

Cystic Fibrosis all about nutrition

Pancreatic insufficiency and nutrition in cystic fibrosis (babies)

With thanks to members of the Cystic Fibrosis Dietitians Group UK (CFDGUK)
for preparing the information in this leaflet.

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Contents

| | |
|--|---|
| Introduction | 3 |
| Feeding your baby | 3 |
| Which milk should I feed my baby, and how much? | 3 |
| Breast milk | 3 |
| Infant formula milks | 4 |
| Nutrient-dense infant formula milks | 4 |
| Special milks | 4 |
| How much milk should babies take? | 4 |
| When can cow's milk be given as a drink? | 4 |
| What about drinks other than milk? | 4 |
| Reflux | 5 |
| Pancreatic enzymes | 5 |
| Tips on giving enzymes to breast and bottle-fed babies | 5 |
| What if I forget to give my baby enzymes? | 6 |
| How do I know my baby is getting the right amount of enzyme? | 6 |
| Salt and vitamin supplements | 6 |
| Is additional salt needed for babies? | 6 |
| What about vitamin supplements? | 7 |
| Summary | 7 |

Introduction

This publication 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. Your baby's weight, length and head circumference will be measured regularly to check that they are growing normally, and your child's dietitian will advise you on any changes you need to make to help with their growth.

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 not producing enough enzymes, they are said to be pancreatic insufficient. This leaflet has been written for parents of babies who are pancreatic insufficient.

Feeding a baby who has CF is similar to feeding any other baby. However, babies who are pancreatic insufficient do have some additional needs.

- Your baby will need pancreatic enzymes with feeds to replace those that are normally produced by the pancreas. These enzymes help break down the fats found in milk and solid foods, and also help break down protein and starch.
- Some babies need extra calories to help them gain weight and grow to their full potential.
- Your baby may need extra fat-soluble vitamins (vitamins A, D, E and K).
- Some babies will need extra salt (sodium chloride), which is given as a liquid preparation. If this is needed, it will be prescribed by your child's doctor.

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

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

Your child's 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 all babies, including babies with CF (unless indicated by a dietitian or another member of the 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. Most babies with CF grow well on breast milk and it is encouraged wherever possible.

Some babies who have CF 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 a nutrient-dense infant feed. If you need to supplement your baby's breast feeds, your child's dietitian will advise you on the best choice of feeds.

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, and usually provide sufficient nutrition for satisfactory weight gain.

Nutrient-dense infant formula milks

If your baby is struggling to gain weight, your dietitian may advise that you give a nutrient-dense infant milk. These milks contain extra energy and other nutrients (eg protein, vitamins and minerals) to help your baby gain weight. Nutrient-dense infant milks are specially produced for babies who are not gaining weight or growing well and they are available on prescription from your GP. There are three brands of nutrient-dense infant milk on the market in the UK and your dietitian will advise which one to use.

Special milks

A dietitian or doctor may occasionally recommend that a baby has a special milk which contains fats, proteins and sugars in a more easily-digestible form. This is because some babies with CF 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.

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 child's dietitian. If you have any concerns about the quantity of feed to offer, or frequency of feeding, your baby's dietitian will be happy to give you specific advice.

When can cow's milk be given as a drink?

Pasteurised cow's 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 infant milk until this time.

What about drinks other than milk?

Until 17 weeks of age, milk is the only drink that most babies need, although in hot weather you may need to supplement this with a little cooled boiled water.

From about six months, if weight gain is adequate, water or well diluted fruit juice may be given with meals. It is important to maintain a daily milk intake of 500–600ml (one pint) or regular breast feeds in babies over six months. This can be offered from a feeding cup at this stage. Try to use an open or free-flow cup without a valve, as this will help your baby learn to sip and is better for your baby's teeth.



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 child's CF team.

Pancreatic enzymes

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

In many people who have CF, the pancreas does not function normally. This is known as pancreatic insufficiency, and is seen in around 8 out of 10 people with cystic fibrosis. Pancreatic insufficiency can make it difficult to digest food, which can lead to slow weight gain and growth in children. It can cause abdominal symptoms such as frequent offensive smelling loose stools, oily stools, bloating and wind.

Your baby 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, which will help your baby gain weight normally with good bowel control. The most common supplement used for babies is Creon® Micro.

The dose of pancreatic enzyme supplements will be prescribed at the hospital clinic and will vary from baby to baby. The dose of enzymes and how your baby is feeding will be reviewed at each clinic visit.

Tips on giving enzymes to breast and bottle-fed babies.

- Enzymes should be given from a flexible plastic weaning spoon at the beginning of the feed.
- It is best to mix the granules with a little milk or in apple/pear puree.
- Do not add enzyme granules to a bottle of milk.
- Some babies prefer using fruit puree as this can hold the granules in a gel, making them easier for your baby to swallow.
- Either homemade fruit puree or any of the commercial baby apple/pear purees are suitable.
- Do not place the dry granules into your baby's mouth as it may cause your baby to choke.
- If feeding lasts over 20 minutes, more enzymes may be needed. Discuss with your dietitian how this can be managed.
- Don't worry about getting the exact amount of enzyme granules in the scoop. It's more about improving your baby's stools and weight gain.
- Check the granules are not left in your baby's mouth or on the skin (eg under the chin), as these may cause blisters.
- If you are breast feeding, check you don't have any granules around your nipple area as this can cause soreness.
- If your baby is breastfeeding every 1–2 hours, talk to your dietitian about how to manage the enzyme dose.
- Make sure that you close the bottle of enzymes after use and store them in a cool place (less than 25 degrees) away from direct sunlight.
- Check the use by date on the bottle.



What if I forget to give my baby enzymes?

Your baby may have a little discomfort and extra runny poos, but don't worry too much. If you regularly forget your baby will start to lose weight so try to get in a good routine.

How do I know my baby is getting the right amount of enzyme?

Babies who are gaining weight and growing well are usually getting enough enzymes. Initially, babies do not need more than one to two scoops per feed, or one-half to one capsule.

Signs of too little enzymes include your baby beginning to poo a lot more, their stools becoming more offensive smelling, looser, pale and/or greasy, a change to the normal colour and a presence of yellow/orange oily looking streaks. Your baby may also have excessive wind and tummy pain.

If your baby is taking too much enzyme, they may pass through and cause a red sore bottom. Any increase in enzyme dose should be done gradually, as too rapid an increase may cause severe constipation.

You may like to fill in this box with the details of your baby's enzyme supplements

| | |
|--|--|
| Date | |
| Type of enzyme | |
| Dose per feed | |
| Note: The enzyme dose needs to be changed regularly as your baby grows and progresses with their feeds. Your baby's dietitian or doctor will advise you. | |

Salt and vitamin supplements

Is additional salt needed for babies?

Breast or infant formula milks are very low in salt and this can occasionally cause problems for babies with cystic fibrosis. Sometimes extra salt is given in the form of a salt solution, which is made up by chemists and is available on prescription from GPs. If your baby needs an extra salt supplement, their CF team will recommend this.

When giving salt solutions:

- Spread the salt solution throughout the feeds. If given in one dose, the taste may put your baby off his/her feed, or it can make them sick.
- The salt solution can either be given via a syringe or added to the milk. The dietitian or another member of the CF team will recommend how best to give it.

What about vitamin supplements?

Babies with CF may lose some fat-soluble vitamins (vitamins A, D, E and K) in their stools.

These vitamins are essential for:

- Vitamin A – good eyesight, healthy skin and improving your baby's immune system.
- Vitamin D – healthy bones and teeth.
- Vitamin E – healthy immune system and to maintain a good working nervous system.
- Vitamin K – healthy bones and to clot blood.

It is important to give your baby additional supplements of these vitamins if they are prescribed.

Caution

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

You may wish to record the vitamins and minerals that your child has been prescribed, in this box:

| Recommended vitamin and salt supplements |
|--|
| Multi-vitamins with A and D Dose: |
| Vitamin E Dose: |
| Vitamin K Dose: |
| Salt in mls: |

Summary

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

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

Cystic Fibrosis Trust

The information in this leaflet is general, please discuss it with your child'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.