



Ketogenic Diet

What is the ketogenic diet?

The ketogenic diet is a carefully designed food regime that helps to control seizures in some children. The diet is very high in fat and low in carbohydrates. The body usually uses carbohydrates (such as sugar, bread, pasta) for its fuel, but because the ketogenic diet is very low in carbohydrates, fats (usually butter and cream) become primary fuel.

The ketogenic diet can be adapted to all ethnic diets and for children who are allergic to dairy products. This regime is nutritionally complete when sugar-free multivitamins and calcium supplements are taken. It is very important for everything to be sugar-free. Even small amounts of carbohydrates, such as a small cookie or the sugar in toothpaste, may nullify the whole effect of the ketogenic diet.

How does it work?

It is still unknown how the ketogenic diet works, but years of experience have shown that it can be a great help in treating intractable seizures. There is considerable research into this area, including a major study at BC Children's Hospital where a ketogenic diet program exists.

Who is a candidate for the ketogenic diet?

The diet is rarely used unless the patient has failed to respond to two or three antiepileptic drugs. The ketogenic diet is most often prescribed for children over the age of 12 months, up to 10 years of age, but some success has also been seen with adolescents.

Although the ketogenic diet may be used on children with any type of seizure, it is particularly effective in controlling childhood myoclonic, absence, and atonic (drop) seizures. The diet helps some patients with generalized tonic-clonic seizures, as well as multi-focal seizures of Lennox-Gastaut syndrome, and Severe Myoclonic Epilepsy of Infancy.

How is it monitored?

It is critical that it be supervised by a neurologist and a dietitian. Do not start the ketogenic diet on your own. The ketogenic diet is started in a hospital setting as an inpatient or outpatient over a period of three to four days under the supervision of a neurologist and a dietitian. Because the allowable food is very specific and each calorie is calculated, only the dietitian can give advice about the food. Do not exchange recipes with other parents whose children are on the ketogenic diet.

How successful is the ketogenic diet?

Approximately one-third of patients become seizure-free or experience a dramatic improvement. A further one-third show some benefit, and the diet is not helpful in the final one-third of patients.

Do I stop with medications?

Your neurologist will advise you about your medications. Generally, Phenobarbital and certain benzodiazepines are withdrawn gradually at the start of the diet. Never stop taking medications without medical supervision or add medications on your own as it can be very dangerous.

Are there any side effects?

The ketogenic diet should be thought of like any anti-epileptic medication, in that it has its own possible side effects and risks. Patients often fast at the start of the diet and it is important to monitor blood glucose at that time. The diet is deficient in certain vitamins and calcium and supplements must be taken. There is a risk of developing kidney stones. Ensuring adequate fluid intake can lessen this risk. Other risks such as dehydration, constipation, high cholesterol levels in blood, abnormal liver function, or changes in behavior can occur as well. The neurologist's and dietitian's supervision helps in minimizing side effects.

How long do I need to stay on treatment?

Patients who become seizure free are usually maintained on the diet for at least two years. The decision to continue the diet depends partly on the EEG at the two-year mark as well as the other factors such as the cause of the epilepsy and the epilepsy syndrome. Discontinuation of the diet is usually done very gradually. The diet is usually discontinued after three months in patients who do not appear to improve.

Are there any other considerations?

The diet can be a difficult treatment choice for families both from practical and emotional points of view. The initial few weeks are often very stressful and it is important that the family have a good support network. There is additional work in preparing food and some children find it very difficult to adhere to such a strict diet regime. However, with thoughtful and creative planning and with sensitivity to the difficulties, these obstacles can be overcome. Many families cope well with the challenges and would agree that the hard work is worth it if the diet eliminates or even significantly reduces their child's seizures.

The resources below are available from the BC Epilepsy Society Resource Library:

The Ketogenic Diet, A Treatment for Children and Others with Epilepsy, Fourth Edition
John M. Freeman, MD, Jennifer B. Freeman, Millicent T. Kelly, RD, LD
Demos Medical Publishing, 2007

A detailed guide for parents, physicians, and dieticians wanting to learn more about the Ketogenic Diet. It reflects current advances in understanding how the diet works, how it should be used, and the future role of the diet as a treatment. It also includes sample meal plans, a food database, and a section on how the Atkins and modified ketogenic diet can be used as alternative diets to help control epilepsy.

The Ketogenic Diet...A Total Commitment
Texas Scottish Rite Hospital for Children
Video, 1997: 16 minutes

A documentary which explains the processes and workings behind the ketogenic diet. This video also includes personal experiences of parents and children on the diet.

First Do No Harm
Jaffe/Braunstein Films
DVD, 1997: 94 minutes

A movie starring Meryl Streep, based on a real life story about a child with epilepsy who has success on the ketogenic diet.

Online resource:

The Charlie Foundation to Help Cure Pediatric Epilepsy
www.charlifoundation.org

The goal of this non-profit organization is to facilitate investigations, educate professionals, and inform families about the ketogenic diet. The website includes online forums to help support and connect families.

Approved for circulation on June 2008 (kf)

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