



KETOGENIC DIET FOR EPILEPSY

ABOUT THE EPILEPSY FOUNDATION

The Epilepsy Foundation is a national voluntary agency solely dedicated to the welfare of the nearly 3 million people with epilepsy in the U.S. and their families and caregivers. We work to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through services, education, advocacy and research. In addition to programs conducted at the national level, people with epilepsy are also served by local Epilepsy Foundation affiliates across the country.

If you have any questions about epilepsy and seizure disorders, living with epilepsy, or helping a friend or family member who has epilepsy, please visit us at www.EpilepsyFoundation.org, or call 800-332-1000.

Our website has comprehensive information about epilepsy and seizures and offers opportunities to connect with other people affected by epilepsy through our eCommunities forums and Web events. Our online publication, epilepsyUSA, is a quarterly digital magazine that reports on developments for people affected by seizure disorders—new treatments and medicines, ground-breaking research, safety tips, personal stories, advice for parents and more.



A DIFFERENT KIND OF TREATMENT

Most people who have seizures, also known as epilepsy, take medicine to prevent seizures.

If the medicines don't work, or cause bad side effects, doctors may recommend other types of treatment. They may suggest surgery to remove the part of the brain where the seizures begin. They may suggest vagus nerve stimulator (VNS) therapy that consists of an implanted device to send electrical signals to the brain via a nerve in the neck.

Or they may suggest trying the ketogenic diet.

The ketogenic diet changes the way a person's body gets energy from food. It's usually tried in children between the ages of one and twelve years who have seizures that are hard to control, or have certain kinds of syndromes, such as glucose transporter or pyruvate dehydrogenase deficiencies.

Some children have fewer seizures on the diet. Some stop having seizures altogether. Some continue to have seizures despite the diet. In recent years, a few adults have chosen to try the diet, but it is more often prescribed for children and adolescents, and even babies.

WHAT THE DIET DOES

Normally, our bodies run on energy from glucose, which we get from food. We can't store large amounts of glucose, however. We only have about a 24-hour supply.

“More and more doctors are suggesting the ketogenic diet to families. Our doctor suggested it after our son had showers of seizures, despite being on several different medications.”



“The diet was a challenge for my child. Kids on the diet can’t eat things like cake or pizza. But it’s worth it because the seizures were gone with the diet.”

When a child has no food for 24 hours, he or she uses up all the stored glucose. In fact, a child beginning the ketogenic diet usually fasts for about a day, usually in a hospital. With no more glucose to provide energy, the child's body begins to burn stored fat. The ketogenic diet keeps this process going.

It forces the child's body to burn fat around the clock by keeping calories low and making fat products the primary food that the child is getting.

In fact, the diet gets most (90%) of its calories from fat. The rest comes from carbohydrates and protein.

Each meal has about four times as much fat as protein or carbohydrate. The amounts of food and liquid at each meal have to be carefully worked out and weighed for each person.

Doctors don't know precisely why a diet that burns fat for energy should prevent seizures, although this is being studied. Nor do they know why the diet works for some children and not for others.

More than 80 years ago, there were reports that seizures could be prevented by fasting, a discovery which led to the development of the ketogenic diet. The diet mimics what the body does when deprived of food.

It was used widely until effective medications to prevent seizures were developed. For most people, it was easier to take pills or tablets than to make major changes in diet.

Families and doctors became aware of the ketogenic diet again in the 1990s. Film producer Jim Abrahams made a TV drama based on the experiences of his son whose seizures were successfully controlled by the diet.

As demand for the diet grew, researchers began to study it. It's now offered at many medical centers and by individual physicians familiar with its use.

THE KETOGENIC TEAM

When children (or adults) are treated with the ketogenic diet, the dietician is a very important member of the medical treatment team. That typical treatment team consists of a physician, nurse, dietician and nutritionist.

The dietician works out how much of one type of food or another should be combined to make the diet work. In helping the family plan the child's meals, the dietician also calculates how many calories the child needs for growth.

Meal plans combine small amounts of fruits or vegetables (carbohydrates), meat, fish or chicken (protein), lots and lots of fat (often in the form of cream, butter, eggs, or mayonnaise) and no sugar.

The following sample meal plans provide a general idea of how these are combined.

Breakfast

Scrambled eggs with butter
Diluted cream
Orange juice

Lunch

Spaghetti squash with butter and parmesan cheese
Lettuce leaf with mayonnaise
Orange diet soda mixed with whipped cream

Dinner

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

These examples don't show the exact amounts of each food because those have to be tailored for each child by the dietitian.

Each portion of food must be prepared very carefully by the parents, by using a gram scale to weigh items exactly.

A tiny mistake in weighing and measuring foods (sneaking foods or taking anything containing sugar including medicines and toothpaste in his/her mouth), can break the diet's effects and cause a seizure.

CHANCES OF SUCCESS

Often, a period of fine-tuning is needed before it's clear whether or not a child is going to respond to the ketogenic diet.

Doctors often ask parents to try the diet for at least one month, and even as long as two or three months, before deciding whether the diet is or is not working.

A child on the diet usually continues taking anti-seizure medicine, but may be able to take less of it if seizures decrease after starting the diet.

If a child does very well, the doctor may slowly taper the medication with the goal of discontinuing it altogether.

About a third of children who try the ketogenic diet become seizure free, or almost seizure free. Another third improve but still have some seizures.

The rest either do not respond at all or find it too hard to continue with the diet, either because of side effects or because they can't tolerate the food.

A side benefit of the diet is that many parents say their children are more alert and make more progress when on the diet, even if seizures continue.

If the diet seems to be helping, doctors will usually prescribe it for about two years. Then, they may suggest that parents slowly begin including regular food in the child's diet to see if the seizures can still be controlled, even with a normal diet.

Sometimes a small amount of seizure medication is started again after the diet is stopped. However, some children may be able to stay seizure free without any further treatment. If the seizures return, the doctors may recommend putting the child back on the diet.

“One of my patients’ families learned how strict the diet is when they fed their little girl seven macadamia nuts one day instead of three as part of her meal plan. This seemingly small miscalculation caused her to go into seizures.”



“My child was so sensitive to medication and it wasn’t even working. So we tried the diet. Eventually, we learned the reason she never responded to medication was that her seizure type was misdiagnosed. Until we found the right medication for her seizure type, the diet worked beautifully as a stop-gap measure to reduce seizures. The diet was our safety net. Today, she is off the diet and takes a small amount of medication.”

WHO SHOULD TRY THE DIET?

Most experts say the diet is worth trying when two or more medications have failed to control seizures, or when medications cause side effects that are having a harmful effect on a child's life.

It also helps to have a child who is willing to try foods that he or she might otherwise not be enthusiastic about, and is tolerant and not fussy about eating.

The diet seems to work for more than one kind of seizure, and for children who have either many or few seizures.

But most doctors say it shouldn't be used instead of medications if the drugs are working and the child is not having bad side effects.

Parents generally decide to try the diet because they hope it will give their children a better chance for a normal life. However, the diet can be a barrier to some normal life experiences for children, especially those that revolve around food and holidays. And, like other treatments for epilepsy, it also can have side effects that affect some children more than others (see page 9). So, as with any kind of treatment, there's a lot to think about before deciding to try the diet.

Going over all the possibilities with your doctor is the best way to make the decision. It may also be helpful to talk with other parents whose children have been on the diet.

“The diet is a lot of work for the family. I was worried about emotional food scars on my child because our family could eat anything we wanted but my child had to be so strict about eating.”

IMPORTANT: DON'T TRY IT ALONE

The ketogenic diet has special appeal to families because changing what a child eats seems like a more “natural” way of preventing seizures than taking pills.

But the diet is anything but natural. It is a highly unnatural choice of foods and it reverses the body’s natural way of using food to gain energy.

In fact, the ketogenic diet, like taking medications or having surgery, is a serious medical treatment.

It is not a “do it yourself” diet.

Trying to put a child on the diet without medical guidance puts a child at risk of serious consequences. Every step of the ketogenic diet process must be managed by an experienced treatment team, usually based at a specialized medical center.

GETTING STARTED

The diet usually starts in the hospital with a 24 hour fast, although sometimes the ketogenic diet team opts to start it as an outpatient.

The child is closely watched to be sure he or she is handling the stress of not getting any food during that time.

The blood glucose is checked to make certain it does not become too low.

Once the child begins burning fat for energy instead of glucose (a state called ketosis) the doctors gradually introduce the foods that are part of the diet in amounts that are right for that child.

There are some centers that start the diet without the 24 hour fast. It may take a little longer for the diet to take effect. When the child goes home, the parents continue to carry out the diet at home, weighing every item and making sure that the balance between fat and other nutritional elements is maintained. Doctors and dieticians follow the children closely to make sure they’re getting enough nutrition and are growing.

Caregivers use special paper strips to check the ketone level in the child’s urine.

Ketones are the chemicals that the body produces when it burns fat. Parents also test the urine weekly for blood, which could be an early sign of kidney stones, a possible side effect of the diet.

“My son was too sleepy on his medicines. He continued to average about 20 seizures a month while on medication. He was not a candidate for surgery because his seizures came from the speech area of his brain. So we tried the diet. He showed real willpower to follow the diet.”

SIDE EFFECTS

Like all the other treatments for epilepsy, the ketogenic diet has some side effects, which may or may not affect a particular child. Some side effects may go away if caught and managed early on. Knowing what to look for can make a big difference.

Reported side effects include dehydration, constipation, and, sometimes, complications from kidney stones or gall stones.

Adult women on the diet may have menstrual irregularities. Pancreatitis (inflammation of the pancreas), decreased bone density and certain eye problems have also been reported. Again, this is why the medical team closely follows children or adults who are on the diet.

The diet lacks several important vitamins that have to be added through supplements. Some of the commercial preparations such as KetoCal are supplemented with the necessary vitamins, but most nutritionists and physicians recommend a multivitamin that meets all of the requirements.

Sometimes high levels of fat build up in the blood, especially if a child has an inborn defect in his ability to process fat. This possibility can lead to serious effects, which is another reason for careful monitoring by the healthcare team.

“We tried the diet with our daughter because her medications were making her lethargic. We wanted to give her a chance to be aware of her surroundings and to be back with us again.”



Vitamin supplements are used to make up for vitamins that the diet lacks.

FREQUENTLY ASKED QUESTIONS

Q. Will my child gain weight from eating so much fat?

A. On this diet, the amount of food is carefully weighed so that your child will eat all the calories he or she needs for good health, but not so many that he or she gains weight. The fat content of the food doesn't affect weight if you strictly limit total calories.

Q. How long should I sit with my toddler before I give up trying to get him or her to finish all the food?

A. Some parents report that mealtimes on the diet can wrap up in twenty minutes, while others say they have to sit with their children for two hours before all the food is finished.

A child must finish all the food because the meal is put together in amounts that will give him or her the right balance between fat, protein and carbohydrates. If it's not all eaten, the balance is lost, and the child may have a seizure.

Since this is important, parents often try tricks like playing a video during meals or playing games to distract the child while they're encouraging the child to eat.

Parents who've been successful advise others to use the diet creatively, and try to offer something new and special for each meal to keep the child's interest.

Older children, who know that the diet is helping to keep their seizures away, may be more cooperative.

Q. Will taking prescription or other medicines affect the diet?

A. All medicines and pharmaceuticals, from toothpaste to cough syrup to vitamins to prescription medicine, must, whenever possible, be free of sugar and other carbohydrates. Remind your doctor to prescribe all needed medications in sugar-free and carbohydrate-free forms.* Read labels carefully and check with your pharmacist.

*An article in the Journal of the American Dietetic Association lists how much carbohydrate is in commonly used medicines. The reference is McGhee B, Katyal N. Avoid unnecessary drug-related carbohydrates for patients consuming the ketogenic diet. *J Amer Diet Assn* 2001;101(1):87-101.

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

A. When children are switched from a normal diet to a 90% fat diet, both cholesterol and triglyceride levels can go up. However, for most children, the ketogenic diet is not a lifetime diet. Children stay on it about two years. When weaned off the diet, most children return to their pre-diet

levels. There are some medical conditions that require long-term or life time use of this diet.

Q. How does my child explain the diet to his friends?

A. Young children say, “I’m a special kid on a special diet.” Older children can impress their friends by telling them about all the shakes, cheesecakes, pancakes and omelets they get to eat on their special diet.



Q. What can my child eat at school?

A. Your dietician will help you plan meals that can go to school with your child. Tuna, egg, or chicken salads are easy to carry in small plastic containers. Warm or chilled food can be carried in a small cooler or insulated bag or wrapped in foil.

There are many celebrations at school that involve food. It's very important for all the teachers and aides to know that your child cannot have the same treats that the other children get. You may want to ask school personnel to let you know in advance when treats are planned so that you can send a keto-correct treat for your child.

It's a good idea to have a meeting with your child's teachers and everyone your child comes in contact with at the beginning of every school year. Make them understand that even half a cookie or a bite of cupcake can lead to the loss of seizure control and perhaps even hospitalization.

Post a notice at school: *This child must not be fed anything not brought from home.*

Q. What about special holidays like birthdays and Thanksgiving?

A. The dietician will be able to give you special recipes to keep the mood festive while allowing children to stick to the diet. If your doctor or dietician is treating other children on the ketogenic diet, those parents may have good ideas to share with you. However, always check with your child's dietician before trying something new.

One family offers the following suggestion for Halloween, which is all about candy and sugary treats. They let their keto kid go trick or treating like the other neighborhood children, but when the child gets home, the parents buy back the candy and the child then uses the money to buy a special toy.

PARENT TIPS FOR SUCCESS:

- ◆ Don't be too worried about the initial fasting process when starting the diet; most children handle it surprisingly well because of the promise of fewer seizures.
- ◆ Getting into a routine when fixing meals should make things easier.
- ◆ Involve your child in measuring his food by guiding him while he places food on the gram scale.
- ◆ Your child may feel hungry (because the diet restricts calories) and may try to sneak food from the refrigerator, and even from the pet's dish. Using water with saccharine, and splitting meals in half may help fight hunger pains.
- ◆ Use a salad plate to present each meal, because the smaller plate makes it look as if the child is getting more food.
- ◆ If your child loves dessert, always keep a stock of homemade cream popsicles in the freezer. These are then calculated into meal plans.
- ◆ Keep a few prepared keto meals in small plastic containers in the fridge. Label them carefully for your older child's use if you are not home or your child goes to a friend's house.
- ◆ Steam vegetables for best nutritional value.
- ◆ Because some liquids are also restricted by the diet, check with your doctor about how to handle days when it's hot and your child perspires more than usual.
- ◆ Be creative with meal choices!
- ◆ Cut foods into interesting shapes to make them more appealing.
- ◆ Ask your child about her favorite keto food and serve it as a treat (but according to the overall meal plan).
- ◆ Praise your child often for being so cooperative and sticking with the diet.



Epilepsy Foundations throughout the country have additional materials and offer a variety of programs to help people understand this common disorder.

For further information about epilepsy and the name of the Epilepsy Foundation nearest you, log on to **www.epilepsyfoundation.org** or call **800-332-1000**.

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.

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