

# Frequently asked questions about the ketogenic diet

## 1. What is the ketogenic diet?

The ketogenic diet is a special high-fat diet that is used for difficult to treat seizures. Heavy cream, butter and vegetable oils provide the necessary fat. The diet also completely eliminates sweets such as candy, cookies, and desserts. Other carbohydrate rich foods such as bread, potatoes, rice, cereals, and pasta are not allowed on the strictest form of the diet, but are allowed on more liberal forms of the diet. All foods must be carefully prepared and weighed on a gram scale. Each meal must be eaten in its entirety for the diet to be most effective.

## 2. Who can be helped by the diet?

Children with seizures from infancy through the teenage years may be helped by the diet. There is no way to predict beforehand whether it will be successful. Traditionally the diet has been used for children with myoclonic, atonic and tonic-clonic seizures. In every decade since the 1920's, studies consistently show that 50-75% of children with difficult to control seizures of all types are helped by the diet. Children over the age of 5 years may find the diet difficult to follow due to its strictness.

## 3. How effective is the diet at controlling or eliminating seizures?

The diet has never been evaluated in a controlled scientific study. Studies that have followed children on the diet for long periods reveal that 1/3 of children treated with the ketogenic diet have greater than 90% seizure control with half of these children becoming seizure free. An additional 1/3 gain a 50% reduction in seizures. The remaining 1/3 discontinue the diet due to its ineffectiveness or its difficulty.

## 4. How does the diet work?

No one is certain how the diet works. A metabolic change occurs in the body which affects brain chemistry. One theory attributes the anti-seizure effect of the diet to the ketones that the ketogenic diet produces. Ketones are the products of fat breakdown. Our body normally burns glucose (sugar) for energy. The body can use these ketones as a source of energy instead of glucose. The ketones circulate through the blood in the body and then are excreted into the urine.

## 5. How is the diet prepared?

Ketosis is produced by eating a balance of foods that provide just the right amount of fat, protein and carbohydrates. A calorie level is determined by a dietitian for each child based on their age and activity level. To achieve a desired level of ketosis, the diet is calculated in terms of ratios such as 4:1, 3:1, and 2:1. In a 4:1 ratio, there is 4 times as much fat as there is protein and carbohydrate combined. The dietitian devises meal plans that complete the required fat, protein and carbohydrate for each meal. Each meal plan indicates the exact gram weight of each food which must be weighed on a gram scale. A typical meal includes a small amount of fruit or vegetable, a protein rich food, and a source of fat such as heavy cream and butter or vegetable oil.

## 6. Will anti-seizure medications be reduced after my child goes on the diet?

If the child is on more than one anti-seizure medication, one may be reduced as the child starts the ketogenic diet. The reduction of remaining seizure medication may be made if the child's seizures improve over time. Some children are able to have their medications completely discontinued. Medications may act stronger with the ketogenic diet therefore close medical monitoring is necessary.

## **7. How do you begin the diet?**

The diet is started under close medical supervision. The diet is begun gradually and increased to the full amount over a 3 to 4 day period. During this time blood sugar and ketone levels are monitored. A fasting period is not necessary to start the diet according to recent studies.

## **8. How soon does it take for the diet to reduce or eliminate seizures?**

The diet can become effective immediately or can take several months. Each child is unique and has different seizure patterns and frequency. There is usually improvement within the first 10 weeks on the ketogenic diet.

## **9. What would happen if my child “cheated” on his/her diet?**

If a child ate or drank something that was not part of his/her diet, they could experience a seizure within a short period of time due to a loss of ketosis.

## **10. Is the diet healthy for my child?**

The diet alone does not contain enough vitamins or minerals. A nutritional deficiency could develop without supplements. Special vitamin and mineral supplements are prescribed for each child while on the ketogenic diet. It is also important that the child drink adequate liquids while on the diet.

## **11. How long is the diet used for?**

The diet is generally used for a period of 2-3 years if it is helpful in reducing or eliminating seizures. If the diet is not helpful, it will be stopped within a few months.

## **12. Are there any adverse effects of the ketogenic diet?**

The most common adverse effect of the diet is constipation. There are dietary options to prevent this problem including eating high fiber vegetables that are allowed on the diet and drinking enough water. A less common adverse effect is kidney stones. This problem can be prevented by making sure that the child drinks adequate water. The two anti-seizure medications which can cause kidney stones should be avoided or monitored very closely with the ketogenic diet are Zonegran® and Topamax®.

## **13. Will my child gain too much weight with this high fat diet?**

The ketogenic diet is calculated at a specific calorie level for each child. The dietitian will keep track of your child's growth to determine if a change in calories is needed to ensure normal growth.

## **14. Will the diet cause high cholesterol?**

Most children do not develop high cholesterol levels while on the diet. If a child develops high cholesterol or lipids, the diet can be modified to lower these. Lipid levels are drawn prior to starting the diet and at regular intervals throughout the course of the diet.

## **15. Can the diet be used for children with feeding tubes?**

The ketogenic diet can be provided to children with feeding tubes. Special ketogenic formulas are designed for this purpose. A dietitian will determine the type and amount of formula for your child.

## **16. Are there any special tests that are needed before starting the diet?**

There are blood tests that may be needed to determine if the diet is safe for your child. These include metabolic tests to rule-out fatty acid disorders or a carnitine deficiency.

## **17. Are there other diets that can reduce seizures?**

The Atkins and the Low Glycemic Index diets are low carbohydrate diets that are less restrictive than the traditional ketogenic diet. Studies are in progress to determine how beneficial these diets are and who will benefit from them.

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