

Sanford Medical Center

Aunt Cathy's Guide to Nutrition:

Why Are Children with Chronic Illnesses or Handicapping Conditions at High Risk of Receiving Suboptimal Nutrition?

A Quick Overview of Reasons:



Aunt Cathy

Cathy Breedon PhD, RD, CSP, FADA
Clinical/Metabolic Nutrition Specialist,
Sanford Medical Center, Dept. of Pediatrics &
UND School of Medicine Dept. of Pediatrics
Fargo, ND

1) Some children have higher than usual needs for energy (calories)

Sometimes this is because of the **increased effort required for breathing** in children with broncho-pulmonary dysplasia or congenital heart defects, or because of being especially physically active. Some children need to continually **heal wounds**. At the same time, they may have **decreased ability to take food because of the effort required to eat or because a fluid limit is imposed**. As a result, they often fail to grow optimally. Their intake of vitamins, minerals and protein can also be compromised, leading to: poor immune function, inadequate energy to explore and learn, poor skin integrity and wound healing and other problems.

Increasing the calories of formulas usually involves concentrating the product to make a higher caloric density. For example, **using only 9 oz of water instead of the usual 13 oz when preparing a 13 oz can of infant formula concentrate will make the formula have 24 calories per ounce instead of the usual 20**. The nice thing about this approach is that it provides ALL nutrients in higher amounts (not just calories,) it does not distort the ratios of nutrients per calorie, it contributes no additional cost, and it is safe to use.

Sometimes fat or carbohydrate calories will still need to be added, but these should generally be used only to add calories beyond the 24-26 calorie per ounce concentration. How to increase calories beyond the 24-26 calories per ounce should be determined with the help of a person familiar with these issues, as there are sometimes important reasons to use one additive over another in a particular child's case.

Many of the substances added to foods or formulas to add calories can seriously distort the nutritional balance unless the protein, vitamins and minerals are carefully adjusted. For example, corn syrup, sugar, glucose polymers (like "Polycose®" by Ross), butter/margarine, cream, regular vegetable oil, MCT oil® (Mead Johnson/Novartis), and emulsified fat products like Microlipid and Intralipid all have one thing in common. **They all just add empty calories.** In small amounts there is no concern, but if a significant percentage of the child's calories is contributed by these products there is potential for distorting the ratio of calories relative to the nutrients needed to metabolize them.

Some children will have higher needs for all nutrients in addition to calories. In this situation it is important to recognize that just adding protein and/or calories will not work well in the absence of the critically important vitamins and minerals that the body needs to convert fuel (calories) to make usable energy, and or to construct tissues. This is key in conditions that require extra production of tissue, such as wound healing and increased need for immune system activity. Failure to assure adequacy of micronutrients can make other efforts unsuccessful.

Unfortunately, this issue often does not get the attention it deserves and it is not uncommon for children to be given protein-only supplements without assuring adequacy of the necessary vitamins and minerals to use the protein. Also, giving just protein in the absence of adequate calories will result in the protein being burned as an energy source instead of using it for construction. Most nutrients have many important roles, some of which will be described further a bit later.

One should keep in mind that the usual recommended amounts of calories and nutrients such as the RDAs or RDIs or AIs are based on the needs of “most healthy people.” They do not address the needs of people with illness or other health conditions. The health care professionals will need to think through the particular challenges of a child’s situation and make adjustments in goals accordingly.

A good example is zinc, a mineral needed in over 200 different places in a person’s body. Every time we try to make a new cell, we need zinc to make the DNA in the center of it. **That means that people who need to make a lot of new tissue will need a more generous intake of zinc.** Poor zinc status impairs growth in children, and it limits the ability to heal wounds – another situation that requires a lot of new tissue formation. Recovery from wounds and staying healthy in general also depend on zinc because the production of T-cells of the immune system is very dependent on adequate zinc. At the same time, **excessive amounts of zinc can cause problems.** Determining the right amount requires a close look at the individual’s situation.

A generous intake of **vitamin B12 and folic acid** (another B vitamin) is also required for making DNA (for making all cells) and in particular for making new red blood cells. **Sometimes anemia is not caused by inadequate iron but by a relative inadequacy of these nutrients, or others (like vitamin E) that are needed to keep red blood cells from being broken apart too soon.** Vitamin C helps protect the white blood cells of the immune system to let them live longer to keep on killing germs. **Vitamin C and copper** are also players on the team that lets us build connective tissue for wound healing, and both are also required to use iron in the body.

And on and on. These are just a few of many examples of the critical role played by vitamins and minerals in health, and why this aspect of children’s nutrition cannot be ignored. For some specific additional information, please see my handouts on Sanford’s website (www.dsanfordhealth.org) on folic acid, vitamin B12, magnesium, chromium, vitamin D, copper, zinc and iron. Just type my name in the key word box and then click “handouts.”

Another issue is cost. The “regular food” items are many times cheaper than the commercial additives. For example, consider **fat additives** commonly used: MCT oil ® is about \$1 an ounce (\$65 per quart) and the calories are about 5 calories less per teaspoon than most food fats. The advantage of using emulsified products is that they are better at staying mixed into formulas. But unless that is a major problem, it is useful to know that they are even higher in cost.

This is because they are primarily designed to be used in i.v. feedings. Microlipid ® is 88 cents per oz, but has only half the calories of other fats so you need to use twice as much. Compare these with the cost of canola oil (a good choice for a general vegetable oil.) Some other issues about the use of particular forms of fat will be discussed later.

Protein additives are also much more expensive than excellent quality protein in foods. At about 7 g protein per egg, **egg protein costs about a penny a gram** and it contains some additional nutritional value like choline and biotin. A can of “Resource Beneprotein ®” provides about 192 g protein per can (as whey protein,) and I found prices on line of \$13-\$15 per can, purchased as a case of 6 cans. That means that it can cost anywhere from 6.5 to 7.8 cents per gram of protein, or 6-8 times as much as egg protein.

The liquid pasteurized “no yolk” egg protein products available in grocery stores are more expensive than eggs, but cheaper than special additive products. “EggBeaters ®,” for example, provides 6 g protein per ¼ cup. They have the advantage of being pasteurized so they can be added to foods that are not intended to be cooked, such as a smoothie or eggnog, or in a tube feeding. Powdered milk is another very inexpensive product, with 1.5 g protein per tablespoon, and some calcium and other nutrients provided with it.

Glucose polymers (such as “Polydose ®” by Ross) **are simply starch in solution and they have no advantage over regular food carbohydrates like sugar or food starch.**

They are designed primarily as a carbohydrate that can be added to beverages without adding a sweet taste. There is usually no reason to avoid sweetness in children’s feedings. **The risk of tooth decay is identical** because any carbohydrate fed orally is food for bacteria in the mouth. The main factors that increase risk of tooth decay are frequency of carbohydrate-containing feedings and contact time of carbohydrate with the teeth. Whether the carbohydrate is in the form of sugar (mono- or di-saccharides) or starch (polysaccharide) appears to make little difference.

Similarly, there is not a significant difference in osmolality (the number of particles per amount of fluid) because the starch is digested very promptly to the sugars maltose and glucose once it reaches the small intestine. That means that it is not less likely to contribute to loose stools.

There is **no danger of causing a “sweet tooth”** to be developed in the child. Children just come that way . . . human milk is sweet and it is all part of the design to make babies want to nurse. I have found that using regular table sugar can often make many foods and formulas more palatable for children, and therefore it is more effective because they eat more. And, of course, the dental and sweet tooth concerns are even less of a concern when the child is fed through a tube instead of orally.

A teaspoon of **sugar** weighs 4 grams and adds
16 “empty calories” from carbohydrate;

A teaspoon of **glucose polymer** products weighs 2 grams and provides only
8 “empty calories” from carbohydrate.

That means you need only half as much sugar to get the same calories. A 12.3 oz (350 grams) can of a glucose polymer product costs about \$8.30 from one of the cheapest on-line sources. Compare that with table sugar. Nutritionally and calorically they are the same.

In most circumstances there is no need to use these expensive special products at all. MCT oil ®, for example, is designed for special needs related to certain liver diseases or intestinal malabsorption problems such as Cystic Fibrosis. It is often inappropriate for other uses because besides being very costly, it is **all saturated fat** (from coconut oil) and so it provides **no “essential” fats or any omega-3 and omega-6 polyunsaturated fats at all . . . just calories.** I have found that using regularly available food products also has the psychological advantage of “de-medicalizing” at least one part of the child’s care.

Sometimes health care professionals are not familiar with these issues, because they have to know so much about everything else. So, it might be beneficial to show this paper to them if these very costly products are suggested in order to use them only when regular carbohydrates and fats available at the grocery store will not do. And in addition, remember that **just adding fat or carbohydrate calories or just protein from any source will contribute no other nutrients and so should be used as a small part of the child’s higher calorie feeding regimen.**

And finally, it may be necessary to use other feeding routes in order to achieve appropriate growth and the best possible health. This may involve feeding through a tube from the nose to the tummy (an NG tube – a “naso-gastric” tube.) Sometimes tubes are placed through the skin to go directly into the tummy. They are called a PG tube, a PEG tube, or other variations. PG stands for “Percutaneous” (through the skin) “gastrostomy” (through an opening into the stomach.) Sometimes it is positioned into the jejunum of the small intestine instead. The health care professionals will know the benefits and problems associated with using one approach over another for a particular child.

At times it may be necessary to feed the child through the veins (i.v.) and bypass the usual feeding route completely. This is called TPN (Total Parenteral Nutrition”) or some variant. Sometimes it is called PPN (Partial Parenteral Nutrition) if it is used to supplement a feeding that uses the intestines. [The word “enteral” means using the intestines; “parenteral” is short for “para enteral,” which means the feeding route is outside of or along side (but not by way of) the intestines.] This kind of feeding is not done if the stomach and intestines are able to be used well enough to meet the child’s nutrition needs.

2) Some children have physical eating problems.

Poor head control, chewing, swallowing, mouth control, or mouth sores, etc., can also lead to poor nutrition. Children may receive an inadequate intake because of the time and effort required to eat even a small volume of food. Sometimes they get enough calories but inadequate protein, vitamins and minerals because of textural manipulations that can seriously limit the amount and variety of foods eaten.

Children with neurologic injury (such as cerebral palsy) may continue to struggle with infant feeding reflexes that do not fade away. “**Tongue thrust**” is an example of the reflexive pushing of food out of the mouth. **Poor lip closure, an excessive or absent gag reflex, a “bite reflex,” and dental problems (such as “malocclusion” and difficulty providing appropriate dental care)** are other common problems that make oral feeding difficult. Unfortunately, careful analysis of the diet is often not undertaken and the diet is assumed to be appropriate and adequate as long as some food is found that can be easily/safely fed and the child’s weight seems to be adequate.

For some neurologically impaired children with unrecognized **dysphagia (poor control of swallowing,)** even the safety of oral feeding may not be considered, and aspiration pneumonia can result from food going into the lungs. Also, texture adjustments for dysphagia themselves can cause nutritional imbalance. The diet can easily be too high in starchy thickeners and too low in foods that provide other nutrients such as protein, vitamins and minerals. Careful adjustment of the diet can minimize these problems. “Video fluoroscopy” is test to be sure that the child is not swallowing unsafely. **Speech pathologists** have programs to help children gain eating skills or to become less “orally defensive”(being very resistant to being fed by mouth.)

If increasing the caloric density of the feeding is a goal, the same cautions involved in Section 1 above will also apply here. Sometimes a tube feeding is necessary to provide some or all of the child’s nutrition. **If swallowing is unsafe, it will need to provide all of it.** The timing of tube feedings can be planned to fit in best with the family’s schedule or situation.

For example, all tube feedings might be given during the day, or some (or all) may be administered by a pump overnight. The latter approach can be especially helpful when one wants the child to be most interested in working on eating skills during the day, or if the child is very intolerant of high volume intakes at feedings.

If the child can eat but just cannot eat enough, the tube feeding can be an excellent help because it allows the child to be passively fed as needed. It can also help administer medications. Bad tasting medications certainly do not help a child just learning to eat look forward to taking anything by mouth.

This combination approach also lets the child continue to work on eating skills, to eat just preferred or safe foods, and the rest of the nutrition can be easily fed passively. I think of this as contributing to another important feeding issue: “**the happiness factor.**” Check the part of Section 1 above: (“Some children will have higher needs for all nutrients in addition to calories”) as the **vitamin and mineral issues will be important here as well.**

3. Some children are unable to perceive hunger or satiety, or they may perceive it but be unable to communicate it to the caretaker.

Some children behave as if they are simply uninterested in eating, or unaware of eating in general, or they may limit their food choices to only a very few items. In such cases, there can be great pressure on the caretaker to “just get SOMETHING into the child,” and so serious imbalances in nutrition can easily occur even when calories are adequate and effort is huge. Many children with autism present problems of this kind. And with so many major issues for the caretakers to deal with, nutritional adequacy may be pretty far down on the list of things that grab their attention. In such cases, individual problem solving with a nutrition professional familiar with these issues would be especially helpful.

After infancy, most children with Prader-Willi Syndrome (PWS) have the opposite problem: They behave as if they are ALWAYS hungry and in search of food. They seem to be “driven to eat” and they tend to eat many more than their bodies appear to need. However, new understanding of the metabolism problems in this genetic condition helps explain the reasons for this particular behavior and have provided some new approaches that are very helpful. **Recent research suggests that there are ways to help with this specific serious problem associated with PWD, including the supplementation of carnitine and CoQ10 and treatments that involve growth hormone.** Discussion of carnitine continues in the next section.

4. Some children have markedly decreased energy needs

This may be because of very low energy expenditure and/or low muscle tone (e.g. spina bifida, Down Syndrome, muscular dystrophy, Prader-Willi Syndrome (PWS) and “general hypotonia”). **They may need a very low calorie intake to prevent debilitating obesity.** Excessive fat accumulation can make it much harder for the child to develop mobility skills . . . it’s like trying to learn to crawl with weak muscles and a ten-pound weight on your back. It makes it harder for the caretakers to safely lift the child, and it can also result in more frequent adjustments of braces, wheel chairs, car seats and other equipment.

The child with less muscle mass because of less physical activity can often appear to receive adequate-but-not-excessive calories when actual calories taken in are much higher than needed. This is because we are looking at arms and legs with certain general assumptions about how much is muscle, how much is bone and how much is fat. An overly fat child who has low muscle and/or bone mass will often have fairly normal limb contours and appearance. The excessive fat the child has to deal with in terms of extra weight to move around, etc., can be hidden.

That is one reason why other measurements besides height and weight can be very helpful in assessing the nutritional appropriateness of feeding plans for children with non-average body composition. By **measuring fat on the arm and back with a caliper**, for example, one can see if the child has fat stores that are too low, too high or just right. These measures are also helpful when we are making adjustments in feedings of children who are unable to express hunger or satiety. As a rule-of-thumb, the less typical a child’s mobility or muscle tone, the less likely standard weight and height growth charts will provide the key information needed.

Interestingly, **for some types of low muscle tone, supplemental carnitine has been shown to help very much.** Carnitine is usually made in an adequate amount in our bodies, but certain medical conditions or medication use can result in a general inadequacy of this important substance. This situation is a bit similar to the fact that although most people make plenty of insulin, children with diabetes can't make enough, and it simply has to be provided to them.

The carnitine helps the child move fat into the furnaces in the cells of the muscles so it can be burned for fuel. **Having too little carnitine can result in low muscle tone from inadequate fat fuel to the muscles, very poor exercise endurance, lethargy, excessive sleepiness, hunger and unwanted high-fat weight gain because it can't be used for fuel normally.**

Some medications interfere accidentally with carnitine adequacy, and these symptoms show up as side effects of the drug. More will be discussed about carnitine in the section on drug/nutrient interactions later in this paper. However, if these descriptions describe your child, you may want to download my handout on this topic to learn a bit more about this important substance. It's called:

“By Request: A Short Carnitine Discussion that Might Be Helpful”

It has now been shown that vitamin D inadequacy can be an important cause of muscle weakness as well, with many consequences including increased risk of falls and even congestive heart failure, a type of heart problem in which the heart muscle is too weak to pump blood normally. **Inadequacy of vitamin D at present is actually extremely common even in the general population.** It has now been identified as a previously unrecognized epidemic! The failure to recognize deficiency was because, until very recently, it was simply not checked as part of a normal doctor's visit. We all just assumed it was fine.

In the population of **children with special medical problems, the likelihood of inadequacy is even greater,** in part because of certain medications (e.g. seizure medications) or being unable to be outside enough even in sunny summer weather. The vitamin D issue is discussed in much greater detail in my downloadable handout called:

“Aunt Cathy's Guide: My Current Top Five Easy
Ways to Improve Your Family's Nutrition
(subject to change at any moment! ☺)”

In general, children with low caloric requirements or low volume intake for any reason will benefit from careful micronutrient supplementation. Simply adding a standard vitamin drop will not solve the problem, nor will just adding the standard “complete type” children's chewable vitamin with minerals. There are still big holes in the diet regimen. **Intake of essential nutrients is inadequate on very low calorie diets unless the health professional looks closely at the feeding plan and makes adjustments to replace inadequate nutrients.** Check the part of Section 1 above because the **vitamin/mineral issues will be important here as well.**

- 5) **Some children have troubles with constipation, including some of those whose caloric needs are low and some whose caloric needs are high.**

For children with lower caloric requirements:

Children with lower-body paralysis like those with spina bifida or other spinal cord injury, or those with a surgically-correctible condition called Hirschprung’s disease, may experience constipation because of **difficulty moving things along in the intestines**. Some children may also have **problems with bladder infection**. A number of the traditional dietary interventions (such as corn syrup, cranberry or prune juice, etc.) contribute an unacceptably high number of calories for this group of children. Cranberries may have a role in decreasing recurrence of bladder infection (as was shown in a study of elderly women) but an artificially sweetened product may be needed.

Regular “cranberry juice cocktail” or prune juice provides about 20 calories per ounce, which is equal to the calories in whole milk. Corn syrup provides 60 “empty” sugar calories per tablespoon. Well-intentioned interventions to solve one problem can make another problem much worse. Low/non-calorie approaches to helping with constipation (e.g. milk of magnesia, lactulose, etc.) are available and some of these are discussed below.

Contrary to popular belief, simply increasing water or other fluids will not resolve constipation unless inadequate fluid intake was a contributing problem. Extra fluid is clearly needed if fiber is being added, but in the absence of added fiber any additional fluid is simply absorbed from the intestine and excreted via the kidney.

In addition, **adding fiber may not be a helpful approach to constipation for a child whose neurologic ability to push food through the lower intestinal tract may be impaired.** In fact, it may actually contribute to bowel obstruction. Some types of fiber actually slow transit time through the intestine instead of moving things along. Extra fluids are also beneficial for decreasing risk of bladder infections and kidney stones, but for the child with low calorie needs, it is important that the calories from the added fluids do not contribute to weight problems. Additional information about constipation issues in general is included in the section below.

For children with constipation problems for whom a nutrient-dense high-calorie diet is needed: In contrast to the issues described above, it is useful to know that **there are pretty generous calories in some of the foods and beverages we commonly use for constipation or kidney health.** Examples include cranberry juice (“cocktail”) or prune juice (20 calories per ounce – as high as whole milk,) and corn syrup (60 kcal per Tablespoon.) When trying to increase fluids for this child, remember that juices are 99.9% water. That means that they contribute the same amount of fluid as plain water would, but they have the advantage of adding some calories, some beneficial phytochemicals and a few nutrients. **It makes little sense to concentrate a child’s formula and then feed plain water . . . it just re-dilutes the feeding.**

Consider whether some of the ways we add extra calories are possible contributors to the constipation. For example, “casein” is a curd-forming milk protein that can be quite constipating for some people. Whey protein is not curd-forming, and therefore it is generally less constipating. There are several commercial nutritional beverage products used for children that are readily available, such as Boost® or KinderCal® (by Mead Johnson), Carnation Instant Breakfast® or Nutren Jr.® (by Nestle), or PediaSure® (by Abbott.)

If using these products, check the label to see if the protein is primarily in the form of casein. You may see the word “caseinate” on the label. This is a perfectly fine protein source for growth, but for the chronically constipated child it would be worth trying one that had less casein. Powdered products added to milk (like instant breakfast products) often include powdered milk as the protein source, so the protein would still be 82% casein.

This is also an issue in infant feeding. Mother’s milk is very useful for MANY reasons, including fat blend, immune-boosting factors and better absorbability of many nutrients. In addition to these great benefits, it is unusual for babies to be constipated when exclusively fed breastmilk. However, some children’s health situations can result in a degree of constipation even when fed with mother’s milk.

Soy formulas are milk-free and so they have no casein, although for some children soy is constipating, too. Of the milk-based products, a variety of protein sources are available: Nestle Good Start Supreme® is all whey (no casein) and the whey is partly chopped up. This product has been helpful for use with chronically constipated babies. Standard Enfamil Lipil® (Mead Johnson) and Similac Advance® (Abbott) products have adjusted the casein-to whey ratio from 82%-to-18% (regular milk) to an easier to digest 40% to 60% ratio in an effort to try to approach the ratios in human milk.

The protein in all the “lactose free” milk-based formulas is 100% casein. Enfamil’s “GentleEase®” product has less lactose than their standard Enfamil Lipil® and it has both casein and whey in the same ratio (40% casein to 60% whey.) The difference is that they have hydrolyzed (chopped up) both of these proteins. This may be helpful for constipation. Similac’s lactose free infant formula recently had a name change to “Similac Sensitive®.” It still has 100% of the protein as casein.

Dairy fat (butterfat) can also be quite constipating. Butterfat is the form of fat in cream, whole and 2% milk, butter and cheese. In addition to the constipation issue, it is a very saturated fat and (like MCT oil®) it always a very poor source of the essential fatty acids, including any type of omega-3 or omega-6 polyunsaturated fats. In spite of this, some diets, such as the **ketogenic diet for seizure control**, may contain a very high amount of cream.

The ketogenic diet is (not surprisingly) constipating for many children. Using other forms of fat in place of at least some of the cream can help a lot, both for constipation relief and for good nutrition. The heavy cream is used in that diet because it is more palatable when the child has to be fed orally, but it continues little except calories. As noted above, it has essentially no vitamins or minerals (e.g. no calcium or vitamin D) and it is a poor source of essential fatty acids.

Beverages like “KetoCal” from Nutricia provide much better nutrition along with the ketogenic properties of the formula, and they taste fine. For for an infant or a tube-fed child on the ketogenic diet, one can also starting with a base product like Abbott Nutrition’s “RCF®” formula (“Ross Carbohydrate Free.”) It has all the nutrition of a standard infant formula except

the carbohydrate is omitted, including a standard fat blend. For oral use in an older child it can be flavored with non-carbohydrate flavorings if necessary.

Some iron sources can contribute to constipation, and it is not uncommon to find that the heavily iron-fortified infant cereal can contribute to the problem. High doses of “**inorganic**” iron (that is, the “ferrous” or “ferric” forms found in plants or in pills) can be constipating and since they are also far less well-absorbed, they are actually not the best route to improving iron deficiency in an individual. **Iron in breastmilk is “organic” and it is not constipating and it is very well absorbed.** The standard amount of inorganic iron in formulas is not constipating. For example, “Nestle Good Start Supreme ®” formula (a whey based product) is often useful for helping constipated babies and it only comes with iron. [Note that none of the standard infant formulas are made in “low iron” versions anymore because it was not useful for constipation and it was also nutritionally incomplete.]

Highly absorbable and non-constipating “organic” iron is also the kind found in meat. It is called “heme” iron, and there is also a substance in meat called “Meat Protein Factor” that improves the absorption of the inorganic iron in the meal as well. For more detail on solving iron problems, please download my handout called: “Aunt Cathy’s Guide to: Nutrition Support of Iron Deficiency”

Products to relieve constipation: Both Milk of Magnesia ® (magnesium hydroxide) and MiraLax ® (polyethylene glycol) attract water to the bowel by osmosis and so they can be useful for keeping stools from hardening. This is especially helpful when intestinal transit time is slower than average . . . the slow transit time gives the large intestine more time to extract water, contributing to harder stools.

Both of these products contribute no calories. Prune juice and corn syrup add considerable calories, but they act the same way (an osmotic effect,) and the prune juice naturally has additional phytochemical substances that encourage defecation. The prunes themselves are helpful . . . not just the juice.

Glycerol suppositories can act locally at the rectum to ease passage of stools, but they do not prevent the formation of dry/hard stools. Other products such as those containing senna can work by means of irritating the bowel to stimulate activity. Others can interfere with the absorption of nutrients. For this reason it is important to talk with your pharmacist or other health care provider about the usefulness or safety of any constipation products or approaches for your child.

6. There are many pediatric conditions that greatly alter nutrient requirements and metabolism such as cystic fibrosis, diabetes, inborn metabolic errors (such as PKU) and inflammatory bowel disease.

The health care professional must examine diet alterations for children with these conditions. As always, adjustments of the child's diet must not only correct the obvious problem (such as glucose control in diabetes,) but it is also essential to examine the feeding plan to be sure it provides adequate and appropriate levels of all of the other nutrients. **This step is often overlooked.** Different patterns of growth and body composition associated with certain conditions must also be considered in the nutrition plan.

Increased nutrient excretion or turnover, or decreased absorption will also alter nutrient requirements so that the "normal" guidelines of adequacy or safety (such as the "RDA" or "RDI" or "AI" level) or expected patterns of "normal" growth rates may not apply. They may not apply for other reasons as well, such as altered body composition or the effects of medications. **Most guidelines only address intake goals and growth expectations for "healthy" people.**

In many cases, special levels of certain nutrients can greatly affect the risk of complications and worsening of chronic conditions. One area of encouraging micronutrient research is diabetes and antioxidants such as vitamins E and C, minerals like selenium and zinc, and a number of brightly colored plant pigments described later. Other substances that look promising are the B vitamins (all, but especially B6 and biotin,) magnesium, carnitine, alpha-lipoic acid, and gamma linolenic acid.

The same patterns are emerging for many conditions that feature altered metabolism and/or inflammation. Please see my handouts specifically focusing on each of certain conditions for more information: Diabetes, Hemochromatosis, Multiple Sclerosis (MS,) Epidermolysis Bullosa (EB – a severe skin condition) and Celiac Disease are currently available.

A) Antioxidants

For diabetes and many other autoimmune diseases like lupus, juvenile rheumatoid arthritis, and inflammatory bowel disease, and for genetic conditions like Down Syndrome and apparently many others, **the medical condition itself (or the therapy) results in increased production of damaging free radicals.** This leads to increased frequency and severity of complications beyond those due to the condition or medication use alone. For this reason, **appropriate generous antioxidant supplementation** is advisable.

In addition to vitamin/mineral antioxidants, there are many potent **antioxidants available in brightly colored fruits and vegetables.** The food pigments themselves are often antioxidants. Examples include orange colored "beta-carotene" in carrots and squash, red "lycopene" in tomatoes and watermelon, green "lutein" in dark leafy greens, red/blue "anthocyanins" in blueberries and beets, yellow xanthophyll in corn and kale, and white/yellow "flavones" in onions and garlic.

This class of substances is usually called "**phytochemicals,**" which simply means "plant chemicals." [Note that all "plant chemicals" are NOT health-promoting. Poison ivy comes right to mind as an example of a phytochemical that is not friendly.] Many vegetables and fruits have a wide variety of phytochemicals that have benefits in addition to the antioxidant content, so children's diets (and the diets of adults) should be as generous in these foods as possible. A great example: Lycopene, the red pigment in tomatoes, is 200 times as potent as a protective antioxidant than vitamin E. There is much to be gained from including brightly colored fruits and vegetables in the diets of everyone in the family.

I have had some success using pureed fruits and vegetables that are frozen in an ice-cube tray and then popped out and stored in a freezer bag. These are then quick and easy to add to strongly-flavored foods like soups, spaghetti sauce, chili, meatloaf, etc. For a tube-fed child, any combination of fruits and vegetables can be pureed all together with formula or other nutritious liquids (e.g. prune juice) and frozen as described.

Blenderizing the “veggie cubes” with the formula to be fed will usually thin it down enough, but it can also be strained if there is a concern about clogging the tube. This sounds time-consuming, but it can be done all at once for a month’s supply. One can use canned, frozen or fresh (use low sodium vegetables if using the canned type.)

Some folks have a routine of freezing any leftover fruits and vegetables immediately after a meal in a freezer bag and then blenderizing them all at once when a good amount has been stored up. Also, many Grandmas or friends who keep asking how they can help are often very happy to take on this kind of project. For everyone, of course, clean and safe food-handling techniques are very important.

Another option is to add readily available fruit and/or vegetable juices (e.g. carrot juice, cranberry juice, prune juice, low sodium “V-8” type) as part of the liquid used to reconstitute infant formula. Variety is very important because the various beneficial phytochemicals are not all in the same food.

There are many new products out there to investigate now that the public is becoming aware of the importance of these phytochemicals for health. Some are powders, juice concentrates or combinations of vegetable and fruit juice. For the latter, be sure to check the calories, and whether or not they are additionally sweetened when choosing. More information on this topic is available in my handouts:

“Aunt Cathy’s Guide to: Nutrition and Eye Health”

“Aunt Cathy’s Guide: My Current Top Five Easy Ways to Improve Your Family’s Nutrition (subject to change at any moment! ☺)” and Aunt Cathy’s Guide to: Some Ideas for Trying to Eat More of Those Terrific Antioxidant Phytochemicals. . . and Liking It.”

B) Omega-3 / Omega-6 Oils

Along with antioxidant supplementation, manipulation of the inflammatory response by altering the **ratio of omega-3 to omega-6 fatty acids** is also looking very promising in the autoimmune and inflammatory diseases in particular. This ratio also appears to be very important in other areas of health research as well, such as risk of heart disease, cancer, HIV, depression, epilepsy, cognitive function, and degenerative eye diseases.

In each case, the direction of change that shows benefit is increasing the proportion of dietary fats that are rich in oils of the omega-3 family in relation to the intake of fats from the omega-6 family. Vegetable oils that are high in “omega-6” (such as corn oil) contribute to a strong inflammatory response. Adjusting the intake of dietary fat to displace some omega-6 oils with oils from the omega-3 family can significantly reduce the strength of an inflammatory response. This is particularly important in conditions characterized by excessive inflammation.

Compared with corn oil, other vegetable oils like canola oil, flaxseed oil, walnut oil and soy oil (only if non-hydrogenated) contribute to a much better balance of omega –3 to omega-6 oils. Ground flax seeds, soybeans, walnuts and other nuts and seeds have other nutritional benefits that the oil alone will not have. Additionally, displacing some omega-6 fat with oils rich in a form of fat called **monounsaturated** oils (like peanut oil or olive oil) will have a favorable effect on the omega-3 to omega-6 ratio.

At present, the relative ratio of these fats is an area of some difference in the general pediatric oral/tube-feeding complete nutrition products. For example, Nutren Jr. ® (Nestle) has a lower ratio of omega-6 to omega-3 fats compared with PediaSure (Ross Labs) and Kindercal ® (Mead Johnson.) This might be a consideration especially in conditions with a strong inflammation component. Some products are being especially designed to provide fats with a less inflammatory potential, such as Modulen IBD ® for inflammatory bowel disease (Nestle.) New products and reformulations will likely be forthcoming as this aspect of nutrition receives greater attention.

As mentioned above, olive oil and peanut oil are mostly “friendly” monounsaturated oils. They are not rich in either omega-3 or omega-6 polyunsaturated oils, but if they replace the high omega-6 corn oil in the typical US diet, they can have a big beneficial effect on the **ratio** of the remaining omega-6 to omega-3 oils. This contributes to decreasing the strength of inflammatory substances that the body makes out of these two families of oil. It has the added advantage of displacing some of the less beneficial fats in the diet, like the saturated fats in coconut oil, palm oil and butterfat. All these oils have about the same number of calories ... about 9 per gram.

Fish oils contain a generous amount of the omega-3 oils, and they are in a form that is especially easily utilized in the effort to control inflammation. **It is becoming very clear that many individuals benefit greatly from having the fish oil form in particular provided because it contains “ready-to-use” EPA and DHA.**

These two fats (EPA and DHA) have direct anti-inflammatory effects, and DHA is a critical fat of the brain tissue. Newer forms of supplements are appearing on the market which can facilitate their use by children. More information is available in my handout on “lipids” ... the family of substances that includes fats and oils and cholesterol:

“Aunt Cathy's Guide To: All Those Lipids: Recommendations for Using Different Types of Vegetable Oils (Omega-3, Omega-6 and Monounsaturated Oils)”

7) Therapeutic diets that eliminate certain foods or entire food groups are in need of careful attention to the nutritional adequacy provided by the foods remaining.

This includes special diets for allergies, celiac disease (“gluten-sensitive enteropathy”), autism, inborn metabolic errors, diabetes or the ketogenic diet for seizure control. It is critical that the nutritional adequacy of the diet is not compromised. Sometimes small adjustments in the foods offered can solve any problems caused by food group limitation, but in the more restrictive diets it is virtually impossible to obtain appropriate levels of vitamins and minerals without careful supplementation.

As the nutrient content of supplement products on the market can be quite variable, it is reasonable to have the diet and supplement plan evaluated carefully by a credentialed nutrition professional (e.g. an RD – a Registered Dietitian) using a computer analysis program. [Some RDs are also “Certified Specialists in Pediatric Nutrition.” Those with this credential will have the letters CSP in addition to the RD after their names.]

Such computer programs for nutrient analysis are available in many hospitals and clinics and in many university settings. They allow for the clinician and the family to be very sure that there are no accidental nutrient inadequacies or excesses in the feeding regimen that

could harm the child's overall health. Most computer programs in stores that sell health products and vitamin supplements are inadequate for the kind of careful micronutrient assessment that is needed in this situation, and in addition, they are often primarily programmed to promote and increase sales of particular nutrition products.

8) Many children are maintained on medications with important nutritional implications.

Here are a few examples:

Chronic use of seizure medications [like phenobarbital, valproate (Depakene®), phenytoin (Dilantin®), Tegretol®, and many others] can cause increased turnover of vitamin D, contributing to osteoporosis and fractures, among other problems. This is a special concern now that the epidemic nature of vitamin D deficiency even among healthy people is becoming recognized; people with health problems are at even higher risk for many reasons.

Vitamin D inadequacy has been found to be quite common especially in the northern half of the country (but all over in the south as well.) It is common among people with dark skin, those whose skin is often covered up or injured, or old, and those who are frequently indoors. It increases risk of developing arthritis, MS, diabetes, muscle weakness, muscle pain, lung problems, cardiovascular disease and several types of cancer.

Other nutrients are also affected by these medications. Health professionals need to consider the influence of the medications when assessing the adequacy of nutrient intake, and they may need to provide a different level of supplementation to safely assure adequacy. Again, for lots more information on this topic and specific recommendations, please see my handout:

“Aunt Cathy’s Guide: My Current Top Five Easy Ways to Improve Your Family’s Nutrition (subject to change at any moment! ☺)”

Phenytoin (Dilantin®) also interacts in a complex way with folic acid and several other vitamins, and its absorption is altered by the presence of food. When folate is found to be inadequate and then supplements are given to people on this medication to correct the deficiency, breakthrough seizures can occur. **This does not happen when their folate level is never allowed to be depleted in the first place.**

Chronic users of this medication often have low erythrocyte (red blood cell) folate levels. Inadequate folic acid is also associated with depression, poor response to antidepressants, and risk of heart disease, stroke, colon cancer, and Alzheimer’s disease. In pregnancy, the relatively poor folate status increases risk of significant birth defects. **It is recommended that anyone starting to use Dilantin should automatically receive supplementation at the RDA level of folic acid to prevent serious difficulties.** If the drug is already in use, the physician should carefully correct the deficiency, possibly by using a temporary increase in the drug during the adjustment period to prevent breakthrough seizures.

Valproic acid (Depakene®) specifically interacts with carnitine and can cause metabolic disturbances including severe hypoglycemia and lethargy that impairs the child’s ability to function. It also severely impairs endurance. One reason is that it can inhibit production of

carnitine in the body, increasing dependence on external sources. Valproic acid also seems to require carnitine for optimal drug effectiveness. **Therefore, inadequate carnitine increases the amount of drug required for seizure control and it is associated with “break-through seizures” and a much greater risk of serious liver toxicity from the drug.**

Carnitine is usually made by a person’s liver and kidneys in adequate amounts so it has not been thought of as an “essential” substance. (“Essential” in nutrition means that you have to take it in ready-made from outside either in foods or in supplements.) However, it is now clear that in circumstances like this, carnitine can become “essential.” You may see carnitine described as a “conditionally essential” nutrient for that reason. **Relative carnitine inadequacy (unrelated to medications) has also been found to be a factor in many conditions involving low muscle tone, poor endurance, and/or disturbed metabolism, including diabetes.**

Other Common Nutrition/Medication Interactions:

Methotrexate also interacts with folic acid. This drug is used as a chemotherapy drug for **cancer**, but it is also an important medication in treatment of **psoriasis and juvenile rheumatoid arthritis**. Assuring adequacy of folic acid has been shown to help the patient tolerate the use of the medication. Inadequate folic acid status is associated with having to stop using methotrexate because of discomfort even when it is clearly helping treat the disease.

Hydrocortisone (an anti-inflammatory) can cause growth failure, increase excretion of nitrogen and zinc, and decrease absorption of calcium and phosphorus. Vitamin D status is also a factor here.

Sulfasalazine (Azulfidine®) an antibiotic used for inflammatory bowel disease impairs absorption of folic acid, and diets of people with this condition are often also low in fruits and vegetables because of bowel discomfort. Their diet may also be lacking in dairy foods and high fiber foods by doctor’s order. The risk of multi-nutrient inadequacy is great due to the combination of dietary limitation, drug-induced nutrient absorption problems, high needs for healing the intestine and high losses of nutrients via gut “weeping.”

It is not surprising that these children need help to grow normally. There is evidence that the thrombotic (blood clots / strokes) and affective problems (mood issues) and higher risk of colon cancer all noted in this population may be related to the very common folic acid inadequacy.

Any antibiotics when used chronically can compromise status of biotin, vitamin K (which can cause bleeding and bone, kidney and blood pressure problems,) and significantly impair folic acid absorption. Antibiotics can also induce a chronic diarrhea (and this may in turn be treated inappropriately with a clear liquid diet or half-strength feedings, resulting in further malnutrition.)

Many people are commonly maintained on chronic antibiotics, including those with spinal cord injury (to prevent bladder infection), cystic fibrosis, acne, certain heart conditions, HIV or other immune-compromised individuals. Some antibiotics contribute to gastrointestinal distress such as stomach pain and diarrhea.

Theophyllin (a broncho-dilator) absorption is influenced significantly by the timing of its administration in relation to food intake.

Acid control medications: Zantac®, Tagamet®, (the “H2 blockers”) and especially Prilosec®, Nexium®, Pepcid®, Protonix® and Prevacid® (all PPI’s: “Proton Pump Inhibitors”) are drugs that decrease acid production in the stomach. Loss of stomach acid can impair absorption of vitamin B12 from natural food sources because stomach acid is required for getting it into a form that can be absorbed.

This means that eating a “well balanced diet” will fail to provide adequate vitamin B12 when these medications are used. Vitamin B12 deficiency is very serious, so this issue should not be ignored. **However, absorption of the form found in vitamin supplements is NOT affected by loss of acid, so this problem can easily be avoided with the regular use of a multivitamin product.**

Because of increasing use of the PPI medications in infants as an attempt to treat gastroesophageal reflux (throwing up after feedings,) it is useful to know that **a breastfed baby maintained on these drugs will need a vitamin drop that contains vitamin B12 in addition to assuring a vitamin D drop.** Any standard drop will do and it can contain both easily. A formula-fed infant is already receiving vitamin B12 in a crystalline form that does not require acid for its absorption. [They will still need the extra vitamin D drop, of course.]

One other consideration with PPI’s is they decrease the effectiveness of infant formula products like Enfamil AR ®. This is a standard infant formula that includes rice as part of the carbohydrate. It is designed to help with decreasing gastroesophageal reflux in infants with this problem by causing the formula to thicken and form a gel in the tummy after the baby drinks it. This thickening is accomplished via exposure to stomach acid, however, so the formula product will not do its gel-forming tricks if baby is also being treated with a PPI.

Metformin (Glucophage®) is a medication for people with Type II (insulin resistant) diabetes. It also interferes with vitamin B12 absorption. The mechanism is different from the acid-reducing effects described above. This form of diabetes (Type II) has generally not been a pediatric problem in the past, but **the incidence of “adult type” diabetes is increasing markedly along with increased incidence of obesity in children.** The drug is also being used in children with Prader Willi Syndrome when obesity and potential insulin resistance is noted. I have found several children who were referred to me to be deficient when I checked, but the problem is generally not in people’s radar. The consequences of deficiency are extremely harmful to everyone.

For more information on the vitamin B12 issue, please see my handouts: “Aunt Cathy’s Guide to Nutrition: A Vitamin B12 Update” and “Aunt Cathy’s Guide to: Thinking About OTHER Nutrition Issues in Diabetes”

Serotonin Re-uptake Inhibitors (such as Zoloft®) are used both for depression and for inflammatory bowel disease, especially of the primarily constipation type. **This class of drug does not work well when an individual has a poor intake of folic acid.** This is an example of how careful attention to nutrition can improve the clinical response to a drug, thus avoiding the potential side effects due to raising the drug dosage or changing to a stronger drug.

Many drugs (including “herbal” drugs) can also affect intake by causing nausea, vomiting, constipation, taste changes, lethargy, or altered appetite. For example, Methylphenidate (Ritalin®) for attention deficit disorders may impair appetite enough to slow growth, although there is some evidence now that this may be less of a problem than originally thought. Narcotic pain medications often cause constipation and decreased appetite.

“Herbal remedies” are not nutrients but many people have been given the impression that they are. They are often marketed as “dietary supplements” because by law, the people selling them do not have to prove that their product is safe or effective. It is a loophole in the Food and Drug Administration’s laws that many people are unaware of.

People assume that in America a company could not package and sell health products that were inadequately tested (or not tested at all.) But although labeled as “dietary supplements” in order to avoid having to test them, these products are actually in the category of drugs and medications. This is because whether they are in a natural state or packaged as a pill, the goal of using them is to achieve some pharmacologic reaction.

For children with complex medical conditions and especially those who must use medications of various types, there can be significant and dangerous interactions when unknown to the physician, herbal products (or any “over-the-counter” products) are added to the mix.

As one example, the herbal supplement “St. John’s Wort” which IS promoted as a “natural antidepressant with no side effects” actually interacts with a wide variety of medications and causes the medications to stop working sooner than they should. This effect of St. John’s Wort has been found with medications for heart disease, HIV/AIDS, birth control pills, and drugs that prevent the rejection of transplanted organs. Serious injury has resulted.

This is just one example of why it is very important to discuss the use of ANY herbal product or other over-the-counter product with the child’s physician. “Natural” products certainly CAN have side effects – after all, some of the most potent (and also dangerous) drugs come from plants. For example, digitalis (an important heart medicine) comes from the foxglove plant, and even heroin, cocaine and marijuana are “herbal.”

Summary Providing optimal nutrition for the child with special health needs can:

- optimize physical, intellectual and psychological development.
- prevent serious complications like fractures and medication toxicity.
- optimize immune function to reduce the incidence/severity of illness.
- decrease pain due to inflammation or nutritional inadequacy.
- optimize the safety and effectiveness of any medications used.
- facilitate the care of the individual.
- improve the quality of life of the child and the caretakers.

These goals will only be realized when health professionals are able to take a close look at this important aspect of the child’s care.