

KETOGENIC DIET

The ketogenic diet is a medical therapy that must be used under the supervision of physicians who are familiar with the diet and under the direction of dietitians who have experience with the diet. It is NOT something you can do on your own. The diet may be dangerous if not done properly.

(Information from the John Hopkins Children's Center Ketogenic Diet Fact Sheet)

WHAT IS THE KETOGENIC DIET? The ketogenic diet is a therapeutic diet high in fat and very low in carbohydrates and protein. It is prescribed for children who have seizures that are difficult to control with current medications. It has had more limited use in adults who do not seem to respond as readily to it. It was developed in the 1920's and was a primary treatment prior to the introduction of antiepileptic drugs in the 1950's.

WHO CAN BE HELPED BY THE DIET? Many children with seizures can be helped by the diet. There is no way to predict whether it will be successful- except to try it. Traditionally, the diet has been used in children between 2 and 10 years of age; however, it has been used in children as young as one year, and in teens. It is difficult to begin & maintain in children under 1 year, and older children may rebel at the food restrictions. The diet seems to be most effective in children with myoclonic, atonic or tonic-clonic seizures or in the Lennox-Gastaut syndrome. When traditional anticonvulsant medications have not been effective, or if they produce unwanted side effects, the ketogenic diet may be an alternative.

HOW EFFECTIVE IS THE DIET? Studies done over many years suggest that 20-25% of children on the ketogenic diet will have their seizures well controlled. An additional 30-40% will have their seizure frequency decreased by 50%. Approximately 25-30% of patients who try the diet will find that it is not effective.

HOW DOES THE DIET WORK? No one is certain how it works. The diet is designed to place the body into a state of starvation forcing it to burn more fat than normal for energy. It actually simulates the biochemical changes of starvation. This results in the production of ketones which are the by-products of incompletely burned fat. The brain normally burns glucose (sugar) manufactured from muscle tissue as its source of fuel. When the body is fasting & there is no glucose, the brain is forced to use ketones manufactured from body fat as its source of energy. . When this happens, the body is in a state of ketosis. How the burning of these ketones controls seizures is unknown.

WHAT IS THE DIET ALL ABOUT? Ketosis is produced by eating foods that are ketogenic (fats) and avoiding foods which are anti-ketogenic (carbohydrates and proteins). Dietitians calculate how many calories a child needs for energy and growth. This amount is about 75% of the usual recommended daily allowance (RDA) for the child's age. The diet is usually started in a 4:1 ratio (4 parts fat to 1 part protein & carbohydrate) or in a 3:1 ratio. The dietitian calculates meal plans and each meal is very precisely calculated to give the exact number of grams for each food item. It is imperative to maintain the diet exactly as planned. Even small amounts of carbohydrates such as a cookie, several nuts or a carbohydrate-containing toothpaste may eliminate the ketosis and nullify the effects of the diet.

The diet is usually started in the hospital and is always done under careful medical supervision where the child can be strictly monitored. It is usually started by not allowing the child to eat anything and giving limited amounts of water. After several days of starvation the ketones in the blood and urine rise and the diet is then gradually introduced. The parents learn how to prepare the diet and monitor its effects by measuring the ketones in the urine with a tablet or special test paper.

ARE CHILDREN GETTING ENOUGH NOURISHMENT ON THE DIET? They are getting enough calories, but the amount of food seems very small by normal dietary standards. This is because fat, which is concentrated in calories, is included in large amounts. Protein is adequate to maintain weight and perhaps some growth. However, the diet is not nutritionally adequate and daily vitamins and mineral supplements are necessary.

WHAT ARE THE BENEFITS OF THE DIET? The obvious benefit is the potential for seizure control. Sometimes seizures are controlled as soon as the child becomes ketotic, but this effect may sometimes take a month or two, occasionally longer. Another benefit is that frequently the antiepileptic medications can be gradually reduced or discontinued, leaving the child with none of the side effects of medication.

HOW RESTRICTIVE IS THE DIET? The diet is very restrictive, but the restrictions are usually worthwhile if seizures stop or are significantly reduced. Only the foods and the quantities calculated into the diet can be consumed. Medications which are not sugar-free must be avoided.

ARE THERE COMPLICATIONS WITH THIS DIET? During the initiation of the diet there may be nausea, vomiting and even low blood sugars. This is the reason for starting the diet in the hospital. The ketosis decreases the child's appetite, so even though the portions are small, hunger is not a problem for most children. Occasionally children develop kidney stones, but adjustment of the calcium supplements in the diet and increasing the daily fluids usually resolves the problem. Constipation is often a problem. Ketosis increases absorption of some medications; therefore each child should be monitored for toxicity, and medication dosage should be adjusted when necessary.

ARE THERE VARIATIONS ON THIS DIET? The main variation of the diet is the MCT (medium-chain triglyceride) diet which allows a slightly greater proportion of carbohydrates and protein while maintaining ketosis. While reported to be as effective as the traditional diet, it seems less well tolerated causing nausea, vomiting, cramps and diarrhea.

HOW LONG IS A CHILD ON THE DIET? When a child's seizures are well controlled, the diet is usually continued for two years. If seizures are controlled, the diet is then decrease to a 3:1 ratio and after six months to a 2:1 ratio, than discontinued after another year. Children whose seizures are improved but not controlled may remain on the diet for years. Many children continue to go without seizures or other medications when the diet has been discontinued.

For further information:

A Ketogenic Diet video & additional information are available from the Charlie Foundation to Help Cure Pediatric Epilepsy, 1223 Wilshire Blvd #815, Santa Monica CA 90403-5406, 1800-367-5386

The Ketogenic Diet: A Treatment for Epilepsy, John Freeman, MD, Jennifer Freeman, and Millicent Kelly, RD, LD, Demos Medical Publishing, Inc., NY, 2000 can be ordered through your local bookstore, the publisher, or the EFA catalog (1-800-213-5821).

Packard Children's Hospital, Stanford University Medical Center
<http://www.stanford.edu/group/ketodiet/> Information on the ketogenic diet and ketogenic diet resources