Early Nutrition and Growth for Your Young Child With Cystic Fibrosis

CYSTIC FIBROSIS FOUNDATION®

Learning that your child has cystic fibrosis can be overwhelming, but having the right information can help your child thrive as they get older.

HOW DOES CF AFFECT NUTRITION AND GROWTH?

CF is thought of as a lung disease, but it also affects other parts of the body. The lungs work hard to clear thick, sticky mucus out of the airways. In patients with CF, the **gastrointestinal (GI) system** — which includes the stomach and intestines — also works hard to clear mucus and perform normal functions.

Before **newborn screening**, CF was often diagnosed by poor growth. Despite advances in **CF treatment**, it is difficult for kids with CF to grow well. This is because CF causes them to burn calories quickly and they cannot absorb all of the **vitamins** and nutrients that they eat.

The difficulty with digesting food properly is often due to the pancreas not releasing enough digestive juices to help break down food.

Children with CF will have their digestive pancreas function tested at diagnosis and will get extra **enzyme pills** if their pancreas is not working well. Not all CF patients will need enzymes but they still need to focus on nutrition.

Strategies that **your CF team** may recommend include monitoring food intake, using praise and rewards, maintaining a regular meal schedule, and limiting how long meal times last.

WHY THIS MATTERS

Young children with CF who grow well early in life seem to have better lung function and overall health, with effects that last into adulthood.[1] Research studies looking at patients in the **Cystic Fibrosis Foundation Patient Registry** have helped us understand how important early nutrition is.

WHAT YOU CAN DO

1. It is important to focus on a diet high in calories (especially **protein** and fat). From the day your child is diagnosed, your CF nutrition team will:

- Focus on your child's growth, adding nutritional supplements as needed
- Ensure correct enzyme, salt, and vitamin dosing
  - Pancreatic enzymes should be given prior to meals and snacks, and vitamins should be given with a fatty food.
- Advise on stool softeners to ensure your child's bowel movements are soft and passing fully

2. Feeding your child can be a struggle. Discuss your challenges with your CF care team. They can provide tips and and offer support every step of the way.

3. Sometimes a **feeding tube** placed in the stomach is recommended to give your child the extra calorie boost they may need for a strong start to a healthy life.

Ask your CF care team about your child's nutrition or how your child's weight gain and growth compare to their goals.

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[1]Evidence-based practice recommendations for nutrition-related management of children and adults with cystic fibrosis and pancreatic insufficiency: results of a systematic review. *J Am Diet Assoc.* 2008 May;108(5):832-9.PMID: 18442507

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