



Good nutrition plays an important role in your child's overall wellbeing. This information sheet will explain your child's special nutritional requirements and what is needed to ensure your baby grows well and gains weight.

Eating well and maintaining a good nutritional status is very important in the treatment of cystic fibrosis (CF). There is evidence that improving and maintaining a good nutritional status has a positive impact on prognosis and overall well being.

All children with CF should see a dietitian for individualised nutrition assessment and advice on diagnosis and on a regular basis thereafter to ensure provision of ongoing education, advice and support.

The aim of nutritional support in children with CF is to achieve optimal growth and weight gain. Nutritional support should be an integral part of overall care and requires close clinical supervision. All children need to eat a variety of foods to achieve a balanced diet. Most children with CF need a diet that is high in both calories and protein.

Individual tailored dietary advice is required to ensure malabsorption is minimised (introduce enzyme therapy) and to ensure the overall diet is appropriate.



Which Milk Should I Feed My Baby?

Breast milk or standard infant formula is suitable milk for most babies with CF. Breast milk contains everything needed for growth and development during the first 6 months of life. It also contains antibodies which offer some protection against certain infections such as coughs and colds, ear infections and tummy upsets.

Once it has been established which breast feeding technique is good, feeding times and enzyme supplementation are optimised. Your CF dietitian will advise on this.

If you are unable to breast feed your baby, or choose not to, there are a large number of infant formulas on the market for babies between 0-12 months old. Most babies with CF will gain weight satisfactorily on these formulas. Again your CF dietitian will advise on a feeding regimen and enzyme requirements. This dietary advice is very specific and tailored to each individual.

Occasionally babies do not gain adequate weight on infant formula milk or breast milk alone. It may therefore be necessary to give extra calories and protein to your baby. High calorie ready-made baby milks or calorie supplements added to breast milk or infant formula may be required. These options should only be introduced under supervision from the CF dietitian.

How much milk should babies take?

There are no set rules. It is best to feed babies on demand and they will usually take adequate milk.

Feel free to discuss frequency and quantity of feed offered to your baby with the CF dietitian who will give you specific advice for your baby's requirements.

Pancreatic Enzymes

The pancreas is essential in the normal process of food digestion. The pancreas, which is a gland, produces enzymes which pass into the intestine where they help digest and absorb the food we eat.

In people with CF the small channels within the pancreas, through which the enzymes flow, can become blocked with mucus and the digestive enzymes do not reach the food to digest it. Therefore the individual with CF needs to take pancreatic enzymes in order to ensure they can digest their food.

NUTRITION FOR YOUR Baby

For Parents of Newly Diagnosed Children with CF



Does your child need enzymes?

About 85-95% of babies with CF need enzymes. On diagnosis, a test can be done on a stool specimen to establish whether pancreatic enzymes are needed. This is called a faecal elastase test.

Pancreatic enzymes or Pancreatic Enzyme Replacement Therapy (PERT) come in several different forms but the most popular is Creon 10,000 which comes in capsule form and Creon for Children which is a loose granule preparation sometimes used for infants.

Dose

The dose of pancreatic enzyme supplements will be prescribed by your CF team.

There is no 'set dose' and the amount of enzymes required will depend on the type of feed and frequency of feeding. Your CF dietitian will give you specific advice for your baby's requirements.

Method

- Enzymes should be sprinkled either directly (Creon for Children) or capsules (Creon 10,000) opened and contents sprinkled onto fruit puree and taken from a spoon. This will hold the granules into a gel and make them easier for the baby to swallow. This can be done from birth.
- Do not add enzymes to baby's bottle of milk. Enzymes are generally taken at the beginning of a feed. However, if your baby is a very poor feeder and feeds take greater than 30 mins, the enzyme dose can be split, i.e., beginning and end of the meal. Discuss with your dietitian.

General advice

- Avoid leaving enzyme beads in or around baby's mouth – this can make the area sore.
- Always keep the lid on them to protect them.
- Store enzymes as directed on the box – away from direct sunlight and out of heat. Do not store in glove compartment of car or in your pocket. If the weather is very good (>25°C) enzymes will need to be kept in a fridge.

How do I know if my child is taking the right amount of enzyme?

Children who are gaining weight, growing well and have normal bowel motions (this varies from baby to baby) are probably getting enough enzymes.

Too little:

- Number of stools may increase
- Stools may increase in appearance (large, pale, greasy, orange spots, "fatty appearance")

Too many:

- You might notice your infant's bottom becoming red as the enzyme is coming through unabsorbed

Vitamin Supplementation

Requirements for some vitamins, namely the fat soluble vitamins are much higher in people with CF than are needed in the general population. Therefore vitamin supplementation is required, i.e., these levels cannot be achieved through diet alone.

Your CF team will advise you on what additional vitamin supplementation your child needs.

What are fat soluble vitamins?

Vitamin A	Helps maintain the health of skin, strengthens immunity from infections and is essential for vision, especially in dim light
Vitamin D	Regulates the amount of calcium and phosphate in the body, which is needed to keep bones and teeth healthy
Vitamin E	Helps protect cell membranes and supports the immune system by acting as an antioxidant. Also important for healthy nerves and muscles
Vitamin K	Involved in clotting and also needed to build strong bones



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Weaning

Weaning is the process of introducing solid foods into an infant's diet. As for all infants, it is recommended not to begin until they are at least 17 weeks old, but not later than 26 weeks. At this age, milk alone is not enough to meet a baby's nutritional needs fully and specific nutrients such as iron need to be taken from food sources.

For the first few months after starting weaning, babies will continue to rely on milk feeds for much of their nutrition so formula or breastmilk should still continue to be given until an infant is at least 1 year old.

The type and texture of food you introduce to your infant should change as they move through the stages of weaning, as for any infant.

Some infants taking digestive enzymes will already be familiar with taking fruit puree off a spoon. If this is the case for your infant, you may find that the weaning process is easier to proceed with. Infants with cystic fibrosis may eat the same weaning foods as any other infant.

Your CF dietitian will guide you through the overall weaning process; discussing food types, textures, amounts and

enzyme requirements. As discussed before, occasionally babies do not gain adequate weight on infant formula milk or breast milk alone.

Your CF dietitian may discuss ways to introduce extra calories and protein into your baby's weaning diet. This advice is individualised and introduced under supervision from the CF dietitian.

Is Additional Salt Needed For Babies?

Some children with CF may require additional salt. If your baby needs an extra salt supplement your CF team will recommend this.

This salt can either be added to infant milks/breast milk or can be given directly to your child. The dose and frequency is very specific and should only be introduced under medical guidance.

Summary

Feeding a baby with Cystic Fibrosis is not different from feeding any other baby. Remember your dietitian or staff at the CF Clinic will be happy to help with any queries you have about feeding.

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Further Information:

- A Guide for Parents of Newly Diagnosed Children with Cystic Fibrosis (CFI)
- Paediatric Nutrition and Cystic Fibrosis (CFI)
- CF Advocate Service Information Sheet (CFI)
- How Cystic Fibrosis Affects Daily Life (CFI)
- Cystic Fibrosis and the Work of CFI Information Leaflet
- High Calorie Recipes For People with Cystic Fibrosis (CFI)
- CF Chef – Online Nutrition Resource including recipes and meal tips for People with CF: www.chef4cf.com