

NUTRITION

Eating well with Cystic Fibrosis – A guide for feeding infants

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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 doctor,
dietitian or CF Centre.*

Contents

A guide for feeding infants.....	2
Which milk should I feed my baby?	2
Breast milk.....	2
Infant formula milks.....	2
Supplementing infant formula milks.....	2
Nutrient dense infant formula milks.....	3
Special milks	3
How much milk should babies take?	3
When can cows' milk be given as a drink?.....	3
Pancreatic enzymes	4
Weaning	5
When should weaning start?	5
Which solids are suitable?	5
First stage:.....	5
Second stage: 7-9 months.....	5
Third stage: 10-12 months.....	6
Questions you may have.....	7
Summary	8
Further information	8

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A guide to feeding infants

Feeding a baby with Cystic Fibrosis (CF) is similar to feeding any other baby. However, babies with Cystic Fibrosis do have some additional needs:

- Most babies need pancreatic enzymes (see below) with feeds. These will 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.

Which milk should I feed my baby?

Breast 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.

The 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 four–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. Research shows that babies with Cystic Fibrosis grow well on breast milk and it should be encouraged wherever possible.

However, some babies may have difficulty gaining weight because of their extra energy needs. If this is the case, and the breast feeding technique (attachment and positioning on the breast) is good and frequent feeds are being given, then it may be necessary to consider giving additional formula milks or nutrient dense infant formula. Your dietitian or doctor will give advice if this is needed.

If your baby needs pancreatic enzymes, your dietitian or doctor will advise you on how much to give and how to give them (see page 4 for more information about pancreatic enzymes).

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 which 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.

Supplementing infant formula milks

Sometimes babies do not gain weight on infant formula milk. It is therefore necessary to give extra calories and protein to your baby. Your dietitian will either recommend the use of a

nutrient dense infant formula or concentrate the formula milk, by adding slightly more milk powder to each bottle.

Caution

Concentration of infant formula milk is a process that should be carried out very carefully to ensure the correct quantity of extra powder and liquid is added. If the feed is too concentrated it may cause diarrhoea and vomiting. It should always be done under the supervision of a dietitian who will give clear instructions on what to do.

Nutrient dense infant formula milks

A simpler alternative to concentrating an infant formula milk is to use a nutrient dense infant formula which already contains extra energy and other nutrients such as protein, vitamins and minerals, e.g. SMA High Energy (SMA Nutrition) or Infatrini (Nutricia). These feeds are specially produced for babies who have poor growth and weight gain. They contain more nutrients, are more hygienic and are more convenient than concentrating feeds. They are available on prescription from your GP. Your dietitian will recommend this type of milk if it is necessary for your baby.

If you are advised to give your baby one of these feeds, you may need to give extra pancreatic enzymes, because nutrient dense infant formula milks have a higher fat content than regular infant formula feeds. Your dietitian or doctor will advise you about this.

Special milks

Occasionally, a dietitian or doctor may recommend a special milk which contains fats, proteins and sugars in a more easily digestible form (e.g. Peptijunior – Cow & Gate). This is because some babies with CF may have problems digesting standard infant milk following surgery for meconium ileus (a bowel blockage which occurs in a small number of babies with Cystic Fibrosis). However, most babies who have presented with meconium ileus should be able to tolerate breast or infant formula feeds.

Some babies may suffer from reflux, causing vomiting and aggravating wheezy symptoms. If this is the case, thickening the feed with a thickener eg Thick N Easy (Fresenius), Thixo D (Vitaflo) or Carobel (Cow and Gate) will help. Alternatively, anti-reflux milk, e.g. Enfamil AR (Mead Johnson), 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 or infant formula 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 quantity of calories as normal baby milk. Unfortunately, follow-on milk is not available free of charge on milk tokens for families on income support.

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.

However in most people with CF, the pancreas is prevented from functioning normally, which is known as pancreatic insufficiency or pancreatic failure. This is seen in 85–95% of those with Cystic Fibrosis.

This can cause malnutrition, which can lead to poor growth and physical weakness.

Most babies with Cystic Fibrosis will therefore 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 administered 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 or fruit puree and give from a spoon at the beginning of the feed. This will hold the granules into a gel and make them easier for the baby to swallow. Either homemade fruit puree or any of the commercial baby fruit desserts 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 four months of age.

Signs that your baby is ready to start solids include your baby being hungry after a good feed, waking at night when they have previously slept through the night, or demanding more frequent feeds.

First stage: from weaning to seven months

Try a little cereal such as baby rice mixed with formula milk or expressed breast milk, puree fruit or vegetables as the first foods

Quantity

- Solids at this stage should be smooth purees.
- One–two teaspoons at one or two feed times is plenty at the start. After one or two weeks, give solids at a third feed.
- Over the next few weeks, gradually increase the amount of solids given, and towards the age of six–seven months, increase the thickness of the puree and start to introduce some soft lumps.

Suitable foods

- Start with baby rice mixed with baby milk or expressed breast milk or fruit / vegetable puree.
- Once your baby is taking these, introduce more variety, including:
 - Purees of meat, poultry, pulse vegetables, vegetables and potato or rice
 - Custard made with full fat cows milk or formula milk
 - Commercial first stage weaning foods can also be used. If using powdered baby food, try mixing with breast or formula milk, even if the packet states to use water. This will increase the nutrient content of the food.

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.

Second stage: between seven–nine months

Encourage your baby to start chewing by introducing more lumpy foods. Increase the variety of solids to include both savoury and sweet foods.

Your baby will also enjoy finger foods at this stage. Suitable finger foods include fingers of buttered toast, slices of peeled fruit, and fingers of soft, cooked vegetables. ***Do not leave your baby alone with food in case of choking.***

Your baby will also be ready at this stage to start drinking from a cup
Try to introduce family foods and family mealtimes so that your baby gets used to the foods you and your family eat.

Quantity

- All babies are different and the amounts taken will vary, however your baby should be taking solids three times daily, and taking around 500–600ml of infant formula or follow on formula or breast feeding three–four times daily.
- If you are concerned about the amount your baby is taking, contact your dietitian.

Suitable Foods

- As before.

Pancreatic enzymes

- As before.

Third stage: between 9–12 months

Foods should now be chopped or minced, and your baby should be eating a variety of sweet and savoury family foods.

Let your baby feed itself with your help, and encourage drinks from a cup.

Mealtimes may be messy, but this is a time of learning and should be fun.

Quantity

- Offer solid food three times daily, plus 500–600ml infant formula or follow on formula or two–three breast feeds daily.

Suitable foods

- As before.

Pancreatic enzymes

- As before.

Caution

If solids are started early, they 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 four months 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 the 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 with 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 the 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 allow your child to feed itself when old enough.

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

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

☎ 0845 859 1000

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