

Ketogenic Diet



This pamphlet contains general information for the public. It is not medical advice. All decisions about ketogenic diet treatment, or any therapy for epilepsy, should be made only after discussion with the treating physician.

Introducing: An Alternative Treatment for Epilepsy

Epilepsy is a disorder characterized by repeated seizure events in the brain. The most common method of treating and reducing these seizures is to take anti-epileptic medications. In many cases of epilepsy, the medications may cause allergic reactions, undesirable side effects, or simply not be very effective.

Medications are usually the first avenue of treatment; however there are other alternative therapies that are commonly practised. Surgery to remove a small area of the brain may be an option if the neurologist believes it has potential to help reduce the seizures. Another alternative is the vagus nerve stimulation

(VNS) implant. This device makes use of the vagus nerve in the body to send electrical signals to the brain. And then, there is the ketogenic diet.



The Ketogenic diet is often suggested for children between the ages of one and twelve that have intractable epilepsy (hard to control). Usually these children have myoclonic, atonic, tonic-clonic seizures or Lennox-Gastaut syndrome and are refractory to many other anti-epileptic treatments. In most cases, the child would have had ineffective responses or undesirable side effects to different anti-epileptic medications. It may also be prescribed to some adults; however the high diet restrictions may prevent them from following this diet. There are also some differences in the metabolism of fats and production of ketones between adults and children.

The usual length of the diet is 2-3 years. A normal diet is slowly re-introduced toward the end of this period depending on the progress of the child.

Goal: The Ketogenic Diet is designed to control seizures by making changes in the diet. It is a high fat, low carbohydrate, low protein diet that mimics starvation in the body and changes the way the body gets its energy from food. It will still be necessary for the child to be on anti-epileptic medications; however the dosage and number of drugs prescribed is often much less than without the diet.

The Ketogenic Diet

The ketogenic diet works by replacing a large percentage of the energy gained by the body from carbohydrates and proteins in the diet with energy from fat (fatty acids and triglycerides). The potential energy contained in food that can be used by the body upon metabolism is measured in units called calories (kilocalories).

Ordinarily, the body uses glucose from carbohydrates for immediate energy. There is approximately one day's worth of glucose store in the body. Once the stored glucose is used up, the body must start to breakdown fatty acids and triglycerides in order to provide enough energy.

In general, the ratio of fat to carbohydrates and proteins is three to four times. This ratio must be tailored specifically for your child. A neurologist and dietician will work together to decide the best ratio for each individual child.

There are many aspects of the Ketogenic diet that are unknown. Doctors are still not certain the exact mechanism of how it works. They are not sure why this diet that encourages the body to use fat for energy and minimise energy obtained from outside sources of glucose can help prevent seizures. In addition, they are not sure why this diet is effective for some children over others.

While much is unknown about this diet, it has been shown to be effective in children who have poor response to other treatment options. After following this diet, up to 75% of children with intractable epilepsy experience reduced seizure activity. While they will still be on anti-epileptic medication, the dosage is often much reduced and the number of drugs taken is often less.

History

Restricting dietary intake and fasting to reduce seizures has been practised for thousands of years. In the 1920s, the ketogenic diet (as a diet) was first examined and developed. It was widely used until the 1940s when the discovery of anti-epileptic drugs provided an easier and effective treatment rather than heavy dietary restrictions.

In the past ten years, with the increasing number of children who have become resistant to anti-epileptic medication, the ketogenic diet has been reintroduced as an effective way to control seizures.

Beginning the Diet: Stage 1

Before the ketogenic diet begins, the neurologist will weigh carefully your child's progress with his/her medications. He/she will also check to confirm if your child has been diagnosed with the right seizure type (many types of seizures have similar symptoms). If the neurologist believes that the medications are not controlling the seizures well enough and that there are no other alternatives the ketogenic diet may be suggested.

It is the parents' choice if they choose to follow use of this treatment for their child. If there are any questions or uncertainties you should consult your neurologist or even a second opinion, if necessary. The ketogenic diet is a strict diet. Any

variation from the regular routine can cause the return of seizures. Parents must understand this before they choose this method of treatment for their child.

Once you and the neurologist have decided that this is the best alternative for your child, the process will begin.

The Ketogenic Support Team:

The ketogenic should not under any circumstance be administered on your own. It requires careful monitoring by a medical support team. Key members of this team include your neurologist as well as the dietician.

What happens next:

The diet will begin with your child in a hospital with a Ketogenic Centre. However, not all treatment centers and hospitals require hospitalization to start the ketogenic diet. A 24-hour fast will be necessary at the start in order for the body to use up all of the glucose available.

The neurologist and dietician will then work together to formulate the right ratio of fats to proteins and carbohydrates. The dietician will be able to provide you with different sample meals that you can make for your child.

When you go home:

It is important that you carefully weigh each food item using a gram scale. Even the slightest deviance from the correct portions can result in a seizure. A little bit of extra sugar, or even medicines like cough syrup (which can contain sugar and alcohol) can throw the diet off track.

The dietician will help guide you and your family through how to properly choose and weigh foods for your child.

You will also be given some special paper strips to help measure the ketone level's in your child's

urine. Ketones are produced by the body when it burns fat.

Sample Diet

Here are a few examples of sample diets (the proportions have been left out because it is essential that this information be calculated by your neurologist and dietician). These meals contain a large percentage of fat along with much smaller portions of protein and carbohydrate.

Breakfast:

Scrambled eggs with butter
Diluted cream
Orange juice

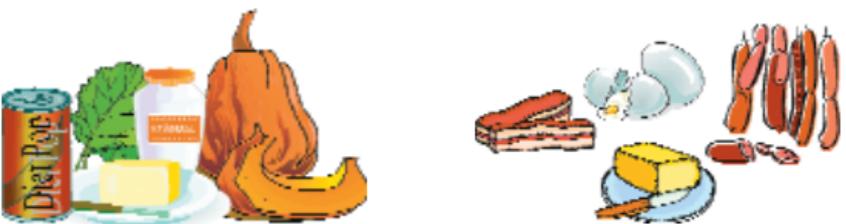
Lunch:

Spaghetti squash with butter and Parmesan cheese
Lettuce leaf with mayonnaise
Orange diet pop mixed with whipped cream

Dinner:

Hot dog slices with sugar-free ketchup
Asparagus with butter
Chopped lettuce with mayonnaise
Sugar free vanilla cream popsicle

Note: The restrictions of this diet vary depending on the ratio of fats: proteins: carbohydrates prescribed by your doctor. Sometimes a few strawberries can be used for day's carbohydrates.



How Effective is the Ketogenic Diet?

The diet may not begin to work right from the beginning. Depending on how well it is controlling the seizures, the ratios of fats to proteins and carbohydrates may be needed to be adjusted.

The diet should reduce seizures and overtime your child's doctor may also gradually reduce the dosage of the medications being taken.

Figures:

Approximately 25% of children on the ketogenic diet become seizure-free or almost seizure free.

Approximately 50% of the children have a noticeable decrease in the frequency of their seizures.

Approximately 25% of children do not show any change in response or are unable to continue with the diet for a variety of reasons. These reasons may include difficulty tolerating the high fat content of the food or unpleasant side effects.

The doctor may recommend that you try the ketogenic diet for a period of two to three months before deciding to quit.

Is the Ketogenic Diet right for my child?

This diet is usually recommended when two or more anti-epileptic medications have failed to adequately control the seizures or result in harmful side effects.

Throughout the diet, you should remember that the goal is for your child to either be seizure free or to at least have reduced seizures after the diet has been completed.

Your child should also understand that this diet is going to help them control their seizures. Younger



children may have difficulty understanding why they cannot eat the sweets their friends are eating, but it should be stressed what will happen if they even eat a little crumb of something that isn't in their daily diet plan.

Doctors may suggest this diet, but if you have any reservations or feel that your child and/or family may not be able to maintain this regimen, then you should express these concerns to your neurologist.

Before undertaking the diet, you should think ahead to the future and see if this is an option for you and your family. The diet can be especially tough around the holidays, birthday parties, school, or other special occasions. It can also be tough if your child is a picky eater.

You should also be prepared to notify the school and teachers as well as the parents of your child's friends, so they know that he/she cannot eat anything outside of what you have prepared for him/her. This can be extremely tough. The best way is to prepare something for your child to bring when they go to a friend's house.

Benefits and Side Effects

Benefits:

- ✓ The prospect of reduced and more well-controlled seizures in your child
- ✓ The prospect of a possible reduction in anti-epileptic drug medication by the end of the treatment
- ✓ Return to normal eating habits after the diet 2-3 years while still maintaining the benefits of reduced seizures

Side Effects:

Like other medications and any other treatment method there is also the potential for side effects.

- ✗ Dehydration
- ✗ Constipation
- ✗ Bone thinning
- ✗ Kidney stones
- ✗ Liver problems
- ✗ Hair thinning

- ✗ Changes in behaviour
- ✗ Vomiting
- ✗ Slowed growth
- ✗ Low selenium and cardiomyopathy
- ✗ Movement disorders (Basal Ganglion Atrophy)

Throughout the process, the doctor will be monitoring your child for any of these side effects.

Also keep in mind that if your child does experience some side effects it will not be all of the ones listed but rather just a few.

Questions & Answers

1. Will my child gain weight?

Usually no. The doctors usually restrict weight gain to 1kg per year, at the most. The calories taken in by your child are carefully calculated. If there appears to be a dramatic increase in weight, then the calorie intake will be decreased. Your child should continue to grow accordingly with his/her height.

2. How long should I sit with my toddler before I give up trying to get him to finish all of his food?

Some meals may be finished in twenty minutes, others in a couple of hours. You must make sure that however long it takes, your child must eat all of the food. You have carefully weighed out all of this food according to the proportions given by the neurologist and it is essential to the diet that your child still eat everything otherwise they may risk a relapse.

3. Will taking prescriptions or other medicines affect the diet?

It is best to consult with your physician and/or pharmacist before giving your child any other medicine (prescription or over-the-counter). Some medications contain sugar and other carbohydrates. Even the small amounts of sugar that are found in toothpastes or vitamins may affect the progress of the diet and increase the frequency of seizures. Read the labels of the medication. They should list all the ingredients. If uncertain, do not hesitate to ask your pharmacist.



4. Does the diet cause a problem with high cholesterol?

The levels of cholesterol and triglycerides in the body will increase, however this is not a permanent diet. The diet lasts from 2-3 years. At the end of the diet, the cholesterol and triglyceride levels in most children return to pre-diet levels.

5. What can my child eat at school?

The dietician will work with you to plan some meals that your child can take with him/her to school. After a period of adjustment you will be able to tell which foods your child will like and pack his/her lunch accordingly. Food can easily carry to school in plastic containers or foil wrap and in an insulated lunch bag.

For school activities, make sure your child's teachers understand that he/she cannot eat anything other than what you have sent from home. It is also important that your child understands this. If you know of an event ahead of time, you can prepare something for your child to bring so they can eat and not feel left out.

6. What about special holidays like birthdays and Thanksgiving?

For the holidays, ask your dietician for some recipes that will keep the theme of the celebration while still allowing your child to follow the diet properly.

Certain times of year like Halloween or during the winter holidays can be especially tough. If your child enjoys Halloween, let them dress up and go around with their friends, but offer to give them an alternative treat in exchange for the candy they have collected. Perhaps they can be given a new toy or treated to a movie or extra pocket money.

Also make sure that your relatives and friends know that during other holidays they should not bring your child candy or other food.

7. What happens if my child cheats on the diet?

Sometimes a slip in the diet may happen. This can be unintentional or intentional. In either case, often it may be possible to find out what the “extra” snack was and calculate the rest of the day’s meals accordingly. Depending on what the snack was the resulting reaction may vary from no change to an increase in seizure frequency. This is why it is important that your child must understand the commitment to the diet.

8. What if my child is lactose intolerant?

There are modified versions of the standard ketogenic diets that your dietician can provide you. Being lactose intolerant may reduce the choices of foods your child can eat since they won’t be able to have the heavy cream etc., however it is still possible to successfully undertake the diet even with this limitation.

Tips

- ★ Your child may not like the diet at first and refuse to eat. Younger children may have difficulty understanding the importance of eating all the food at every meal. You must insist that they eat everything as this is essential to the diet.
- ★ Try to make your child’s most favourite foods in the diet.
- ★ You can also try to arrange and cut them into different shapes and make it more appealing.
- ★ Other suggestions may include arranging it on a smaller plate to make the portions look larger or distracting your child with a favourite movie or game and have them eat at the same time.
- ★ When your child goes to visit a friend, pack them a special snack that they can take with them.



Recap

1. Usually, the diet will begin with your child in a hospital with a Ketogenic Centre. However, not

- all treatment centers and hospitals require hospitalization to start the ketogenic diet.
2. The neurologist will assess your child and may instruct him/her to fast for 24 hours (this whole process will be constantly monitored)
 3. The neurologist will work with the dietician to recommend foods to be introduced into the diet that are high in fat content
 4. The diet will slowly be introduced to the child in hospital and monitored to see how he/she will react to the change
 5. At home, the parents will follow the instructions and weigh the food properly as well as balance it with the other elements in the diet. Vitamins are also usually prescribed to ensure that the child is getting his/her daily amount.
 6. The urine of the child will also have to be constantly monitored in case there is any blood. This could indicate kidney stones.
 7. The child's progress will be constantly monitored by the doctor to make sure that he/she is progressing well
 8. After 2-3 years, a normal diet is usually reintroduced gradually.

Resources



The Ketogenic Diet: A Treatment for Epilepsy, 3rd Edition
by [John Mark Freeman](#), [Jennifer B. Freeman](#), [Millicent T. Kelly](#), [Jim Abrahams](#).

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Brochures can be ordered on-line at www.epilepsy.ca or through your local epilepsy association.



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