

CF Health Matters



This information sheet is published by the Cystic Fibrosis Dietitians across Canada.

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Nutrition, Cystic Fibrosis and the Newly Diagnosed Infant

This information sheet will give you information about your baby's special nutrition needs and about the nutrition treatments that will help your baby grow and gain weight well. Most infants have good weight gain and a regular pattern of growth. An infant that is not growing well is a worry to parents and doctors. If the family doctor or pediatrician becomes concerned about an infant's growth or feeding, or loose stools, then tests are done to find the reason. While most children with Cystic Fibrosis (CF) are diagnosed when problems are found, some infants will be diagnosed very early (through prenatal testing or newborn screening) before any problems of CF are found.

Signs and Symptoms

- Infants with CF may have one or more of the following problems:
- Slow weight gain and or growth
- Irritability or difficulty sleeping
- Bloating stomach
- Very large appetite or a very poor appetite
- Many loose, foul (sour) smelling and/or oily stools ("poop"); a large amount of gas
- Salty taste to the skin
- In some cases, a skin rash that won't go away

Everyone would like to see an infant grow well. Before the diagnosis, in infants with poor weight gain and looser than normal stools, the milk feeding may have been changed (for example taken off breast feeding or put on lactose-free or soy formula). In most cases of CF, this change in feeding does

not help. Once the diagnosis of CF is made, treatments to improve nutrition and lung health will help the infant to gain weight and grow and catch-up in size to other babies their age! Good nutrition is important for infants with CF as it helps them to grow, fight infections and develop normally. Your dietitian/CF team will track your infant's growth with you.

Investigations

Once CF is diagnosed other tests will help make sure that your baby receives the right nutrition. These tests include blood tests for anemia, protein and vitamin levels. The stool tests (i.e. a 72 hour fecal fat collection and/or fecal elastase test) will help to know how well your baby can absorb food. These tests will help the CF team decide whether your baby needs to take medicines called pancreatic enzymes. Pancreatic enzymes are needed to correct the nutrient malabsorption that often occurs in CF.

Nutrition Care for Infants with CF

First Foods:

Breastfeeding is the best food for all babies and is especially great for babies with CF. If not breastfed most babies with CF can grow well on a cow's milk formula. In a few cases a specialized infant formula may be recommended. Babies with CF often have higher energy (calorie) needs than other babies. To provide this extra energy, formula may be added to breast milk or, for bottle fed babies, a high energy formula may be recommended. Breast or formula feeding will give your baby all of the nutrition needed until 6 months of age.

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Adding Solids:

Just as with other babies, solids such as cereal, strained fruit and vegetables should be added to your baby's diet at six months of age. Your baby needs an iron source so either infant cereal or meat should be given. For extra energy butter, margarine or oil may be added to the baby food. Your dietitian will help you with this.

Enzymes and Vitamins:

Babies with CF often have problems with growth and weight gain because of a lack of proper digestion of food. Fat is an important source of calories (energy) needed for energy and growth. If the pancreas is not working well, there is poor digestion of fat. This may lead to frequent, oily, smelly stools. Some vitamins are also not well absorbed. These problems can be treated with pancreatic enzymes, given by spoon (mixed with applesauce or another fruit) with feedings, and by giving the fat soluble vitamins, A, D, E and K in a liquid form. Both the enzymes and vitamins may be prescribed by the CF team for your baby.

Salt:

Infants and children with CF lose more salt than other infants and children, through their sweat especially on hot summer days or during very active sports. Older children can add salt to their food to make up for this loss. Many CF babies can get enough salt in the breast milk, formula or food to make up for this loss. However, in some infants who sweat a lot, the salt needs to be replaced. This can be done by giving the infant extra salt using a special solution that is mixed in applesauce or directly in breast milk or formula. Your dietitian/CF team will help you decide on whether salt replacement is needed.

Summary

- Pancreatic enzymes given by mouth (for most but not all babies with CF)
- Breast feeding or formula feeding (high energy breast milk or formula for some babies)
- Fat soluble vitamins
- High energy solids
- Extra salt (in a special solution) may be needed

Once treatment for CF is started you may find that your baby's appetite slows down. This is to be expected as your baby is now absorbing food better, is catching up in weight and so does not need to eat as much. CF infants may take weeks to months to catch-up in their growth. It is very important that infants with CF are followed regularly by the CF clinic team and community health care teams. The dietitian with the CF team will be able to support and guide you on the dietary and enzymes changes needed to help your baby grow and gain weight.