

General Thoughts about Safely Discontinuing the Ketogenic Diet for Seizure Control



Cathy Breedon PhD, RD, CSP, FADA, FAND
Clinical/Metabolic Nutrition Specialist and Perinatal/Pediatric Nutrition Specialist
Sanford Medical Center and UND School of Medicine, Fargo, ND

People 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 physician want to do a trial off the ketogenic diet one 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 patient 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 the child goes out of ketosis there could 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 for seizure control is that the diet is NOT the kind of thing from which a person can be "slowly weaned off."

Once a certain threshold of carbohydrate intake is reached, a person will almost immediately stop producing ketones. There is no gradual change in ketone production ... when that particular amount of carbohydrate comes in, ketones go away.

So if ketones HAVE been helping to control seizures, some other protection against seizures needs to be put in place before stopping the diet.

The exact amount of carbohydrate will vary with individuals, so it is best to be on the cautious side. The physician or metabolic dietitian can design individual plans to move toward changing the diet components for an individual, but they do not go “cold turkey” unless other things like their seizure-control medications have been adjusted.

Bottom line: you can “walk down” with the person’s seizure-control medications, but the diet is either "all or none" so there is no safety net.

[People using the ketogenic diet for one of its other many OTHER applications (i.e. non-seizure-related) may be able to safely discontinue the diet much more abruptly. Check with the physician.]

The actual trial off the ketogenic diet is easy from a food 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 or some macaroni and cheese ... 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. “Adult” foods will work just the same way.

(The nutritionist / dietitian can help figure out what carbohydrate-containing foods and how much would work if there are any questions.)

2. For the **tube-fed person using commercial formula products like RCF** (Ross Carbohydrate Free), **Ketocal**, or **KetoVie**, the simplest solution is to just add carbohydrate to the formula.

For example, 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 in standard infant formula at 20 kcal/oz.

(Calorie issues to consider are the same as the person's needs would usually be ... ketogenic diet or not ... so the product can simply be mixed to provide the total caloric density (kcal/oz) that is needed for a particular individual.)

Additional water can be used to alter the caloric and nutrient density if a lower kcal/oz feeding is necessary. Supplementation of vitamins/minerals/ and the omega-3 fats EPA and DHA may also be needed, especially if one's total caloric requirements are lower than "average." (The DRI-type nutrient levels are not designed to account for the needs of folks who are not members of the "Healthy Population" group. That's where RDs come in ...)

Also, there is no reason that the "added back" carbohydrate needs to be just from table sugar as described or from a commercial carbohydrate polymer additive or whatever. These are still just "empty calories."

[Fruit juices and blended foods can provide the necessary carbohydrate but they also have some beneficial phytochemical antioxidants (examples: resveratrol in grapes, anthocyanin in cranberries, and raspberries, and lycopene in tomatoes, etc., and other nutrients.) So, this comment is not about safely stopping the ketogenic diet; it's about the fact that those lovely plant substances are really good for all of us. Don't get me started! 😊]

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 an experienced RD nutritionist after the person has been off the diet for a while to take a look at the nutrient intake on the new unrestricted diet.**

Sometimes a person may have 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 figure out some things that will make sure to we still provide good nutrition while people are getting used to the new foods. This requires careful attention to micronutrients, “conditionally essential” nutrients and other issues beyond the standard calories, protein and fluid requirements.

- 2. When people do well with seizure control after they go off the diet, they still may need some amount of seizure medication.** Needing none would be terrific, but it might turn out that a person still needs to have some. The physician and family will decide this.

Since **there are some nutrition issues associated with the use of any kind of seizure medication use** (whether one is on the ketogenic diet or not,) 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.

For example, ALL seizure-control medications alter requirements for vitamin D, biotin, or for other vitamins and “conditionally essential” substances like “carnitine.” Optimizing intake of the affected nutrients can be very beneficial by supporting general health, helping to minimize side effects, and in certain conditions it can actually help the seizure medication work better.

I do have **separate papers available on Drug/Nutrient Interactions**, with discussion of many commonly used seizure-control medications and others. Like this paper, they were written primarily for health professionals who had asked me questions. Just ask if you would like to see them. They are free.

There is also terrific (and much more thorough) help available about the ketogenic diet from organizations such as the **Charlie Foundation**, which has championed the use of the ketogenic diet for seizure control for many years. They have expert physicians and metabolic dietitians, and educational resources. They provide great assistance to folks following this special diet.

Here is their website: <https://www.charlifoundation.org/>

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