



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

Diet and Nutrition Issues with CdLS

By Joni Rampolla, L.D., CdLS Foundation Clinical Advisory Board Member

Diet and nutrition play an important role in the growth and development of children. For children with CdLS, balancing good nutrition, diet and willingness to eat can be a challenge. This article addresses some common dietary challenges associated with CdLS, and responds to questions frequently asked by parents.

Proper growth

The growth of a child with CdLS occurs at a slower rate than that of his peers without CdLS. It's important that your physician is plotting growth on the specific CdLS growth charts (available through the CdLS Foundation). If a child's individual growth curve levels off or begins to decline, he may need additional calories to support growth. Prior to adding extra calories, it's important to evaluate other issues that could cause weight loss, such as recent illness or diarrhea, which can indicate malabsorption. Sometimes a change in tube feeding formula can resolve a malabsorption issue (such as a hypoallergenic, or semi-elemental, or fiber containing) rather than increasing calories.

Food allergies

Many children with CdLS have a lactose (milk sugar) intolerance. Consuming milk products may lead to bloating, gas, cramps, or diarrhea. The amount of lactose that each person can handle is different. You can choose to include a lactase enzyme such as Lactaid™ to help with milk digestion or switch to rice milk, soy milk, yogurts, or cheese. Make sure your child gets enough calcium by including a supplement with vitamin D for enhanced absorption, Tums™, or high calcium foods, such as salmon, tofu, almonds, beans, or calcium-fortified foods and liquids (orange juice, breakfast bar, etc.).

Hypoallergenic supplements are available for children that need to supplement an oral diet. Two common products are Elecare by Abbott Nutrition and Neocate Jr. by Nutricia. For wheat allergies, wheat-free grains should be included in the diet. These include amaranth, buckwheat, corn miller, quinoa, rice, and tapioca. A great resource to learn about food allergies is the Food Allergy and Anaphylaxis Network, www.foodallergy.org.

Gastrointestinal Concerns

Diarrhea is a common issue in individuals with CdLS. It's important to keep your child hydrated and replace lost electrolytes by including plenty of fluids. You may consider an electrolyte replacement such as Gatorade™, Pedialyte™, or Crystal Lite Hydration™. You can also include salty foods such as pretzels, bouillon or pickles, and a high potassium food or drink, such as orange juice, broccoli, spinach, tomato, summer squash, or cantaloupe. Diarrhea causes a loss of sodium and potassium, so including any of these foods will help.



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Other suggestions include an over-the-counter, antidiarrheal medication or a natural remedy of banana flakes, which controls diarrhea and can add flavor and texture to foods or tube feedings. Nana Flakes is one brand you can look for.

Some foods or beverages make diarrhea symptoms worse.

These include caffeinated beverage and foods that are fried, spicy or artificially sweetened (sorbitol, maltitol, mannitol, etc.). If you notice symptoms get worse after your child eats a certain food product, eliminate that item for a few days and reintroduce after symptoms stop.

To relieve symptoms of constipation, include plenty of fluids, high-fiber foods and exercise. For added fiber, choose a high-fiber breakfast cereal or bar (five grams of fiber or more per serving), fresh fruit with the skin on, and vegetables like spinach, broccoli, collard greens, okra, or beans. Add fiber gradually to prevent gastrointestinal upset. The formula to determine the amount of daily fiber needed is the age of the child plus five. So, for a 10 year old, aim for 15 grams.

In addition to over-the-counter fiber supplements, such as Metamucil, Benefiber or Citrucel, a natural fiber source is ground or whole flaxseed, which can be added to foods for a nutty taste and slight crunchy texture. For a smoothtextured, natural remedy, try Fruit-Eze™, a prune-based fruit puree.

For symptoms of gastroesophageal reflux, certain foods may need to be eliminated from the diet, including acidic foods, such as oranges and grapefruits, fried or fatty foods, and spicy foods. A food diary can be kept to monitor foods that irritate your child. Try excluding the suspected irritant and see if the symptoms resolve. To ease symptoms, avoid dressing your child in tight fitting clothing, have him remain