

A Closer Look

G---tubes, A Tale of Two Children

For children with CdLS, eating by mouth can be a challenge or not possible, and many rely on getting their nutrition via a tube, either inserted into their abdomen (a gastric feeding tube— more commonly called a G-tube) or nose (a nasogastric feeding tube, or NG-tube).

Some children are tube fed for a short period of time, while others need tube feeding their entire lives. Here are two families' stories.

Ben received a NG-tube shortly after birth due to aspiration and inability to suck. When he was five months old and big enough for surgery, a G-tube replaced the NG-tube.

A Nissen fundoplication (a procedure in which the upper part of the stomach is wrapped around the esophagus to prevent gastric reflux) was performed at the same time the G-tube was placed. "We struggled with the idea of surgery, but he was so miserable from the reflux," says mom Karen.

Following surgery, Ben's vomiting stopped, and after a month on G-tube feeds, he started gaining weight. "We never looked back," says Karen. "It was the best thing we could have done for Ben." At age four, Ben is now 27 pounds, which is about the 90th percentile for boys his age on the CdLS growth chart.

The MIC-KEY button version of the G-tube was the best option says Karen because it's easy to put back in if comes out (Ben has pulled the tube out a few times—he wears overalls during the day and has it wrapped in ace bandages at night to prevent him from pulling on it) and she doesn't worry about aspiration or aspiration pneumonia, caused by fluid getting into the lungs. Ben vomited a lot on the NG-tube, so aspiration was always a fear.

The negatives, she says, is that it's difficult to know when to size up the tube, it's inconvenient to lug around the feeding pump and supplies, and it's expensive. While her health insurance covers the costs, she once saw the bill, and it exceeded \$1,000 for one month.

The ultimate goal is to have Ben eat orally during the day and supplement with tube feedings at night. However, Ben isn't that interested in food, says Karen. Since he was one, Karen and her husband Mark have tried spoon feeding, to no avail. "There's no medical reason he can't eat," says Karen, "it's a behavioral issue."

Karen does have hope that Ben will make the transition. When her husband made homemade broccoli soup recently, Ben seemed interested. "It's a work in progress," she says.



For some children with CdLS, tube feeding is not long-term. That was the case with Breeze, who had a G-tube for 15 months, starting from the time she was six months old.

“Breeze never sucked, had an immature swallow and awful reflux,” recalls mom Margaret. “She never took to bottle or breastfeeding.”

Breeze started with a NG-tube like Ben, as the doctors wouldn’t place a G-tube until she reached eight pounds. Margaret says the NG-tube was a nightmare because Breeze ripped it out after every feeding, leaving Margaret to snake the tube through her nose every two hours to feed her.

Once the G-tube was placed, it was, according to Margaret, “a lifesaver.” Breeze gained weight and her reflux was controlled. The G-tube helped in other areas as well. With the NG-tube, physical and occupational therapy were problematic because the therapists couldn’t move Breeze around too much. The G-tube changed that.

At 17 months old—and after Margaret brought home “every type of drinking device on the market”—Breeze began using a sippy cup. Margaret hit the jackpot with the Take and Toss cup, a valve-less cup that doesn’t require sucking.

Once she started drinking, Breeze moved on to baby food and Pediasure. Those gave her enough nutrition and the tube came out when she was 21 months old.

Four years later, Breeze, now six, continues on Pediasure and only eats pureed foods, but she remains tube free.

Margaret’s advice to other parents is to “keep trying and then try some more. I tried every cup on the market and found the cheapest, most available ones worked best.” She also believes that controlling reflux, which Breeze takes medication for, was a big part of being able to eliminate the G-tube.

