

EATING WELL WITH CdLS

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Feeding any child can be difficult; however, a child with Cornelia de Lange Syndrome presents a whole new set of challenges. My goal when working with children who have CdLS is to provide a safe route of nutrition, enough calories, protein, and calcium for growth, and to eliminate discomfort of reflux, constipation, or diarrhea. Following are some nutrition tips that may help when feeding your child with CdLS.

REFLUX

The goal of nutrition management of reflux is to decrease symptoms such as vomiting, heartburn, or discomfort associated with the reflux of gastric fluid into the esophagus. Certain foods can aggravate symptoms and should be avoided. These foods include: onions, fried foods, spicy foods, fatty foods, acidic foods such as citrus or tomato products, carbonated beverages, caffeine, chocolate, and peppermint. Overfeeding as well as obesity is considered a risk factor for reflux. Certain medications can exacerbate reflux such as caffeine, calcium channel blockers, benzodiazepines, theophylline, narcotics, and anticholinergics (some anti-depressants).

Nutrition Therapy for Reflux: Choose smaller, more frequent meals and snacks. Remain upright after eating. Elevate upper body in bed at night or lie on left arm using appropriate sleep positioning. Do not eat two to three hours before lying down at night. Ensure appropriate burping. Choose to eat in a relaxing atmosphere and be well rested. Choose loose fitting clothing around the abdominal area. Although controversial, studies have found that thickening feedings with rice cereal have resulted in a decrease of symptoms. (Orenstein et al., J Pediatr 1987; 110:181-186) Medication is often given to help the stomach empty faster and reduce acidic production; therefore, reducing symptoms of reflux.

LACTOSE INTOLERANCE

Some children with CdLS are lactose intolerant or milk intolerant (unable to consume either the carbohydrate or the protein in milk). Symptoms of lactose intolerance are excess gas, distention of stomach, and cramps. Those without a milk allergy may also benefit from a milk-free diet. It is important to get enough calcium and protein in the diet if milk is eliminated. Foods that may cause distress include: all forms of milk (whole, low-fat, chocolate, buttermilk, condensed, evaporated), cheese, yogurt, sour cream, ice cream, mayonnaise, butter and bread, crackers and cereal prepared with cow's milk protein.

Ingredients on food labels that may indicate the presence of cow's milk *protein* include casein, caseinate, calcium caseinate, sodium caseinate, curds, whey, lactalbumin, lactoglobulin, butter flavor, cheese, cottage cheese, nougat, custard, half and half, hydrolysates (milk protein, whey casein).

Non-dairy, calcium-rich foods are salmon, tofu, almonds (100 mg in a 2-ounce serving), and beans. Many foods such as orange juice, a breakfast bar, and soy milk come in calcium fortified forms. Calcium absorption is enhanced when there is enough vitamin D in the body. A balanced diet should provide an adequate supply of vitamin D. Sources of vitamin D include eggs and liver. However, sunlight helps the body naturally absorb or synthesize vitamin D, and with enough exposure to the sun, food sources may not be necessary.

When choosing a calcium supplement, read the label. A supplement “serving” may be divided in two tablets. This is because calcium is best absorbed when taken in doses of 500 mg of calcium or less. If you are taking greater than 500 mg, take one tablet in the morning, one tablet at night for best absorption. *TUMS* may assist with symptoms of reflux. Calcium citrate may be better if you are constipated or taking drugs that block stomach acid such as Pepcid, Prilosec, or Protonix.

CONSTIPATION

To overcome constipation, I recommend *gradually* adding high-fiber foods to the diet. The American Dietetic Association recommends 20-35 grams of fiber per day. To achieve this, eat at least two servings of fruit per day with one of them being in a raw form, including skins and seeds. Eat two servings of vegetables per day and have raw vegetables at least every other day. Use raw vegetables for snacks. Include beans, nuts, and seeds in your diet. You should be getting at least eight cups of fluid daily including milk, water, juices, or tea. Choose whole grain breads and cereals rather than more finely ground white breads or highly milled cereals. Examples of such cereals would be bran, shredded wheat, whole grain, oatmeal, and granola. Use baked potato, either sweet or white, rather than mashed potato. The potato skins are a good source of fiber. Use popcorn, nuts, and dried fruit rather than potato chips or french fries for snacks. Plan regular meal hours, allowing sufficient time for meals. Eat food slowly. Get some form of exercise daily. Set aside a regular time each day to have access to the bathroom when there is no rush or disruptions. Get adequate rest. It may be helpful to drink a warm/hot beverage before going to the bathroom. Use fruit or fruit-based foods for dessert. A product that other families have tried successfully is *Fruit-Eze*, a pure fruit regularity blend which you can obtain information about at www.fruiteze.com or phone at 1-888-REGULAR. If your child is tube-fed or taking an oral nutrition supplement such as Pediasure, you may want to look into a tube-feeding or supplement that is fortified with fiber such as Pediasure with fiber.

DIARRHEA

To improve symptoms of diarrhea, eat small, frequent meals and snacks throughout the day. Limit high-fiber foods (fresh fruits with peel, fresh vegetables, whole grain cereal or bread); avoid milk products, and see if diarrhea subsides. Add milk back to diet if there is no effect. Replace electrolytes lost in diarrhea by eating bananas, mashed potatoes, bouillon, or nibbling on salty foods such as crackers and pretzels. Avoid gassy foods such as cabbage, brussel sprouts, beans, corn, onions, highly-spiced foods, carbonated beverages and fatty foods. Avoid caffeine, alcohol, sorbitol, and fat substitutes. Drink plenty of fluids to remain hydrated. With each loose bowel movement, drink an additional cup of fluid. Choose liquids such as apple juice, broth, or sports drinks. A supplement that I recommend is Banatrol, which is comprised of banana flakes. It can be obtained from National Nutrition, Inc. at 717-569-8561.

GLUTEN-FREE DIET

I have recently heard many questions regarding a gluten-free diet. A gluten-free diet benefits those with celiac disease, those with dermatitis herpetiformis (skin symptoms of severe itchiness and burning of the skin or ulcers in the mouth), or a small population that exhibits a gluten intolerance. Gluten is a general name given to the storage proteins present in wheat, rye, barley, and oats. This diet eliminates all foods containing wheat, rye, barley, and oats. Starches could be eaten if they are made from corn, rice, soy, potato flour, sorghum, or flax. It is important to read food label ingredients as some rice cakes, rice and corn cereal, lunch meat, pudding mixes, egg substitute, peanut butter, flavored potato chips do actually contain gluten as well as the obvious

made from wheat flour. Many additives, stabilizers, and preservatives may contain gluten, as well as medications, toothpaste, and mouthwash. You can call a manufacturer if you are not sure about a specific product labeling. A resource to find basic information on gluten is www.wildoats.com. This site has pamphlets you can download on specific diet information, FAQs, and additional resources. They also have guides for gluten-free products. Another good product resource is www.glutenfreemall.com to shop for specialty food items, or www.glutenfree.com for the Gluten Free Pantry. There is also the Gluten Intolerance Group out of Seattle, WA at www.gluten.net. If you click on “diet” at this link you will also get some great information. You can subscribe to Gluten Free Living Magazine at www.glutenfreeliving.com.

In summary, it is important to monitor your child’s weight, eating behaviors, and intake to determine if their nutrition needs are being met. Try to include a variety of tastes, textures, and colors when choosing foods. If your child is school-aged, evaluate the nutrition that he/she receives at school. Ensure that “rewards” given to your child are non-food rewards to assist with weight control. Eating should be pleasurable. Do what you can to make it an enjoyable, shared experience while still meeting your child’s needs.