CYSTIC FIBROSIS

CFfacts
cystic fibrosis fact sheet

Nutrition for Babies

Babies with cystic fibrosis (CF) can be affected very differently, so each baby will have individual dietary needs which vary from other babies with CF. A balanced diet that includes enough calories and the right vitamin and mineral supplements is key to good nutrition and health. Babies with CF require access to a specialist team including a CF dietitian, who should guide individual requirements.

Enzymes

Babies with CF who are pancreatic insufficient (PI) will need to take pancreatic enzymes with food (milk) from birth to aid digestion. They should be mixed with an acidic mixture such as apple puree and administered with a soft baby spoon at the start of each feed. The dose of Creon is calculated based on how many grams of fat is in the feed. Incorrect dosage of enzymes can lead to malabsorption (inadequate uptake of nutrients from food).

Milk

In most cases, either breastfeeding or formula feeding will provide enough nutrition during the first 6 months. Breast milk is encouraged where possible, however, for some women can be very difficult. Be assured that formula is suitable for babies with CF. Energy supplements/concentrated infant formula top-ups can be used on referral.

Salt

People with CF, including babies, lose more salt through their sweat and require salt supplementation. For infants, this usually comes in liquid form and can be added to a bottle of expressed breast milk/formula or with water in a syringe.

Vitamins

Babies with CF often have deficiencies in fat-soluble vitamins A, D, E and K, and will therefore require vitamin supplementation. VitABDECK is a CF-specific multivitamin that is commonly prescribed. It is generally crushed and mixed with apple or pear puree or else mixed with water and administered with a syringe.

Solids

Solids should be introduced at 6 months, unless otherwise prescribed. It is a good idea to talk to your CF care team about starting solids as you will need information on enzyme dosage.

Bowel Health

Babies with CF can experience malabsorption, which can be revealed by their bowel movements.

Signs of malabsorption include:

- ulcers in the mouth or bottom
- excessive tummy pain, diarrhoea or wind
- very bad smelling bowel movements
- loose or greasy/oily bowel movements
- nappy rash
- mouth sores and irritation around the mouth (this can be common during the first month of taking enzymes)

These symptoms can occur from incorrect enzyme dosage. If this is a common recurrence, you should speak with your CF dietitian.

Meconium Ileus

Many babies with CF experience meconium ileus when first born. Meconium is the first bowel movement, formed in the intestine, while still in the mother's womb. In babies with CF, the meconium is much thicker and stickier and can clog part of the intestine (ileum), preventing the baby from having a bowel movement once born. Meconium ileus must be treated immediately and in most cases, can be flushed out using an enema. Meconium ileus is often the first sign of CF in many newly diagnosed babies.

Useful Resources

- CFFood: A Guide for Feeding Infants www.cfwa.org.au/wp-content/uploads/2017/12/Nutrition-for-Infants.pdf
- Cystic Fibrosis: New Diagnosis Information for Parents www.cfwa.org.au/wp-content/uploads/2017/12/CF-Fact-Newly-Diagnosed-Support.pdf

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