

# **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 (butter, mayonnaise, oil and cream) become primary fuel.

The ketogenic diet can be adapted to all ethnic diets and for children who are allergic to dairy products. The diet is nutritionally complete when sugar-free multivitamin and mineral 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.

# What are the different types of ketogenic diets?

There are different types of dietary therapies other than the classic ketogenic diet including the modified ketogenic diet, MCT (Medium Chain Triglyceride) oil diet, and low glycemic index treatment. These other diets are still regimented in their content but offer more flexibility and may be preferable in certain individuals. You and your Neurologist will discuss which is the optimal diet for you.

### 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 seizures that have not responded to medications.

# 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. It is the therapy of choice for Glucose Transporter 1 Deficiency and some mitochondrial disorders.

# How is it monitored?

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

# 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.



Your neurologist will advise you about your medications. 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 minerals so supplements must be taken. Other risks such as dehydration, constipation, kidney stones, high cholesterol levels in blood, abnormal liver function, or changes in behavior can occur as well. The team'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 one to two years. The decision to continue the diet depends partly on the EEG as well 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 first 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 significantly reduces their child's seizures.

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

Ketogenic Diets, Treatments for Epilepsy and Other Disorders, Fifth Edition Eric Kossoff, John M. Freeman, Zahava Turner, James Rubenstein Demos Health, 2011

This is a detailed guide for parents, physicians, and dietitians wanting to learn more about the ketogenic diet. It covers how the diet works, how it should be used, and the future role of the diet as a treatment. This includes information on modified versions of the diet including the Modified Atkins Diet for Epilepsy. It also includes sample meal plans, and information on how to calculate foods.

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 resources:**

The Charlie Foundation for Ketogenic Therapies <u>www.charliefoundation.org</u> The goal of this non-profit organization is to facilitate investigations, educate professionals, and inform families about the ketogenic diet. The website includes recipes and online forums to help support and connect families.

#### Matthew's Friends Canada http://www.matthewsfriends.org/canada/

Originally based in the UK, Matthew's Friends Canada aims to support patients, families, and professionals living and working with Ketogenic Dietary Therapies.

Approved for circulation on Jan 2016 (lh)

You can join the BC Epilepsy Society as a member and receive all the program and service benefits. #610 – 4180 Lougheed Highway, Burnaby, BC V5C 4B3 Phone: (604) 875-6704 Fax: (604) 875-0617 info@bcepilepsy.com www.bcepilepsy.com