- Let your baby enjoy touching and holding the food
- Allow your baby to feed themselves, using their fingers, as soon as they show an interest
- Don't force your baby – wait until the next time if they are not interested this time
- If you are 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
- Start by offering just a few pieces or teaspoons of food, once a day
- Cool hot food and test it before giving it to your baby

Foods from 17 weeks

If after checking with your dietitian or doctor, you decide to introduce solid foods before six months, you should avoid giving your baby certain foods as they may cause food allergies or make your baby ill. These include foods that contain wheat, gluten, nuts, peanuts, peanut products, seeds, liver, eggs, fish, shellfish, cows' milk and soft or unpasteurised cheese.

Foods introduced at this stage will need to be pureed. Pureed fruit, vegetable and baby rice are good first foods, and do not contain additional fat, and so you will not need to worry about giving pancreatic enzymes with these. Keep feeding your baby their usual feed of breast milk, infant formula or nutrient-dense feed.

Once you start to give foods containing fat, such as pureed chicken, meat or fish you will need to give pancreatic enzymes. Your dietitian will advise you how much to give.

Foods from six months

At six months of age, your baby will be ready to eat mashed foods. Good foods to use are mashed or soft cooked fruit and vegetables like parsnip, potato, yam, sweet potato, carrot, apple or pear, all cooled before eating, or soft fruit like peach, melon, banana and avocado as finger foods or mashed. Baby rice or baby cereal can be mixed with your baby's usual milk. Keep feeding them breast milk, infant formula or nutrient-dense feeds as well but don't give them whole cows' milk as a drink until they are a year old.

Next foods: soft cooked meat such as chicken, mashed fish (check very carefully for any bones), pasta, noodles, toast, pieces of chapatti, lentils, rice and mashed hard boiled eggs. Also full-fat dairy products such as yogurt, fromage frais or custard. Whole cows' milk can be used in cooking or mixed with food from six months.

Cups: introduce a cup from around six months and offer sips of water with meals. Using an open cup or a free-flow cup without a valve will help your baby learn to sip and is better for your baby's teeth.

Pancreatic enzymes will be needed for any fat containing food such as yogurts, custard, meat and chicken. Your dietitian will advise you on how much to give.

Foods from eight to nine months

Gradually, your baby will move toward eating three meals a day. It will be a mixture of soft finger foods, mashed and chopped foods.

Your baby's diet should consist of a variety of the following types of food: fruit and vegetables; bread, rice, pasta, potatoes and other starchy foods; meat, fish, eggs, beans; milk and dairy products.

From 12 months

Your baby will now be eating three meals a day, chopped if required, plus breast milk, infant formula, nutrient-dense feeds or whole cows' milk. You can introduce small snacks at this stage such as fruit, vegetable sticks, toast and rice cakes. If your baby needs extra calories to help them grow, your dietitian will advise on suitable high energy snacks.

Your baby can now drink whole cows' milk. Choose full-fat dairy products because children under two need the extra fat and vitamins found in them. You can give your baby:

- Three to four servings a day of starchy food such as potatoes, bread and rice
- Three to four servings a day of fruit and vegetables
- Two servings a day of meat, fish, eggs, dhal or other pulses (beans and lentils)

Pancreatic enzymes

Purees of fruit and vegetables do not need additional pancreatic enzymes. However you will need to adjust your dose of pancreatic enzymes with foods containing fat. Your dietitian will advise you about this.

If solids are started early, you should not decrease the volume of milk taken. In the early stages, solids are given to supplement milk intake, not replace it.

Some questions you may have

What about drinks other than milk?

Until 17 weeks of age, milk is the only drink that most babies need, although in hot weather some need a little extra cooled boiled water.

From about six months, if weight gain is adequate, water, well-diluted fruit juice or baby juice may replace a breast or infant feed at a mealtime, but it is important to maintain a daily milk intake of 500–600ml (one pint) in babies over six months. This can be offered from a feeding cup at this stage.

What about vitamin supplements?

In cystic fibrosis, there is usually some loss of vitamins A, D and E in the stools. It is important to give your baby additional supplements of these vitamins.

Vitamins A and D are usually given together in a liquid medicine which contains other vitamins such as B and C group (e.g. Abidec – Parke-Davis Medical, Dalivit – Eastern Pharmaceuticals).

Vitamin E is given as a separate liquid preparation.

Vitamin K may also be needed. This will be assessed on an individual basis. You will be advised how much vitamin supplement to give.

Caution

There is no need to give routine Mother and Children's vitamin drops in addition to these vitamin supplements.

You should discuss any additional supplements with your dietitian/doctor.

Is additional salt needed for babies?

Breast or baby milks are very low in salt and occasionally this may cause problems for babies with cystic fibrosis. Some doctors give babies extra salt in the form of a salt solution that is made up by chemists and is available on prescription from GPs.

If your baby needs an extra salt supplement, your doctor will recommend this.

Caution

Please do not add extra salt to expressed breast milk or bottle milk without advice from your doctor.

Adding too much salt to a baby's feed can cause vomiting and kidney problems.

Summary

Feeding a baby with cystic fibrosis should not be too different from feeding any other baby. It does require extra time and effort to give the pancreatic enzymes and perhaps prepare baby milk, but if a good routine is developed, these extra tasks should soon become second nature.

At times it can be frustrating to feed any baby, but equally it can be good fun for both parents and babies. Allow your baby to make a mess, and to feed itself when old enough.

Please try and enjoy this experience and remember your dietitian or staff at your CF centre will be happy to help with any queries you have about feeding.

Further information

The Cystic Fibrosis Trust provides information about cystic fibrosis through our factsheets, leaflets and other publications.

Most of our publications are available through our helpline and can be downloaded from our website or ordered using our online publications order form. Visit cysticfibrosis.org.uk/publications.

The Cystic Fibrosis Trust helpline can help you with a range of issues, no matter how big or small. Our trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support. The helpline can be contacted on 0300 373 1000 or helpline@cysticfibrosis.org.uk and is open Monday to Friday, 9am – 5pm.

Calls to 0300 numbers cost no more than 5p per minute from a standard BT residential landline. Charges from other landlines and mobile networks may vary, but will be no more than a standard geographic call and are included in all inclusive minutes and discount schemes. If you are worried about the cost of the call please let us know and we'll call you back.

You can also find more information at our website cysticfibrosis.org.uk.

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More factsheets available at:
cysticfibrosis.org.uk/publications

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