

## Feeding Problems in Babies with Krabbe Disease and Other Leukodystrophies

Feeding problems are common in babies and children with leukodystrophies and other lysosomal storage disorders. Parents should watch for the following:

- **Irritability and arching back** during feeding
- Taking **longer than 15 minutes** to finish a 4 oz. bottle or empty one side of the breast
- **Not gaining weight**
- **Formula or milk leaking** from the nose or mouth when feeding
- **Uncoordinated mouth movements** that make it difficult for the baby to latch onto the nipple
- **Refusing to eat**
- **Choking and coughing while eating**



A baby with one or more of these feeding signs should be evaluated by a doctor. There are a number of ways to help your child feed better and prevent complications such as aspiration into the lungs, pneumonia, dehydration, and irritability.

## How to help your baby get enough fluid and nutrition

There are several things you can do at home to help your child feed:

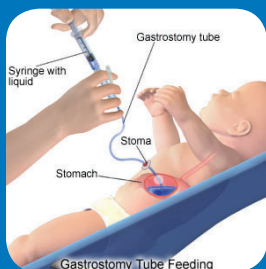
- Place the child in an upright or semi-upright position during and after feedings. This helps prevent vomiting and reflux (when stomach contents flow back up into the throat).
- For children with swallowing problems, make formula and other liquids thicker with products like Thick-It® or SimplyThick®.

### Tube feeding

Some babies and children are unable to get enough nutrition by mouth. For these children, a feeding tube is used to deliver formula, water, and medicine.



The tube (called a **gastrostomy tube**, or **G-tube**) is inserted into the stomach by a surgeon. Your doctor or nurse will show you how to use this tube.



When the G-tube is inserted, the upper part of the stomach can also be wrapped with a band to prevent acid reflux and vomiting, which can cause pneumonia.

This is known as Nissen fundoplication.

## Medications

There are medicines to prevent reflux, vomiting, and gastritis and to help your child absorb nutrients or improve the movement of food through the digestive system. Talk to the NDRD physician for more information about these medicines.

## Parent Resources

NDRD Parent Educational Program

## Food Thickeners

SimplyThick  
[www.simplythick.com](http://www.simplythick.com)

Thick-It  
[www.thickitretail.com](http://www.thickitretail.com)

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