

Sanford Medical Center

Aunt Cathy's

General Thoughts about Safely Discontinuing the Ketogenic Diet for Seizure Control



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Children on the ketogenic diet for seizure control can sometimes go off the diet and continue to experience good seizure control. Often they will continue to need some seizure-control medications, but they may need less.

Any time the family and the child's physician wants to do a trial off the ketogenic diet we can easily set up a trial. However, **there are some important things about the process to know about**, so this information should be shared with all concerned. That way everyone will be on the same page regarding how to safely discontinue the ketogenic diet, and what may need to be done afterward.

What needs to happen before the trial off diet is initiated:

The physician will need to decide if he/she wants to give the child some additional seizure-control medication ahead of time.

Here is the rationale for this:

1. If the child IS still depending heavily on being in ketosis to control seizures, without the extra medication protection at the start of the trial, when he/she goes out of ketosis there would be a risk of an increase in seizure activity.
2. If the child does well after going out of ketosis while on this more generous medication level, the family and the physician can then set about to wean the medications back down to see how well seizure control is maintained off diet.

The nature of the ketogenic diet is that it is NOT the kind of thing from which a person can be "slowly weaned off." Once carbohydrate is introduced, the person almost immediately stops producing ketones. In other words you can "walk down" with the child's medications, but the diet is either "all or none" so there is no safety net. There is no gradual change in ketone production ... when carbohydrate comes in, ketones go away.

The actual trial off the ketogenic diet is easy from a food/nutrition standpoint:

1. **For children who eat foods orally**, just give the child something to eat with a generous amount of carbohydrate in it, like a glass of milk or a jelly sandwich ... whatever is age appropriate and that the child might like. In other words, just switch to a typical diet for age and the carbohydrate normally present there will naturally put a stop to ketone production. (The nutritionist / dietitian can help figure out what carbohydrate-containing foods would work if there are any questions.)
2. **For the tube-fed child using RCF formula** (Ross Carbohydrate Free,) the simplest solution is to just add carbohydrate to the RCF. According to the manufacturer, 3-1/2 level tablespoons of table sugar and 12 of water per 13 oz can of RCF will make a product with the average amount of carbohydrate found in standard infant formula (20 calories per oz.) For this situation, however, it is perfectly fine to just round it off to 4 Tablespoons, which is 1/4 level cup of sugar per can of RCF concentrate. The resultant product will provide closer to 24 calories per oz, another caloric density commonly used in infants.

So, if it is decided to do a trial off diet, the safe way is as described above. If one then weans the medications back down and finds that there is good seizure control in spite of the diet change, here's what should be done next:

1. Get together with the pediatric nutritionist after the child has been off the diet for a while to take a look at the nutrient intake on the new unrestricted diet. The reason is related to the fact that the child often has had such an unusual diet for so long, it may take a while to learn to like a nice variety of food. Maybe he/she will dive right in ...that would be great! ... but if it doesn't go that way the nutritionist can always figure out some things that will make sure to provide good nutrition while the child is getting used to the new foods.
2. When children do well with seizure control after they go off the diet, they still may need some amount of seizure medications. Needing none would be terrific, but it might turn out that the child still needs to have some. The physician and family will decide this. Since there are some nutrition issues associated with any kind of seizure medication use, the nutritionist should look the whole picture over and figure out what, if anything, needs to be done to adjust for the drug/nutrient interactions associated with any medications used.