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## Development of a Modified-Atkins Ketogenic Diet Educational Handbook for Children With Epilepsy

Sydney Kayler

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DEVELOPMENT OF A MODIFIED-ATKINS KETOGENIC DIET EDUCATIONAL  
HANDBOOK FOR CHILDREN WITH EPILEPSY

By

SYDNEY KAYLER

B.S.F.C.S., The University of Georgia, 2020

A Master's Project Submitted to the Graduate Committee  
in the Department of Nutrition at Georgia State University in Partial Fulfillment  
of the  
Requirements for the Degree

MASTER OF SCIENCE

ATLANTA, GEORGIA

2021

## HISTORY OF THE KETOGENIC DIET

Since the 5<sup>th</sup> century BC, fasting and other dietetic regimens have been utilized as therapeutic measures to treat epilepsy. In the Hippocratic collection, it is noted that a man who had been afflicted with epileptic convulsions was prescribed “complete abstinence from food and drink,” and was cured of his ailment.<sup>1</sup> While ancient medical practitioners each held different philosophies on which dietary intervention was most effective, fasting maintained its place as a treatment for epilepsy into biblical times. As documented in the book of Mark, when a child is brought upon Jesus with convulsions, “...this kind can come out by nothing but prayer and fasting.”<sup>2</sup>

A study by two Parisian physicians in 1911 is often cited as the first modern use of starvation to treat epilepsy, although the intervention applied would today be better classified as intermittent fasting. The diet prescribed in the study consisted of 4 days with no food but unlimited beverage intake plus a 30 g/day administration of sodium sulphate, a laxative, followed by 4 days of a vegetarian diet. The authors report that seizure activity was less severe during their treatment, however no data was presented.<sup>3</sup> The idea of intermittent fasting to treat epilepsy was also present around this time in the United States. For several years, Dr. Hugh W. Conklin, an osteopathic physician, claimed to have treated hundreds of patients with epilepsy by prescribing fasting as a treatment; however, he did not maintain adequate records of the severity of seizure activity before and after the fast.<sup>4</sup> Despite the inconsistent documentation of Conklin’s experience, it garnered the attention of Dr. H. Rawle Geyelin, an endocrinologist, who then adopted fasting as a treatment for epilepsy. Geyelin reported at the American Medical Association Convention in 1921 his preliminary success in 20 out of 26

epileptic patients who fasted.<sup>4</sup> This presentation propelled research of the subject forward, resulting in the discovery of the ketogenic diet rather than simple fasting as an intervention.

Following the presentation, Dr. Stanley Cobb, an associate professor of neuropathology at Harvard Medical School, was approached by the parents of one of Geyelin's patients who asked him to explain the mechanism behind the success of starvation on seizure activity. Cobb conducted a study with the assistance of W.G. Lennox, in which they determined that patients who had undergone a 14-day fast showed an increase in serum uric acid and acidosis that would only be excreted if the fast was broken with carbohydrate or purine-free protein intake, but not if broken by the intake of 40% cream. It was also discovered that these serum concentrations developed around day 2 to 3 of the fast and were accompanied by a decrease in seizure activity.<sup>5</sup>

Simultaneously, two other key discoveries were made regarding the mechanistic action of starvation in the treatment of epilepsy. R.T. Woodyatt, a physician, was researching diet adjustments in diabetes and noted that the presence of serum uric acid and acidosis were present in both patients subject to starvation and patients who consumed too low a proportion of carbohydrates and too high a proportion of fat.<sup>6</sup> R.M. Wilder, a physician at Mayo Clinic, was examining Dr. Geyelin's findings and concluded that the beneficial effects were dependent on ketonemia. He acknowledged that ketonemia occurred when "a disproportion exists between the amount of fatty acid and the amount of sugar ... burning in the body."<sup>7</sup> With the knowledge that it was possible to provoke ketogenesis by high fat-low carbohydrate feeding regimens, Wilder suggested that the "ketogenic diet" should be used to treat epileptic patients. His

personal trials with such diet resulted in a dramatic reduction in seizure incidence among three refractory epileptic patients.<sup>8</sup>

Following Wilder's success, M.G. Peterman, a pediatrician, proposed the initial calculations for the intervention in children: 1 gram of protein per kilogram body weight, 10-15 grams of carbohydrates per day, and the remaining calories from fat. He also advocated for the importance of educating caregivers on the diet before discharge, individualization, and close monitoring and evaluation.<sup>9</sup> For the next two decades, the ketogenic diet saw a rise in popularity among pediatricians, with almost every textbook on epilepsy in children including a description of the diet and guidance on initiation and calculations.<sup>5</sup>

However, with the discovery of new antiepileptic drugs in 1938, focus shifted away from the ketogenic diet. Many physicians believed that medications were easier to administer than the diet, with one physician noting that they found the diet "difficult, rigid, and expensive."<sup>10</sup> Use of the diet became less commonplace over the next several decades, until it resurfaced in 1994 due to national exposure on NBC's *Dateline*. The episode featured the story of Charlie Abraham's, a two-year-old with intractable myoclonic, generalized tonic, and tonic-clonic seizures. His father shared how after visiting several physicians, trying numerous medications, and undergoing surgery, Charlie's seizure activity did not improve, and he was faced with a prognosis for continuous seizures and progressive intellectual disabilities. Mr. Abraham's sought out other treatments on his own and discovered the ketogenic diet, which was still in use in the epilepsy center at Johns Hopkins under the supervision of Millicent Kelly, RD. Charlie was brought to the hospital and the ketogenic diet was initiated in 1993. Soon, he became seizure free and saw developmental progress.<sup>11</sup> As a result, Mr. Abraham's founded The Charlie

Foundation, which is still active today, to provide information about diet therapies for people with epilepsy, other neurological disorders, and select cancers.<sup>12</sup>

The awareness brought by Charlie Abraham's story led to the reemergence of the ketogenic diet. Modern research has established the diet as an effective treatment for epilepsy, however many physicians still believe that the diet should be used a last resort due to its rigorous and demanding protocol.<sup>13</sup> Future initiatives are needed to improve the perception of the ketogenic diet among medical professionals. Still, the ketogenic diet as a treatment for epilepsy is gaining momentum and is available nearly worldwide.<sup>14</sup> As clinical use of the diet has grown over the last three decades, so has research on the subject. Between 2010 and 2020, the number of journal articles published examining the ketogenic diet and epilepsy was over twice that of the previous decade, and over ten times the number of published articles between 1990 and 2000.

Despite the increase in research and utilization of the ketogenic diet for the treatment of epilepsy, the mechanism by which it decreases seizure activity is still poorly understood. However, several hypotheses have been studied to explain the phenomenon. Ketone bodies, consisting of acetoacetate and  $\beta$ -hydroxybutyrate, have traditionally received the most attention as the primary mediators of antiseizure activity effected by ketogenic diet therapy.<sup>15</sup> Under normal conditions, glucose metabolism in the brain produces rapidly available energy that is required for seizure activity. It is believed that when blood glucose levels are low, the anaerobic metabolism of ketone bodies decreases energy availability, thus reducing seizure activity.<sup>16</sup> Other proposed mechanisms focus on increased synthesis of gamma-aminobutyric acid (GABA), the major inhibitory neurotransmitter. Two explanations exist for the increase in

GABA synthesis: 1) metabolism of ketone bodies in the brain results in reduced production of aspartate from glutamate, increasing glutamate availability for GABA synthesis, 2) modification of the gut microbiota by a decrease in alpha-diversity results in decreased gamma-glutamyl amino acids in the blood, increasing glutamate and GABA concentration in the brain.<sup>17</sup> Although current research is not conclusive as to how the ketogenic diet reduces seizure activity, it is likely that a combination of metabolism-altering mechanisms is responsible for its efficacy. Future research is necessary to gain a more complete understanding of how the therapy reduces neuron excitability.

#### **TYPES OF KETOGENIC DIETS FOR CHILDREN WITH EPILEPSY**

There are currently five variations of the ketogenic diet, these include the classic ketogenic diet, the modified ketogenic diet, the medium chain triglyceride (MCT) diet, the modified Atkins diet (MAD), and the low glycemic index treatment (LGIT) diet. The different types of ketogenic diet vary in the ratio of grams of fat to combined grams of carbohydrate and protein, but all are high fat-low carbohydrate diets that require medical supervision and the use of vitamin and mineral supplements.<sup>18,19</sup> The type of ketogenic diet prescribed should be individualized and based on the child and family situation.<sup>20</sup>

The classic ketogenic diet, initially proposed by Wilder and Peterman, is the most restrictive type of ketogenic diet. However, it may offer higher ketogenic potential than other forms. This diet requires all foods and beverage to be precisely calculated and weighed on a gram scale that is accurate to a tenth of a gram. It utilizes a 4:1 or 3:1 ratio of grams of fat to combined grams of carbohydrate and protein.<sup>21</sup> The modified ketogenic diet is a less restrictive

form of the classic ketogenic diet. It utilizes a 2:1 or 1:1 ratio of grams of fat to combined grams of carbohydrate and protein. This form of the diet is designed with flexibility in mind to support compliance.<sup>22</sup>

The MCT diet is a more liberal form of the ketogenic diet, using an approximately 1:1 ketogenic ratio, with less restrictive carbohydrate intake due to high intake of MCT-rich fats. MCTs yield more ketones per kilocalorie than long chain triglycerides (LCT), allowing for greater inclusion of carbohydrates and protein. This allows for a wider range in food choice, but foods still must be weighed or measured to ensure adherence to the diet.<sup>19,20,21</sup> Traditionally, the MCT diet included 60% of total energy intake from MCTs. However, this caused gastrointestinal discomfort in some children, so a modified MCT diet was created.<sup>23</sup> The modified MCT diet utilizes 30% of total energy intake from MCTs and 30% from LCTs. Individual toleration to the MCT diet should be assessed to determine what percentage of total energy should come from MCTs. Some children may be placed on a 40-50% MCT diet, rather than either the traditional 60% or modified 30%. Due to gastrointestinal side effects that occur with consumption of high concentrations of MCT oil, this type of ketogenic diet is less commonly used in the United States. However, because of the beneficial effects of MCTs on ketone formation, small concentrations of MCTs are sometimes incorporated into the classic ketogenic diet, the MAD, and the LGIT diet.<sup>21</sup>

The MAD typically provides a 1:1 to 2:1 ketogenic ratio, but no set ratio is required, so it can be variable. Instead, the diet dictates net carbohydrate intake to 10-15 grams per day in pediatric patients and 20 grams per day in adolescents and adults. The MAD does not limit protein intake, although too much is discouraged, making it a more lenient diet that makes



adherence easier.<sup>20,21</sup> It also does not require the use of a gram scale. Carbohydrate intake is instead measured by standard household measurements. The MAD is typically used in older children and adolescents due to its flexibility. Despite being less restrictive than other types of ketogenic diets, a net intake of 10-15 grams per day of carbohydrates has been shown in practice to be overwhelming to some patients. Because of this, a variation of the MAD created by Robyn Blackford, RD, at Lurie Children's Hospital of Chicago is becoming more widely used among ketogenic dietitians. This variation requires average daily carbohydrate intake to be estimated from a 3-day diet history, which is then decreased by 50%. After the initial reduction, carbohydrate intake is decreased by 10 grams each week until either adequate seizure control is achieved, total daily carbohydrate intake equals 30-40 grams, or the patient does not tolerate further carbohydrate restrictions.

The LGIT diet utilizes a 1:1 ketogenic ratio but places emphasis on low glycemic index carbohydrates. It is not intended to promote ketosis, but instead focuses on maintaining steady glucose levels.<sup>19</sup> Daily carbohydrate intake is limited to 40 to 60 grams per day of foods with a glycemic index less than 50.<sup>21</sup> The rationale behind consuming low glycemic index foods is to prevent rapid changes in blood glucose and insulin levels.<sup>24</sup> Protein intake is not regulated, but the diet encourages fat intake and discourages high protein intake. Like the MAD, carbohydrate intake on the LGIT diet is measured by standard household measurements.

## **INDICATIONS FOR USE OF THE KETOGENIC DIET**

The ketogenic diet as a therapeutic intervention for epilepsy is usually indicated after a patient has tried a second antiepileptic medication without improvement in seizure activity.<sup>20</sup>

The diet is indicated for patients of any age, including infants, if drug treatment failure occurs and the epilepsy is classified as drug-resistant epilepsy (DRE).<sup>25</sup> There are some exceptions to this guideline, as consistent evidence has shown that for several conditions, early initiation of the diet is more beneficial. These conditions include: Angelman syndrome, complex I mitochondrial disorders, Dravet syndrome, Doose syndrome, GLUT-I deficiency syndrome, febrile infection-related epilepsy syndrome, infantile spasms, Ohtahara syndrome, pyruvate dehydrogenase deficiency, super-refractory status epilepticus, and tuberous sclerosis complex. A diagnosis of any of these conditions could be an indication for early use of the ketogenic diet; patients with one of these conditions do not necessarily have to first attempt two antiepileptic drugs before being considered a candidate for the ketogenic diet. However, cases should be assessed on an individual basis by the multidisciplinary care team. For GLUT-I deficiency syndrome and pyruvate dehydrogenase deficiency, the ketogenic diet should be the initial treatment choice, as it is the only effective therapeutic measure. Because of this, it is considered the gold standard in treatment for these conditions.<sup>20</sup>

## **CONTRAINDICATIONS AND ADVERSE EFFECTS OF THE KETOGENIC DIET**

The ketogenic diet is contraindicated in several conditions. Due to the alteration in metabolism and the use of lipids as the primary energy source that occurs during ketogenic diet therapy, patients with conditions affecting fat metabolism may be severely harmed by the diet. Conditions that have an absolute contraindication to the ketogenic diet include primary carnitine deficiency, carnitine palmitoyltransferase I or II deficiency, carnitine translocase deficiency,  $\beta$ -oxidation defects, medium-chain acyl dehydrogenase deficiency, long-chain acyl

dehydrogenase deficiency, short-chain acyl dehydrogenase deficiency, long-chain-3-hydroxyacyl-CoA deficiency, medium-chain-3-hydroxyacyl-CoA deficiency, pyruvate carboxylase deficiency, and porphyria.<sup>20</sup>

Along with conditions affecting fat metabolism, non-metabolic contraindications should also be addressed. Inability to maintain adequate nutrition, propofol concurrent use, patient or caregiver noncompliance, and surgically focused seizure activity are classified as relative contraindications. These factors should be assessed on an individual basis before initiating ketogenic diet therapy.

The presence of ketoacids that occur as a result of the ketogenic diet alter a patient's internal chemistry; blood pH is lowered, and osmolality is increased. Because of this there are several potential adverse effects of the therapy that should be considered before initiation. Possible side effects of the diet include constipation, diarrhea, vomiting, loss of appetite, dehydration, kidney stones, dyslipidemia, hypoglycemia, hyperuricemia, gastroesophageal reflux, hypertriglyceridemia-induced pancreatitis, and growth retardation.<sup>26</sup> Vitamin and mineral deficiencies have been previously reported, so it is now recommended that all patients following a ketogenic diet are supplemented with several key vitamins and minerals. Additionally, some antiepileptic medications can potentially exacerbate adverse effects. Patients who are concurrently following the ketogenic diet and taking acetazolamide, topiramate, zonisamide, or valproate should be carefully monitored.<sup>27</sup>

## **CALCULATION AND IMPLEMENTATION OF THE KETOGENIC DIET**

Prior to initiating the ketogenic diet, a comprehensive evaluation of the patient should be conducted by the multidisciplinary care team to ensure that there are no contraindications. Laboratory evaluation should include a complete blood count with platelets, an electrolyte panel, serum liver and kidney tests, a fasting lipid profile, a serum acylcarnitine profile, urinalysis, urine calcium and creatinine screening, urine organic acid screening, serum amino acid screening, and serum levels of anticonvulsant drugs if applicable. A nutritional evaluation should assess anthropometrics and nutrition intake history including food preferences, allergies, and intolerances.<sup>25</sup> After considering the findings from the evaluations, the decision on which variation of the ketogenic diet that will be initiated can be made and the calculation of calories, fluid, and ketogenic ratio can be conducted.

Once it has been determined which variation of the ketogenic diet is best suited for the patient and the ketogenic ratio has been selected, calculations can begin by determining the total energy requirement. In the classic ketogenic diet, calculations rely on the ketogenic ratio. The ratio should be used to determine how many calories are in each dietary unit. The total number of calories needed by the patient should then be divided by the number of calories per dietary unit to determine how many dietary units are required each day. The ketogenic ratio should then be applied to determine how many grams of fat, protein, and carbohydrates should be consumed each day. Protein requirements should meet the DRI for the child's age.

*Example calculation, classic ketogenic diet:*

Estimated energy requirement (7 y/o child, 23kg) = 1,430 kcal/day

Selected ketogenic ratio: 3:1

Fat: 3 grams x 9 kcal/gram = 27 kcal

Protein + CHO: 1 gram x 4 kcal/gram = 4 kcal

27 + 4 = 31 kcal/dietary unit

1430/31 = ~46 dietary units/day

Fat allowance: 3 x 46 = 138 g/day

Protein + CHO allowance: 1 x 46 = 46 g/day

Protein minimum: 1 g x 23 kg = 23 g/day

CHO allowance: 46 g – 23 g = 23 g/day

*Final diet prescription: approximately 1,430 kcal/day composed of 138 grams fat, 23 grams protein, and 23 grams carbohydrate*

*\*\*Breakdown by meal (3/day): 46 grams fat, 7.6 grams protein, 7.6 grams carbohydrate*

In the MCT diet, calculations rely on the percentage of MCTs used. Initially, the diet is calculated as 50% MCT, 21% LCT, 19% carbohydrates, and 10% protein. The 10% of total calories from protein should meet a minimum of 0.8 – 1.2 grams/kilogram body weight based on the DRI for the patient's age.<sup>28</sup>

*Example calculation, medium-chain triglyceride ketogenic diet:*

Estimated energy requirement (7 y/o child, 23kg) = 1,430 kcal/day

Selected MCT percentage: 50% (21% LCT, 19% CHO, 10% PRO)

MCT: 1430 (.50) = 715 kcal/day

715/9 grams = 79.4 g/day

LCT: 1430 (.21) = 300.3 kcal/day

300.3/9 grams = 33.3 g/day

Carbohydrate: 1430 (.19) = 271.7 kcal/day

271.7/4 grams = 67.925 g/day

Protein: 1430 (.10) = 143 kcal/day

143/4 grams = 35.75 g/day

*Final diet prescription: approximately 1,430 kcal/day composed of 80 grams MCTs, 34 grams LCTs, 68 grams carbohydrate, and 36 grams protein*

Fluid requirements should be calculated using the Holliday-Seger method. Sugar-sweetened beverages should not be consumed while following the ketogenic diet due to their high carbohydrate content. In addition to water, zero-calorie, artificially sweetened beverages such as Powerade Zero, Propel Zero, and Fruit 2-O can be consumed. Diet soda can be consumed, however caffeine-free options should be selected.

The final step in the pre-initiation phase is counseling. The care team should discuss seizure reduction, medication, and cognitive expectations of the diet with the patient and/or caregivers. During counseling, potential psychosocial barriers to adhering to the intervention should be identified. Patients and/or caregivers should be provided sufficient education on the diet, including carbohydrate content in medications and other non-food items.<sup>25</sup>

Once preliminary evaluation and counseling is complete, the diet can be initiated. Initiation should occur under medical supervision, with it almost always occurring during an inpatient hospital admission.<sup>25</sup> Traditionally, the initiation of the ketogenic diet began with a 12-24 hour fast, however this is no longer standard practice; it has been found that a fasting period does not result in significant improvements compared to gradual initiation.<sup>29</sup> Gradual initiation, the current recommendation, slowly increases caloric intake to meet the patient's requirements while maintaining the desired ketogenic ratio. The patient will consume one-third of total calorie needs on the first day, two-thirds on the second day, and full calorie needs on the third day.<sup>20</sup> An alternative method for gradual initiation relies on a ratio-based approach. The patient will consume full calorie needs with a 1:1 ketogenic ratio the first day, a 2:1 ratio on the second day, a 3:1 ratio on the third day, and a 4:1 ratio on the fourth day.<sup>20,29</sup>

While following the ketogenic diet prescription for the classic ketogenic diet or MCT diet, all foods should be weighed to the nearest tenth of a gram using a gram scale. While following the MAD or LGIT diet, all foods should be measured using standard household measurements. Carbohydrate content of non-food items including medications, supplements, and oral hygiene products should be factored into the daily carbohydrate allowance. Liquid medications are higher in carbohydrates, so pill forms of medication should be used instead.

After the initiation phase is complete and the patient is discharged from the hospital, follow-up evaluations should be conducted regularly by dietitians and neurologists during the maintenance phase to ensure nutritional adequacy, support compliance, and advise on supplementation and fluid intake. It is recommended that all patients be evaluated in-clinic 1 month after initiation, and then at 3, 6, 9, and 12 months. However, more frequent visits are indicated if the patient is less than 1 year of age or at high risk for nutritional deficiency. After the first year on the diet, in-clinic visits can occur every 6 months if the patient is free from complications.<sup>20</sup> At follow-up visits, anthropometric measurements and laboratory values should be assessed. In between visits, parents should monitor the child's urine ketones several times per week. If nutritional ketosis is not occurring or seizure control has not improved within 1 month of initiation, the ketogenic ratio may be increased by the patient's care team.

Discontinuation of the diet is individualized based on the patient's response. The care team should consider risks and benefits of the diet to nutritional status and seizure activity prior to making the decision to discontinue. Currently, in children with greater than 50% seizure reduction, the recommended goal is to discontinue the diet after approximately 2 years. However, in children with nearly complete seizure control, the diet may be continued for

several years.<sup>20</sup> Some conditions may warrant different lengths of intervention. For patients with GLUT-I deficiency syndrome, it is recommended that the diet be maintained at least until puberty and potentially further into adulthood; for patients with infantile spasms, there has been evidence that the diet can be discontinued in as little as 6 months with no recurrence of seizure activity.<sup>30,31</sup>

When the decision to discontinue the diet has been made, it should be done in a gradual manner rather than abruptly and nutritional supplementation should be continued throughout the process. The ketogenic ratio can be slowly reduced by half or quarter steps each month (e.g., 4:1 initial, 3.75:1 month 1, 3.5:1 month 2, etc.). After the ratio has been gradually lowered, the patient can begin reintroducing regular foods and greater amounts of carbohydrates until ketosis is lost. Following this pattern, the diet will be completely discontinued. If seizure activity returns or worsens during discontinuation, the ketogenic ratio should be increased back to the effective ratio.<sup>20</sup>

## **METHODOLOGY**

The purpose of this project is to create educational materials to increase understanding of the Modified-Atkins diet for the treatment of pediatric epilepsy by children and families receiving treatment at Children's Healthcare of Atlanta (CHOA). An increased understanding of the diet will promote better compliance to the diet and subsequently better patient outcomes. The outcome document for the project will include a Modified-Atkins diet handbook. A separate handbook for the Modified-Atkins diet is needed because implementation of this variation of the ketogenic diet has become more common at CHOA. The handbook will contain



general information about seizures, a general introduction to the ketogenic diet, an FAQ on the ketogenic diet, a comparison of variations of the ketogenic diet, possible side effects of the ketogenic diet, a guide to urine ketone testing, helpful tips, a diet guide, guidelines for medication use, a low-carbohydrate non-food product list, a supplies list, and additional resources.

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# Modified-Atkins Diet Handbook

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**Children's**<sup>SM</sup>  
Healthcare of Atlanta

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# Welcome

Welcome to the Children's Healthcare of Atlanta Ketogenic Diet Program. The Ketogenic (Keto) Diet Program consists of many team members who all work together with a neurologist to help your child. This includes nutritionists, nurses and medical assistants.

This handbook is meant to help you learn more about the ketogenic diet. This handbook should not replace instruction given to you by your child's care team. It is not meant to cover all information on this subject. Your child's doctor is the best source of information about what is best for your child's treatment. If you have any questions about this handbook, please ask the Children's Keto Diet Team.

## Important contact information

- **Call 911 or go to the nearest Emergency Department right away in case of an urgent concern or emergency.**
- Call 404-785-KIDS (5437) to reach the Keto Diet Clinic. Ask for Keto Diet nurse, nutritionist, or scheduler. The clinic is open Monday through Friday from 9 a.m. to 4 p.m. We will return messages as soon as possible. Messages left after 12 p.m. may not be returned until the next business day. The Keto Clinic phone will go to voicemail when the Keto Team is working in clinic, seeing consults in the hospital and after hours.
- Call 404-785-KIDS (5437) for urgent needs to reach the neurologist on call after hours. Ask for the on call neurology doctor.
- The Keto Clinic fax number is 404-785-3876.
- The Keto Clinic email address is [ketoclinic@choa.org](mailto:ketoclinic@choa.org). Do not email questions or requests that are urgent.
- Please ask about MyChart at your child's next clinic visit if you would like to register and have not done so already.
- Please allow up to five business days for all prescription refills for medicines and formula, forms (such as school forms), and new recipe or recipe changes.



# Seizures

## Patient and Family Education

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

### What is a seizure?

A seizure is caused by an abnormal discharge of electrical activity in the brain. Seizures can be associated with many medical conditions. They may cause one or more of the following symptoms:

- Falling
- Uncontrollable or involuntary muscle spasms
- Drooling from the mouth
- Loss of bladder or bowel control
- Altered awareness

### What do I do if my child has a seizure?

If your child has a seizure:

- Keep calm and stay with him
- Move him to a flat surface and put something soft under his head
- Remove all hot or sharp objects from the area
- Loosen tight clothing, especially around his neck
- Turn him on his side so he does not choke on saliva or vomit
- Do not put anything in his mouth—he will not choke on his tongue
- Do not try to restrain him during a seizure
- After the seizure, your child may fall asleep—this is called the postictal phase—do not attempt to give him food or drink until he is awake and alert
- Call his doctor if
  - He has a different type of seizure than usual
  - He has more seizures than usual
  - He does not return to his normal behavior within 30 minutes

### **Call 911 right away if your child stops breathing or turns blue.**

If a seizure lasts more than 5 minutes, call 911 or your local ambulance service (or follow your child's doctor's instructions). Ask his doctor if any medicine is needed for emergency use.

## **What should I look for and remember?**

Watch and record all seizure activity in a seizure diary. Take the seizure diary with you when your child goes to the doctor. Watch and record these things:

- How long was the seizure? Look at the clock when the seizure starts and again when it is over
- What happened during the seizure? What body parts were involved? Where did it start and how did it progress?
- What happened before the seizure, such as behavior change, crying, repeated movements, or confusion?
- Did your child's color or breathing change? If your child seems to stop breathing, how long did this last?

**In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.**

## **What should I know about my child's medicines?**

- Seizures can be controlled—not cured—by medicine
- Do not let your child stop taking medicine for seizures without asking your doctor first
- Ask your child's doctor what side effects from your child's medicine to look for and what to do about them
- Your child's doctor may want to have your child's blood tested now and then to check medicine levels—keep all of your child's appointments
- Some medicines do not mix well with other's—tell your child's doctor all the medicines he takes and ask which medicines should be avoided

## **What should I know about my child's activities?**

- Talk about your child's activities with his doctor; what your child is allowed to do depends on:
  - The type of seizures he has
  - How often and how severe the seizures are
  - How he responds to medicine or therapy
  - The length of time his seizures have been controlled
- Allow your child to take part in normal activities as much as possible
- Teach his teachers, camp counselors, coaches, and any caretakers about how to take care of him in case of a seizure
- Have your child wear appropriate safety devices, such as helmets to prevent head injuries, as advised

- Avoid activities that involve heights
- Your child should never bike or swim without supervision, even if your doctor approves the activity
- Watch young children at all times while in a bathtub—showers are recommended for older children
- Check with your child's doctor before your child begins driving when he is old enough

# **The Ketogenic Diet**

## **Patient and Family Education**

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care for your child.

### **What is the Ketogenic Diet?**

The ketogenic diet is a way of eating to help the body use fat as the main source of energy instead of carbohydrates. The goal of the diet is to produce ketones through the food your child eats. Ketones are made when the body breaks down fat.

The diet:

- Contains more fat than carbohydrates and protein
- Needs to be followed very strictly

### **When is the ketogenic diet used?**

The diet is most often used in children with myoclonic, absence, and atonic (drop) seizures. The diet may also:

- Help some children with generalized tonic-clonic (grand-mal) seizures
- Be used with children and teens with any type of seizure when medicines do not work

### **How do ketogenic diets work?**

Doctors do not know exactly how the diet helps control seizures. We do know these things:

- The body's main fuel is sugar (glucose); The body burns sugar to make energy and maintain a normal blood sugar level.; The body only stores a 23-hour supply of glucose
- When the glucose stored in the body is gone, the body begins to burn fat for fuel; the body does not burn fat completely, but it breaks it down into ketones
- Ketones in the brain may help control seizures

### **Why should my child follow the ketogenic diet?**

The ketogenic diet is a safe and effective way to treat epilepsy. The goal of the diet is to lower the number and intensity of seizures in children whose seizures are not controlled by other therapies. Possible results of ketogenic diet therapy include:

- Fewer seizures
- Lower severity and intensity of seizures

- Lower length of time seizures happen
- Lower dose of anti-seizure medicine your child needs
- Lower the number of anti-seizure medications your child needs
- Become more alert

However, complete seizure control is not always possible, and every child is different. It is not possible to tell which child will respond to the diet and which will not. Some children will take longer than others to respond to the diet.

### **How long will my child need the ketogenic diet?**

To begin the diet, your child may have to stay in the hospital for about 3 days. Once the diet begins, try it for 3 months.

- If the diet helps to decrease seizure activity, your child will usually stay on it for about 2 or more years.
  - During this time, your child will need regular lab tests and visits to his doctor.
  - Coming off (weaning) seizure medications varies from child to child. It is not always possible.
  - After 2 or more years when it has been decided to discontinue the diet, your child will begin weaning from it. However, if seizures return during the weaning process, your child may need to return to the diet.
- If the diet is not helpful, your child will wean off the diet over time—not all at once.
  - Talk with your child’s neurologist before stopping or changing the diet.
  - Fat content in the diet is slowly decreased, and carbohydrate intake is slowly increased.
  - Your child will slowly return to a normal eating pattern.

### **What are possible side effects with this diet?**

Some possible side effects include:

- Constipation
- Kidney stones
- Hypoglycemia (low blood sugar)
- Excess (too many) ketones
- Sleepiness

Talk with your child’s doctor if you have any questions or if any of these are a problem for your child.

# The Modified-Atkins Diet

The Modified-Atkins diet is one form of the ketogenic diet.

## How is the Modified-Atkins diet different from the classic ketogenic diet?

The classic ketogenic diet has the highest fat content (90% of calories) and the lowest carbohydrate content (2% of calories). It is the strictest form of the diet to follow.

The modified-Atkins diet utilizes a lower fat to carbohydrate and protein ratio, allowing for more flexibility and making it easier to manage.

There are 4 different methods of using the modified-Atkins diet:

- 3-Day diet history reduction
  - Your child's dietitian will estimate your child's current carbohydrate intake from a 3-day diet history
  - At the start of the diet, your child will consume 50% of their average carbohydrate intake
  - Each week, carbohydrate intake is decreased by 10 grams until either seizure control is achieved, total carbohydrate intake is 30-40 grams per day, or the child is unable to tolerate further restrictions
- Follow a 2:1 or 1:1 ratio of fat to protein and carbohydrates combined
  - Your child's dietitian will calculate and provide you with exact macronutrient goals for fat, protein, and carbohydrates
  - Requires the use of a gram scale
- Carbohydrate counting
  - Your child will be limited to 10-15 grams of carbohydrates per day
- Exchange lists
  - Your child's dietitian will provide a fat goal in grams to meet each day
  - Your child will have no limitations on protein intake
  - Your child will consume 1-2 carbohydrate exchanges per meal

## COMPARISON OF DIET THERAPIES FOR EPILEPSY

QUESTIONS	Ketogenic Therapies	MCT Oil	Low Glycemic Index Treatment	Modified Atkins
Is medical supervision required	Yes	Yes	Yes	Yes
Is diet high in fat?	Yes	Yes	Yes	Yes
Is diet low in carbohydrate?	Yes	Yes	Yes	Yes
What is the ratio of fat to carbohydrate & protein?	4:1, 3:1, 2:1, 1:1	Approximately 1:1	Approximately 1:1	Approximately 2:1
How much carbohydrate is allowed on a 1000 Calorie diet?	8gm carb on a 4:1 16gm carb on a 3:1 30gm carb on a 2:1 40-60gm carb on a 1:1	40-50gm	40-60gm	10gm adolescents or 15gm adults for 1 month 20gm afterwards
How are foods measured?	Weighed	Weighed or measured	Measured or estimated	Estimated
Are meal plans used?	Yes	Yes	Yes	Optional
Where is the diet started?	Hospital	Hospital	Home	Home
Are calories controlled?	Yes	Yes	Yes	No
Are vitamin and mineral supplements required?	Yes	Yes	Yes	Yes
Are liquids (fluids) restricted?	No	No	No	No
Is a pre-diet laboratory evaluation required?	Yes	Yes	Yes	Yes
Can there be side-effects?	Yes	Yes	Yes	Yes
What is the overall difference in design of these diets?	This is an individualized and structured diet that provides specific meal plans. Foods are weighed and meals should be consumed in their entirety for best results. The ratio of this diet can be adjusted to effect better seizure-control and also liberalized for better tolerance. This diet is also considered a low glycemic therapy and results in steady glucose levels.	An individualized and structured diet containing Medium Chain Triglycerides (MCT) which are highly ketogenic. This allows more carbohydrate and protein than the classic ketogenic diet. A 2008 study showed that both diets are equal in eliminating seizures. A source of essential fatty acids must be included with this diet.	This is individualized but less structured diet than the ketogenic diet. It uses exchange lists for planning meal and emphasizes complex carbohydrates. The balance of low glycemic carbohydrates in combination with fat result in steady glucose levels. It is not intended to promote ketosis.	This diet focuses on limiting the amount of carbohydrate while encouraging fat. Carbohydrate may be consumed at any time during the day as long as it is within limits and should be consumed with fat. Suggested meal plans are used as a guide. Protein is not limited but too much is discouraged

## FREQUENTLY ASKED QUESTIONS ABOUT THE CLASSIC AND MODIFIED KETOGENIC DIETS

QUESTIONS	ANSWERS
<b>What is the ketogenic diet?</b>	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. The Classic diet consists of a ratio in grams of fat to non-fat (protein and carbohydrates) of 4:1 and 3:1. The modified ketogenic diet consists of ratios of 2:1 and 1:1.
<b>Who can be helped by the diet?</b>	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. Creative recipes have helped to make the diet more palatable in the past few years.
<b>How effective is the diet at controlling or eliminating seizures?</b>	Four major meta-analyses (reviews of many studies) have been published in the past 10 years and have determined that the ketogenic diet is effective in reducing seizure frequency in children with difficult-to-control epilepsy. A controlled study published in 2008 revealed that seizure frequency after 4 months was significantly lower in 54 children on the ketogenic diet than the control group of children who were on medication therapy.
<b>How does the diet work?</b>	No one is certain how the diet works. A metabolic change occurs in the body which affects brain chemistry. Despite many hypotheses, the mechanism by which the diet works to control seizures remains a mystery. Scientists in several laboratories around the world are working to unlock this mystery with animal studies.
<b>How is the diet prepared?</b>	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.
<b>Will anti-seizure medications be reduced after my child goes on the diet?</b>	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.
<b>How do you begin the diet?</b>	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 or longer. During this time blood sugar and ketone levels are monitored. A fasting period is not necessary to start the diet according to recent studies.
<b>How soon does it take for the diet to reduce or eliminate seizures?</b>	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.



## FREQUENTLY ASKED QUESTIONS ABOUT THE CLASSIC AND MODIFIED KETOGENIC DIETS

QUESTIONS	ANSWERS
<b>What would happen if my child “cheated” on his/her diet?</b>	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.
<b>Is the diet healthy for my child?</b>	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.
<b>How long is the diet used for?</b>	The diet is generally used for a period of up to 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.
<b>Are there any adverse effects of the ketogenic diet?</b>	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. There are two anti-seizure medications which can cause acidosis and kidney stones which should be monitored very closely when used with the ketogenic diet (Zonegran® and Topamax®).
<b>Will my child gain too much weight with this high fat diet?</b>	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.
<b>Will the diet cause high cholesterol?</b>	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.
<b>Can the diet be used for children with feeding tubes?</b>	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.
<b>Are there any special tests that are needed before starting the diet?</b>	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.

# What to Expect When Starting the Diet

Starting the modified-Atkins diet will be a big change from the way your child normally eats and can feel overwhelming. Being prepared for what to expect can help alleviate the stress. Below are things you should be aware of that might occur in the first 7 days of the diet and strategies to overcome them.

## Day 1 to 3

- Possible headaches/migraines
- Tiredness and fatigue
- Cravings for carbs and sugars

## Day 4 to 5

- Continued cravings for carbs and sugars
- Dehydration

## Day 6 to 7

- Your child may be going into ketosis, the key to success of this nutritional therapy. Use ketone strips to see if ketosis has been achieved.

<b>Struggles</b>	<b>Strategies</b>
<b>Craving carbohydrates and sugar</b>	Snack on almonds or macadamia nuts
<b>Resentment towards siblings or classmates able to eat foods high in carbs</b>	Talk through the diet with your child and let them express their feelings, or if they are old enough have them write in a journal
<b>Headaches or migraines</b>	Drink plenty of water to stay hydrated
<b>Concerns that your child is not eating enough</b>	Contact your child's dietitian

# Ketogenic Diet Side Effects

## When should I call?

Call us for:

- Questions or concerns about seizures
- Lethargy (more sleepy than usual)
- Prescriptions (medicines or formula)
- Chronic constipation (consistently not having a bowel movement every 3 days)
- Sediment in the urine
- Questions about your child's meals or formula
- Changes in your child's weight (quickly losing or gaining weight)
- To schedule, change, or find out when your child's next visit is

## Constipation

Constipation is not having a bowel movement as often as you usually do or having a tough time going because the stool is hard and dry. In Keto Clinic, we define constipation as not having a bowel movement within three days.

To help prevent constipation:

- Oral diet—Encourage your child to drink keto-approved fluids. Increase fiber in your child's diet by using recipes with Group A vegetables or including the 25 grams of "free food" lettuce each day
- Tube feedings—Flush the tube with water after each use

To treat constipation, you may try one of these over-the-counter laxatives that are carbohydrate-free:

- Milk of Magnesia
- Miralax
- Mineral Oil
- Glycerin suppository
- Fleets Enema
- Dulcolax suppository

Follow the directions on the product package for the correct pediatric dose or ask your pediatrician for dosing recommendations.

# Ketogenic Diet Side Effects

## Low Blood Sugar

Hypoglycemia is when your child's blood sugar is too low (less than 40 mg/dL or has symptoms).

Symptoms may include:

- Nausea
- Pale, sweaty skin
- Fast pulse (heart beat)
- Lethargy (more sleepy than normal)
- Feeling dizzy

### **If your child has these symptoms:**

Give 15 mL of juice. If the symptoms continue, give another 15 mL of juice. Then, call the Keto Clinic or seek medical attention from your pediatrician, urgent care center, or local emergency room.

## Kidney Stones

Kidney stones are a less common side effect of the ketogenic diet. You can help prevent them by giving your child plenty of water to drink. Our dietitian will give you information on how much water your child needs every day.

Please call the Keto Clinic if you child has:

- Any sediment or residue in his urine
- Less urine output than usual
- Consistently dark or concentrated urine

**These may be signs that your child needs more water in his diet.**

## Excess Ketones

Excess ketosis happens when the body is making too many ketones. Symptoms may include:

- Nausea or vomiting
- Fast, shallow breathing (panting)
- Flushing of the face
- Lethargy (more sleepy than normal)
- Urine ketone test strip that quickly changes to the highest color

### **If your child has these symptoms:**

Give 30 mL of juice. If the symptoms continue, give another 30 mL of juice. Then, call the Keto Clinic or seek medical attention from your pediatrician, urgent care center, or local emergency room.

# Ketogenic Diet Sick Days

## Sick Days

Diarrhea, fever, nausea, and vomiting are all common side effects of childhood illness. If your child is sick and is unable to tolerate the diet, you can try these things:

If only a portion of your child's meal or feeding is completed, that is OK. For patients on an oral diet, it is important that they consume the fat source along with the protein and carbohydrate portion of the meal to maintain ketosis.

Keep your child well hydrated. Some keto fluids include:

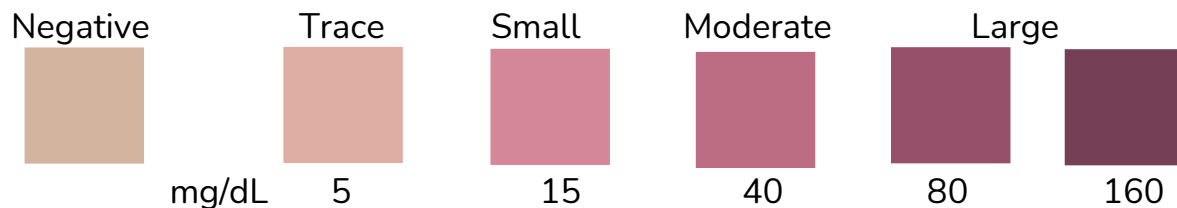
- Water, Powerade Zero, and Propel Zero
- Half-strength Pedialyte: 1 part Pedialyte to 1 part water
- Caffeine-free diet soda
- Sugar-free JELL-O powder can be used to flavor water (1 serving each day is allowed)
- 1/4 – strength Crystal Light: 1 part Crystal Light to 3 parts water
- Bouillon soup: 4 ounces of boiling water mixed with ½ teaspoon of instant bouillon granules

**If your child cannot tolerate his usual diet after 24 hours of keto fluids, please call the Keto Clinic or seek medical attention from your pediatrician, urgent care center, or local emergency room.**

# Ketogenic Diet Urine Ketone Testing

Ketones are made in the body when fats are used for energy instead of glucose (sugars).

Ketone Reading	mg/dL
Trace	5 mg/dL
Small	15 mg/dL
Moderate	40 mg/dL
Large	80 to 160 mg/dL



## What supplies do I need to check ketones?

Gather these supplies to check ketones:

- A watch
- Container to collect urine sample
- Urine sample
- Bottle of ketone strips
- Cotton balls if using a diaper

## How can I make sure the test is correct?

Read the steps before doing the test. Follow these steps exactly. Time the test with a watch. Protect the test strips from damage that might change the results.

1. Do not touch the test area of the strip or allow it to touch the table.
2. Protect the test strips from moisture, direct sunlight, and heat. Keep the test strips in a cool, dry place, but do not store them in the refrigerator. Do not remove desiccant (white packet in bottle). Tightly replace the bottle cap right away.
3. Check the expiration date on your test strips. Do not use if the date has passed. Use the strips within 6 months after first opening the bottle.
4. Do not use test strips that have discolored.

# Ketogenic Diet Urine Ketone Testing

## Diapered Children

1. Place cotton balls in your child's diaper. Be aware that baby boys urinate (pee) more toward the front of the diaper, and girls urinate more toward the middle and back of the diaper.
2. Once your child has a wet diaper, pick out the cotton balls, and squeeze the urine into a container or onto the dipstick.
3. Once the stick is removed from the urine, place it on a flat surface. Begin timing with a watch.
4. The Ketostix test strips advise you to wait for 15 seconds. If you are using a different brand, read the steps on the bottle to see how many seconds to wait.
5. Once the correct time has passed, compare the color of the strip to the color chart on the bottle.

## Potty-Trained Children

1. As your child starts to urinate (pee), allow a small amount of urine to go into the toilet.
2. Catch about one to two ounces of urine in a container.
3. Dip the stick into the container and place it on a flat surface. Begin timing with a watch.
4. The Ketostix test strips advise you to wait for 15 seconds. If you are using a different brand, read the steps on the bottle to see how many seconds to wait.
5. Once the correct time has passed, compare the color of the strip to the color chart on the bottle.

**Note: It is normal for ketones to be lower in the morning than they are at night.**

# Helpful Tips for Parents from Parents

## Starting the ketogenic diet

### Golden Rules

1. Treat the diet just as you would treat medicine.
  - Follow it exactly for every meal every day.
  - You may feel overwhelmed at times, especially if you ever make a mistake, if your child is still having seizures, or if your child begs for something he cannot have. Try not to let this get you down!
2. Keep a notebook with your child's health care details in it.
  - Have different sections for your recipes, doctors' phone numbers, allergies, medicine list, weight chart, list of emergency room visits and hospital admissions, free foods, sugar free list, and other important papers.
  - Take this with you everywhere. It will help in emergencies if you cannot recall certain things. You will be able to look up details and be an advocate for your child.
  - Some parents even take labels off of the foods they use most often to store them in their notebooks. Then, they take them to the grocery store to compare ingredients to make sure they have not changed/
3. Take your time cooking and measuring out your child's meals. It is very easy to make a mistake.
4. Remember to let EVERYONE (family, teachers, babysitters, and others) know about the diet. Explain EVERYTHING to them so they will know how important it is to avoid giving your child anything he asks for to eat or drink. Be sure they know that "only a taste" can cause a seizure.
5. Start off using basic meal plans. Then, talk with your child's care team about adding new things once your child is doing better. That way, you will know why your child is having problems if he starts having them.



## Cooking Tips

1. To cook your vegetable or meat:
  - You can boil, steam, or slice thinly and stir fry vegetables in a pan you have sprayed with Pam nonstick cooking spray.
  - You can bake them or cook them in the microwave.
  - You can cook them on the grill.
2. You may cook enough vegetables or meat for 2 to 3 days, but do not pat out liquids on paper towels until just before measuring or serving them.
3. To keep salads from getting soft for a few hours, try putting your fat on the bottom of the container. Then, layer vegetables, meat, and lettuce. Do not stir until ready to eat.
4. Using lettuce and Jell-O in some of your meal plans will really make the meal look like your child gets more food!
5. To help keep lettuce fresh longer:
  - Rinse lettuce under cold water.
  - Wet a clean kitchen towel and wring out extra water.
  - Wrap lettuce with the towel, and then wrap it again with a dry towel.
  - Keep it in the refrigerator. The lettuce will most often keep fresh for about 1 ½ weeks.

## Shopping Lists

1. Purchase these keto foods before your child starts the diet:
  - Duke's Mayonnaise
  - Pure extracts (vanilla, lemon, orange)
  - Liquid sweetener
  - Sugar free Jell-O
  - Butter (salted or unsalted; sweet cream is OK)
  - Canola oil
  - Pam nonstick cooking spray
  - Heavy cream

It is easier to have some foods on hand when you come home from the hospital rather than run errands to buy things as soon as you get discharged.

2. Masking tape is a huge help for labeling foods in the refrigerator that are “keto-approved” or putting directions on containers for babysitters. It does not work well for freezers though.
3. Kroger and Walmart carry the small rubber spatulas that are great for getting the last little bite of a meal.
4. Tom’s of Main toothpaste is advised for use with the ketogenic diet.

### **Hiding Fats Tips**

1. Flavor cream with a pure extract and add liquid sweetener to drinks. (Do not use more than 5 drops each day.)
2. Add water to cream (after measuring out cream first). Then, add 1 to 2 drops of chocolate extract and liquid sweetener to make chocolate milk.
  - Heat up this chocolate milk to make hot chocolate! Save a few grams of cream from your recipe to make whipped cream for topping.
  - Whip up chocolate milk and freeze to make ice cream.
3. Mix Jell-O and measure it out. Then, add cream and 1 to 2 drops of liquid sweetener to make a sherbet. Ask your child’s care team for the exact recipe.
4. Save small, plastic, empty soda containers — they are great for storing the cream once sweetener or flavor has been added. The screw-on cap is easy to close and helps avoid spills.
5. You can hide oil in cream by weighing out both separately. Then, lightly whip the cream so it is barely whipped. Next, slowly add oil to the cream until you get stiff peaks. Add the sweetener and the flavoring while you add the oil.
6. You can freeze butter! Once frozen, weigh it out, and grate it into cream as a way to hide it.
7. Cut butter into small cubes and sprinkle it over a salad!
8. Make butter candy!
  - Measure out butter and let soften. Do not let melt.

- Add 1 to 2 drops of sweetener and extract. You can also add 1 to 2 drops of food coloring if you want.
- Mix well.
- Spray candy molds with nonstick spray and pat butter into molds. Freeze.
- Pop out of molds and serve with rest of meal.

## **Travel**

1. Salads are great for school or when you are not sure if you will be able to heat up a meal when traveling. They are also great if you will have to weigh/measure out a meal in a hurry. You might want to keep celery, carrot sticks, and sliced tomatoes on hand, too.
2. If your child likes bacon, lettuce, and tomato (BLT) sandwiches, try a BLT salad instead.
3. Use hard, plastic freezer packs to keep lunches and drinks cold when at school.

# Commonly Asked Ketogenic Diet Nutrition Questions

## What do ratios mean?

The ketogenic ratios are based on how many grams of fat are to be consumed for each gram of carbohydrate and protein combined. For example, a 3:1 ratio means that for every 3 grams of fat consumed, your child may have 1 gram of carbohydrate and protein combined. ***Note: on the Modified-Atkins diet, your child might not be assigned a ratio.***

## Will this diet fit into my family's life?

Yes! With a little advance planning and creativity, you and your child can go anywhere on the ketogenic diet. Children are generally very flexible and can adapt to dietary restrictions. The key to making things work is to plan ahead. If you're heading on a short trip, prepare meals in advance and bring them with you. Going on a longer vacation? Try to find lodging with a kitchenette so that you can prepare your child's meals.

## Can children really follow a strict ketogenic diet?

Yes! Children are very adaptable. With a little creativity and planning, you can find a way to adapt and still follow the diet. Treat the diet as your child's new "magic diet" to help with seizure control.

## Do I have to use the exact item/food brand listed in the recipes?

Yes, all keto diet recipes are to be made exactly as they are written. We know that families prefer various brands based on personal preference. If there is a specific brand you'd like to use, please email your dietitian with a picture of the front of the package and the nutrition facts label. Please allow 3 to 5 business days for your item to be added to the database and for your recipes to be updated. Note that the recipe will tell you if an item should be weighed raw or cooked - that doesn't mean it needs to be eaten that way. If the recipe calls for 30 grams of egg (raw), measure the raw egg first before cooking it.

## How can I create more recipes?

While starting out on the ketogenic diet, it's best to start with a limited number of recipes that your child likes so that we can make sure that he will consistently eat all of his meals and snacks. It also helps us figure out if any of the recipes are causing problems. Please ask at your child's follow-up appointment if he is ready for new

recipes and the dietitian will provide you with a login to a web-based ketogenic diet calculator program and a user's guide.

### **If my child doesn't finish all of his meals or snacks, should I save it and offer it later?**

No, food from previous meals and snacks should not be re-offered throughout the day. If your child is consistently not finishing meals, please let the clinic know.

### **Do I need to give my child vitamins and supplements?**

Most children on the ketogenic diet need extra supplements because the diet is lacking in many vitamins and minerals. Check with your dietitian to see which supplements your child needs.

### **What kinds of foods can my child eat?**

Ketogenic diets allow for only a few carbohydrates. Your child can eat high fat foods like whipping cream, butter, avocado, and coconut oil. Your child will only be able to eat a few fruits and vegetables. Your child will not be able to eat any carbohydrate rich foods, such as:

- Pasta
- Bread
- Rice
- Potatoes
- Crackers
- Cookies
- Candy
- Soda
- Juice

Please look over the Fruit and Vegetable list to see which items can be incorporated into your child's diet. Most recipes that include fruits and vegetable are written as either a 10% fruit or Group B vegetable, so that you can select any item from those lists to provide extra variety. If the recipe calls for a 10% fruit – that means you can pick any fruit on the 10% list and use the exact amount specified. If your child wanted to use a 15% fruit instead, you could only use two-thirds of the amount listed in the recipe for the 10% fruit.

# What are Macronutrients?

Food is made up of three components, carbohydrates, protein, and fat. These three components are called macronutrients. Macronutrients contain calories to give your body energy to function.

## Carbohydrates

Carbohydrates include starches and sugars. During digestion, they are converted into glucose (sugar) and are used as the body's primary energy source. This includes both simple and complex carbohydrates. Simple carbohydrates are foods like cake, candy, juice, fruit, and milk. Complex carbohydrates are foods like whole grain pastas and bread. However, when following a ketogenic diet, carbohydrates are limited so that the body will instead use ketones as the primary energy source.

Foods that contain a high amount of carbohydrates include:

- Fruits
- Vegetables
- Dairy products, such as milk and yogurt
- Grains, such as bread, pasta, rice, and cereal
- Beans
- Nuts and seeds, such as cashews, peanuts, chia, hemp, and sunflower
- Processed foods, such as chips and crackers
- Desserts, such as cakes, cookies, and candy
- Juices and other sugar sweetened drinks such as soda, sports drinks, and punch

## Protein

Protein is found in all of the body's cells and is important to help build and maintain muscles, hair, skin, and bones. Protein breaks down into smaller parts called amino acids. Protein does not store in the body like fat and carbohydrates do, so it is important to eat protein every day. However, excessive protein can turn into sugar in the body and negatively impact ketosis. It's all about balance!

Foods that contain a high amount of protein include:

- Meat, such as beef and ham
- Poultry, such as chicken and turkey
- Fish, such as tuna, salmon, and halibut
- Eggs
- Dairy, such as cheese and milk

## Fats

Fat allows the body to store energy, cushion organs, make certain hormones, absorb fat soluble vitamins, and maintain the membranes of cells. Except for oils, many foods that have fat will also have some amount of protein and carbohydrates. Fat is the most important macronutrient when following a ketogenic diet. Large amounts of fat are needed to induce and maintain ketosis to gain seizure benefit, so fat should be consumed at every meal.

Foods that contain a high amount of fat include:

- Oils
- Butter
- Coconut oil
- Mayonnaise
- Heavy whipping cream
- MCT oil
- Avocado
- Ghee
- Sour Cream

# How to Read A Nutrition Label

The Nutrition Facts on a nutrition label can help you find information about the nutrition value on a food product, including serving size, calories, and how many grams of carbohydrates, proteins, and fats. It is important to understand how to read a nutrition label so that you can use this information to help your child meet his daily nutrition goals given by your child's dietitian.

<b>Nutrition Facts</b>	
8 servings per container	
<b>Serving size</b>	<b>2/3 cup (55g)</b>
<b>Amount per serving</b>	
<b>Calories</b>	<b>230</b>
<b>% Daily Value*</b>	
<b>Total Fat</b> 8g	<b>10%</b>
Saturated Fat 1g	<b>5%</b>
Trans Fat 0g	
<b>Cholesterol</b> 0mg	<b>0%</b>
<b>Sodium</b> 160mg	<b>7%</b>
<b>Total Carbohydrate</b> 37g	<b>13%</b>
Dietary Fiber 4g	<b>14%</b>
Total Sugars 12g	
Includes 10g Added Sugars	<b>20%</b>
<b>Protein</b> 3g	
Vitamin D 2mcg	10%
Calcium 260mg	20%
Iron 8mg	45%
Potassium 235mg	6%
<small>* The % Daily Value (DV) tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.</small>	

**Serving size:** Always check the serving size listed on the label. The Nutrition Facts provided are for this amount of food. So, if your child eats twice the amount of the serving size, then you will need to double the grams of fat, protein, and carbohydrate listed.

**Total Carbohydrate:** This is the total amount of carbohydrates in a food, including sugar, dietary fiber, and sugar alcohols.

**Dietary Fiber:** This is a non-digestible form of carbohydrates. Subtract total dietary fiber from total carbohydrate to find the total grams of Net carbohydrates.

**Total Sugar:** This includes all sugars, both naturally occurring and added. All sugars provide carbohydrates. Do not subtract the Total or Added Sugars number from total carbohydrates.

## To find Net Carbohydrates from this label:

Serving size = 2/3 cup

Total carbohydrates = 37 grams

Dietary fiber = 4 grams

**Net carbohydrates = 37 grams – 4 grams = 33 grams**



# Modified-Atkins Diet Easy Start Guidelines

- Try to limit carb portions to the amounts listed below. Each portion contains about 8 grams of carbs
- Protein and vegetable choices may be eaten as desired
- Add at least 1 tablespoon of a fat choice to each meal

## Protein

- Beef
- Chicken
- Pork (including sausage and bacon)
- Venison
- Hot dog
- Lunch meat
- Fish
- Nuts
- Nut butter

\*Choose options with **no breading**

## Vegetable

Any fresh, frozen, or canned vegetable **except potatoes, corn, dry beans, and peas.**

Some examples include:

- Asparagus
- Celery
- Cucumbers
- Tomatoes
- Broccoli
- Carrots
- Onion

## Fat

- Butter
- Oil (any kind, including vegetable, canola, olive, safflower, peanut, and coconut)
- Mayonnaise
- Salad dressing (including ranch)
  - Use regular, full fat dressing only
- Heavy whipping cream

## Carbohydrates (~8 grams per serving)

- Cold cereal: ¼ cup
- Bread: ½ slice
- Hamburger/Hot Dog Bun: ½ of one side
- Tortilla: ½
- Rice: 2 tablespoons
- Pasta: 2 tablespoons
- Beans: 2 tablespoons
- Potato: ¼ cup
- Corn: ¼ cup
- Milk: ½ cup
- Fresh fruit: ½ small piece
- Canned fruit: ¼ cup

# Snack and Beverage Ideas

## Snacks

- Avocado
- Boiled egg with avocado, add mayonnaise to increase the fat
- Celery sticks stuffed with cream cheese
- Lettuce wrap with ham and cheese and a high fat dressing
- Olives (green or black)
- Pork rinds
- Raw vegetables with ranch dip
- String cheese wrapped in a slice of ham or other lunchmeat with a high fat dressing
- Sugar free Jell-O with whipped heavy cream
- Tomato slices with mozzarella cheese drizzled with olive oil

## Beverages

Try to drink at least 6 cups of liquid every day. All drinks must be carbohydrate free.

- Water
- Flavored bottled water (Dasani, Nestle Splash, Fruit2O)
- Crystal Light
- Sugar free Kool-Aid
- Propel Zero
- Powerade Zero
- Gatorade Zero
- Vitamin Water Zero
- Mio liquid water enhanced



## Grade A heavy whipping cream

The butterfat content of the cream should be either 36% or 40%. The label on the carton may not show these percentages. Buy cream that matches the labels below. Your dietitian will calculate meals with the type of cream that you are able to locate. Check the freshness date on the cream before buying it. Avoid creams containing polysorbate or ingredients ending in -ose. Let the dairy manager of your grocery store know that you will be buying the cream regularly so that they may order additional.

### For 36% Cream

#### Nutrition Facts

Serving size: 1/2 fluid ounce (15mL)

#### Amount per serving

Calories: 50  
 Calories from fat: 50  
 Total fat: 5g  
 Total carbohydrate: 0 (or 1g)  
 Protein: 0g

### For 40% Cream

#### Nutrition Facts

Serving size: 1/2 fluid ounce (15mL)

#### Amount per serving

Calories: 60  
 Calories from fat: 55  
 Total fat: 6g  
 Total carbohydrate: 0 (or 1g)  
 Protein: 0g

## Making cream fun to drink and eat

Note: Use only the amount of cream allotted on your child's meal.  
 For recipes with whipped cream, weigh the cream after it has been whipped.

- Mix the cream with water to make it taste more like milk.
- Mix the cream with 5 drops of pure vanilla or chocolate extract. Thin this mixture with water or diet caffeine-free club soda.
- Make a "cream soda" by mixing the cream with diet caffeine-free diet sodas such as root beer.
- Mix whipped cream and a few drops of pure extract and sweetener. Eat with a spoon.
- Freeze whipped cream; flavor with pure extract and allowed sweetener.
- Mix whipped cream with allotted fruit (chopped). Eat with a spoon.
- Make "hot chocolate" by adding unsweetened baking chocolate (must be calculated) or pure chocolate extract (free food). Heat until warm.
- Make sherbet by whipping cream into sugar-free Jell-O™ (must be calculated) that is just about gelled. Serve frozen.
- Make eggnog with cream (from a calculated recipe). Eggnog can be microwaved or frozen.
- Add sour cream to whipped cream (from a calculated recipe). Add chopped fruit. Tastes like yogurt.

## Lean meat options

These meat and protein rich foods are grouped together because they have similar protein and fat content. They are listed on your meals as “Lean Meat”. Other protein rich foods such as chicken and fish, eggs and cheese are calculated separately on your menus. All meat should be cooked before it is weighed. Salt and pepper or a pinch of an herb or spice may be added during cooking.

- Beef roast – arm, chuck, eye, top sirloin, top round, bottom round
- Beef loin cuts – tenderloin, filet mignon, New York strip, t-bone, rib-eye
- Eye round of beef
- Lean ground beef – 80%
- Pork roast – loin end, pork tenderloin, pork loin
- Pork loin cuts/pork chops
- Turkey dark meat – thighs, legs



## Free foods

“Free foods” are foods that have little or no calories or they contain mostly fat calories. These foods are included to make meals more interesting. Some are limited to amounts shown below. See the Low Carb Product List on [www.charlifoundation.org](http://www.charlifoundation.org) for additional products.

**Extracts and flavorings** – Use up to 15 drops in one day. Imitation or pure extracts may be used.

**Examples:** Bickford™ Flavorings, McCormick™, Durkee™ & DaVinci Gourmet Sugar-Free Syrups

**Sweeteners** – Must be calorie and carbohydrate free.

- Liquid Saccharine products: Sweet’N Low, Sweet 10
- Stevia powders or liquids that are carbohydrate and calorie-free: Stevia powder or Better Stevia Original Liquid Extract – NOW Foods
- Necta Sweet™ Saccharine 1/2 grain tablets (dissolve in water)

**Beverages** – Give beverages in the amounts recommended for your child.

- Water or ice chips.
- Water sweetened with the above sweeteners.
- Flavored bottled water beverages that are caffeine, carbohydrate and calorie free.
- Herbal tea – without caffeine

**Nonstick cooking sprays** – Ingredient list should include a vegetable oil only (such as Canola).

One of the following may be eaten each day.

Additional amounts need to be calculated into your child’s meals.

- 25gm lettuce
- 3 small (ripe) black olives
- 1 black walnut
- 1 macadamia nut
- 1 pecan
- 3 hazelnuts (filberts)



**Herbs and spices** – Use just a pinch for flavor.

If you use more than a pinch, it should be calculated into the meal or snack that you are adding it to. Salt may be used as desired for seasoning.

- Pepper, basil, oregano, dill or other pure herbs.
- Cinnamon, nutmeg or other pure spices.

## Where can I find more information on how to handle holidays and special occasions now that my child is on the ketogenic diet?

Check out the following posts on the KetoConnect Blog by Nutricia:

<b>Holiday/ Special Occasion</b>	<b>KetoConnect Blog Post by Nutricia</b>
<b>Birthdays</b>	<a href="http://www.myketocal.com/blog/birthday-cakes-for-children-on-the-ketogenic-diet-part-1/">http://www.myketocal.com/blog/birthday-cakes-for-children-on-the-ketogenic-diet-part-1/</a> and <a href="http://www.myketocal.com/blog/birthday-cakes-for-children-on-the-ketogenic-diet-part-2/">http://www.myketocal.com/blog/birthday-cakes-for-children-on-the-ketogenic-diet-part-2/</a>
<b>Valentine's Day</b>	<a href="http://www.myketocal.com/blog/tips-and-recipes-for-making-valentines-day-fun-for-your-keto-kid/">http://www.myketocal.com/blog/tips-and-recipes-for-making-valentines-day-fun-for-your-keto-kid/</a> and <a href="http://www.myketocal.com/blog/how-to-make-valentines-day-extra-sweet-on-the-ketogenic-diet/">http://www.myketocal.com/blog/how-to-make-valentines-day-extra-sweet-on-the-ketogenic-diet/</a>
<b>Easter &amp; Passover</b>	<a href="http://www.myketocal.com/blog/a-dietitians-tips-for-celebrating-easter-on-the-ketogenic-diet/">http://www.myketocal.com/blog/a-dietitians-tips-for-celebrating-easter-on-the-ketogenic-diet/</a> and <a href="http://www.myketocal.com/blog/a-dietitians-tips-for-celebrating-passover-on-the-ketogenic-diet/">http://www.myketocal.com/blog/a-dietitians-tips-for-celebrating-passover-on-the-ketogenic-diet/</a>
<b>Summer Camp</b>	<a href="http://www.myketocal.com/blog/summer-camp-epilepsy-and-the-ketogenic-diet/">http://www.myketocal.com/blog/summer-camp-epilepsy-and-the-ketogenic-diet/</a>
<b>Back to School</b>	<a href="http://www.myketocal.com/blog/back-to-school-on-the-ketogenic-diet-blog-roundup/">http://www.myketocal.com/blog/back-to-school-on-the-ketogenic-diet-blog-roundup/</a>
<b>Halloween</b>	<a href="http://ketoconnect.com/2014/10/21/celebrating-halloween-on-the-ketogenic-diet/">http://ketoconnect.com/2014/10/21/celebrating-halloween-on-the-ketogenic-diet/</a>
<b>Thanksgiving</b>	<a href="http://www.myketocal.com/blog/celebrating-thanksgiving-on-the-ketogenic-diet/">http://www.myketocal.com/blog/celebrating-thanksgiving-on-the-ketogenic-diet/</a> and <a href="http://www.myketocal.com/blog/keto-friendly-thanksgiving-recipes/">http://www.myketocal.com/blog/keto-friendly-thanksgiving-recipes/</a>
<b>Christmas &amp; Hanukkah</b>	<a href="http://www.myketocal.com/blog/christmas-on-the-ketogenic-diet-blog-roundup/">http://www.myketocal.com/blog/christmas-on-the-ketogenic-diet-blog-roundup/</a> and <a href="http://www.myketocal.com/blog/a-keto-moms-tips-for-managing-the-holidays-on-the-ketogenic-diet/">http://www.myketocal.com/blog/a-keto-moms-tips-for-managing-the-holidays-on-the-ketogenic-diet/</a>

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# Troubleshooting Your Ketogenic Diet

Is your child following a ketogenic diet but not seeing the results? Simple changes to their daily intake such as drinking more water or cutting back on protein could be the difference between success and failure on a ketogenic diet.

Some common mistakes include:

## **Not Eating Enough Fat**

In order for the diet to be successful, you must eat high fat—not just low carb. Fat is a key to success.

## **Eating the Wrong Types of Fats**

Avoid processed fats such as vegetable oil blends. Instead, focus on a variety of natural fats like eggs, avocados, raw nuts, olive oil, butter, heavy cream, and coconut oil. Aim for 4-5 different fat sources throughout the day.

## **Not Drinking Enough Water**

Make sure to drink at least 6 cups of water each day. Water is crucial to keep your body function at it's best by circulating nutrients, flushing out toxins, and burning fats.

## **Eating Too Much Protein**

Eating too much protein will lead the body to convert it into glucose. When this happens, your body may not use fats as an energy source, derailing ketosis. Focus on adding fat sources that don't include protein like butter or oils over eggs and meat.

## **Excessive Snacking**

Be sure you are only snacking when you are truly hungry. Choose snacks like nuts, seeds, avocados, or cheese and focus on small portions.

## **Hidden Carbohydrates**

Many foods claim to be “low carb” but are not actually ketogenic diet friendly. Common hidden sources of carbs can be found in condiments, sauces, and salad dressing. Remember that foods labeled “low sugar” or “sugar free” does not mean low carb and may not be acceptable for your diet. Always read labels carefully.

If you are having trouble keeping your child in ketosis, talk with your child's dietitian about making adjustments.



# What to Know About “Keto” Products

Hundreds of foods have hit grocery stores claiming to be “keto friendly” or “certified keto.” But what do these titles mean and are they appropriate for a medical ketogenic diet?

## What do these titles mean?

Unfortunately, no one regulates the use of these titles. That means that there is no standard definition of what a product can or cannot include to claim that the food is keto friendly. Any manufacturer can put “keto friendly” on a product without any guidelines or standards. This doesn’t mean that these products can’t be included in a medical ketogenic diet, but you should always take a close look at the nutrition label on foods that claim to be “Keto-Friendly,” “Keto-Certified,” “Keto-Approved,” or “Keto Compliant.”

## Why aren’t all of these products ok for a medical ketogenic diet?

Often times, these products only focus on being low carb and do not take into consideration the fat and protein content. In many of these items, there is more protein and net carbs than fat, meaning that the ketogenic ratio is less than 1:1. Ketogenic meals should always have more fat than combined protein and net carbs.

## What is the solution?

Well chosen “keto friendly” products can work for some people. Generally, these should be eaten in small quantities (no more than 1 serving a day) and extra fat may be needed to increase the ratio to fit your diet. Most products can be paired with ½ an avocado or heavy whipping cream to add extra fat.

The following are examples of “keto friendly” products and how to increase the fat content:

### Nutrition Facts:

- Serving size: 1 container
- Calories: 200
- Total fat: 15 grams
- Net carbohydrate: 2 grams
- Protein: 15 grams
- Ketogenic ratio: 0.9:1



If you add 4 tablespoons of heavy whipping cream, the ketogenic ratio becomes 1.8:1.

### Nutrition Facts:

- Serving size: 1 slice
- Calories: 70
- Total fat: 4 grams
- Net carbohydrate: 7 grams
- Protein: 5 grams
- Ketogenic ratio: 0.6:1



If you add 1 tablespoon of butter, the ketogenic ratio becomes 2.25:1.

# Tips for Eating Out at Restaurants

While eating out at restaurants requires a little more planning when following the ketogenic diet, it is still possible to enjoy a delicious meal away from home!

## Keep It Simple

The best advice is to keep the meal simple. Order a plain meat, a plain non-starchy vegetable, and butter or avocado as your fat source. Never feel bad inquiring about menu options or asking for special requests.

- If you are using a ratio to follow the diet, remember to bring your scale so you can weigh the food.
- If you are using any other method to follow the diet, remember to bring measuring cups to make sure portion sizes are appropriate.
- If you think the restaurant might not have a certain food (for example, coconut oil) bring some from home.
- Always ask for the food to be plain. Many vegetables and meats in restaurants are topped with sauces or glazes that can contribute a large amount of carbohydrates.
- Try and choose 2 high fat foods at your meal. For example, ask for avocado slices and olive oil.
- Be cautious of condiments like barbecue sauce or ketchup, as they contain a high amount of carbohydrates.
  - Use keto friendly spices, herbs, and condiments instead! Salt, pepper, mustard, and hot sauce are good carb free options to add flavor.

Remember that most chain restaurants will have their menu available online with nutrition information. Evaluate restaurant options before you go and commit to a ketogenic option.

### Fast Food Options

- **Chicken:** 6 piece grilled chicken nuggets + side salad + 3 packets garlic and ranch dressing
- **Burger:** Bunless bacon cheeseburger + veggies + mayo
- **Sandwich:** Tuna salad + bacon + olive oil + avocado
- **Mexican:** Lettuce blend + carnitas (pork) + guacamole + cheese + fajita veggies + sour cream

### Restaurant Options

- **Mexican:** Grilled steak fajitas (meat only) + avocado slices + sour cream + small amount of white queso and pico de gallo
- **Steakhouse:** 6 ounce sirloin + sauteed mushroom + blue cheese + bacon
- **American:** Buffalo wings (traditional) + steamed spinach + ranch dressing
- **Seafood:** Steamed shrimp + asparagus + extra butter

# Tips for Following the Ketogenic Diet on a Budget

## Don't Fall Into the Name Brand Trap

Many keto recipes use brand-name products but purchasing equivalent store brand or generic brand can save you money. Just make sure to compare the nutrition labels!

## Don't Be Fooled by Marketing Plays

As the keto diet becomes more popular, an increasing number of products are hitting the market. In reality, a cheaper, equivalent product may work just as well. Always look at the ingredient in foods and supplements carefully and compare to other brands.

## Homemade May Be Cheaper

Foods marketed as “keto” such as shakes, energy bars, fat bombs, frozen meals, and desserts may be convenient but often come with a hefty price tag. Ditch these convenience products and make it yourself for cheaper.

## Food Prep is Key

Food prep is key to prevent food waste. Choose meals that have similar ingredients for the week so that you aren't stuck with a bunch of spoiled ingredients you never used. If you make a large batch of something, many meals are easily freezable.

## Fresh Isn't Always Better than Frozen or Canned

Frozen fruits and vegetables are available year-round for lower prices than fresh and are just as nutritional. Canned vegetables may also be okay (read the label to ensure there are no carbohydrate additives). Canned fruits are high in added sugar so make sure to read the nutrition label and use in moderation.

## Stock Up Smartly

Buy in bulk on frequently use ingredients. Be sure they are ingredients you will use before they spoil. Keep your fridge and pantry organized so you can see what is available. Consider re-packaging foods and freezing them into individual servings.

## Build Meals Around Sale Items

Check out the weekly sales ad and build your meals on what is on sale at your store.

## Shop Around

Compare prices on commonly used products. It may be cheaper to buy some things online versus at your local grocery store.

# Helpful Apps for Managing the Ketogenic Diet

There are many phone apps available for nutrition tracking that can be useful in managing a ketogenic or modified-Atkins diet.

## MyFitnessPal

- Contains a large database of nutrition information for packaged products, raw foods, restaurants, and fast food chains
- Features a barcode scanner to easily find nutrition information for packaged products
- Allows you to log and track food intake
- Servings can be entered in grams or measures
- Displays daily macronutrients to easily compare how much fat, carbohydrate, and protein has been consumed

## Cronometer

- Contains a large database of nutrition information for packaged products, raw foods, restaurants, and fast food chains
- Allows you to log and track food intake
- Servings can be entered in grams or measures
- Displays daily macronutrients to easily compare how much fat, carbohydrate, and protein has been consumed

## CalorieKing

- Contains a large database of nutrition information for packaged products, raw foods, restaurants, and fast food chains
- Can be used without internet access

# Acetaminophen and Ibuprofen

## Guidelines for ketogenic diet patients

### If your child weighs less than 24 pounds:

- Use the correct dose of infant acetaminophen (Tylenol) or ibuprofen (Motrin) for your child's age and weight.
- Give an extra 3 grams of oil. This is to make up for the carbohydrates in these medicines.
- Give the added oil with each dose.

### If your child weighs more than 24 pounds:

- You may give the medicines listed below. Use the correct dose for your child's weight.
- You do not have to add extra fat.

**Acetaminophen (Tylenol)** Use 325 mg tablets (regular strength). Split tablets with a pill splitter.

Weight in pounds (lbs)	Weight in kilograms (kg)	Dose in milligrams (mg)	Dose in tablets (tabs)
24 to 47 lbs	11 to 21 kg	162.5 mg	½ tabs
48 to 59 lbs	21 to 31 kg	325 mg	1 tab
72 to 95 lbs	31 to 43 kg	487 mg	1 ½ tabs
More than 95 lbs	More than 43 kg	650 mg	2 tabs

**Ibuprofen (Motrin)** Use 200 mg tablets. Split tablets with a pill splitter.

Weight in pounds (lbs)	Weight in kilograms (kg)	Dose in milligrams (mg)	Dose in tablets (tabs)
24 to 47 lbs	11 to 21 kg	100 mg	½ tabs
48 to 59 lbs	21 to 31 kg	200 mg	1 tab
72 to 95 lbs	31 to 43 kg	300 mg	1 ½ tabs
More than 95 lbs	More than 43 kg	400 mg	2 tabs

### Helpful hints

- It is OK to use generic or store brands of acetaminophen or ibuprofen
- Do not give ibuprofen to a child under the age of 6 months
- Be sure to use regular strength only, extra strength will provide too much

# Ketogenic Diet – Product List

## Low-carb and No-carb products

### Toothpaste

Use a pea-sized amount, and avoid swallowing

#### **Country Gent Tooth Powder (with and without fluoride)**

[www.dentist.net/naturalproducts](http://www.dentist.net/naturalproducts)

Ingredients: Calcium carbonate, sodium bicarbonate, Stevia, cornstarch, sodium fluoride (in the fluoride product)

#### **ECO-DENT Daily Care Tooth Powder**

Ingredients: Fluoride-free. Sodium bicarbonate (baking soda), tartaric acid, sodium methyl cocoyl taurate, dicalcium phosphate dihydrate, calcium carbonate, magnesium carbonate, sea salt, hydrated silica, mentha piperita (peppermint) oil, menthol, anethole, cyamopsis tetragonoloba (guar) gum, commiphora myrrha (myrrh) resin extract. 100% CRUELTY- FREE SLS-Free. NO DYES OR SWEETENERS

#### **Arm & Hammer Advance White Toothpaste with Baking Soda & Peroxide Church & Dwight Co.**

Ingredients: Sodium fluoride (0.24%). Sodium bicarbonate (baking soda), PEG-8, PEG/PPG-116/66 copolymer, sodium carbonate peroxide, tetrasodium pyrophosphate, silica, sodium lauroyl sarcosinate, sodium saccharin, flavor, water, sodium lauryl sulfate

#### **Tropical Traditions Mint Teeth Cleaner**

Ingredients: Purified water, organic virgin coconut oil, baking soda, xanthum gum, wildcrafted myrrh powder, Stevia, organic essential oils of peppermint and spearmint

#### **Tom's of Maine**

The following toothpastes contain less glycerin (carbohydrate) by weight than most toothpastes:

- Peppermint Baking Soda Cavity Protection (36.3% CHO)
- Spearmint Cavity Protection (42.6% CHO)
- Orange Mango Whole Care Gel Fluoride (46.9% CHO)
- Children's Silly Strawberry Fluoride (47.28%)
- Wintermint Cavity Protection (47.7%)

## Lip Balm

### **Burt's Beeswax Lip Balm**

Ingredients: Cera alba (beeswax, cire d'abeille), cocos nucifera (coconut) oil, helianthus annuus (sunflower) seed oil, mentha piperita (peppermint) oil, lanolin, tocopherolrosmarinus officinalis (rosemary) leaf extract, glycine soja (soybean) oil, canola oil (huile de colza), limonen

### **Lifeguard's Choice Lip Balm**

Ingredients: Beeswax, cocos nucifera (coconut) oil, helianthus annu (sunflower) seed oil, tocopheryl acetate, lanolin, titanium dioxide, mentha piperita (peppermint) oil, symphytum officinale (comfrey) root extract, rosmarinus officinalis (rosemary) extract

### **Medicated Lip Balm**

Ingredients: Camphor (0.6%), menthol (0.6%) Inactive ingredients: Vitis vinifera (grape) seed oil, beeswax, cocos nucifera (coconut) oil, lanolin, butyrospermum parkii (shea butter), illicium verum (anise) oil, elettaria cardamomum (cardamom) seed oil, mentha arvensis (cornmint) leaf oil, eucalyptus globulus (eucalyptus) leaf oil, mentha viridis (spearmint) leaf oil, eugenia caryophyllus (clove) flower oil, vanillin, calendula officinalis flower extract, melissa officinalis (lemon balm) leaf extract, ribes nigrum (black currant) leaf extract, hydrastis canadensis (golden seal) extra

### **Coconut Oil (may be found in glass or plastic jars)**

Ingredients: Coconut oil is extracted from the dried inner flesh of coconuts. It is used as an ingredient in foods, cosmetics and moisturizers and is a pure moisturizer on its own for skin and lips.

### **Neutrogena Lip Moisturizer, SPF 15**

Ingredients: Octinoxate - 7.5% Sunscreen, oxybenzone - 4.0% sunscreen Inactive ingredients: Castor (ricinus communis) seed oil, corn (zea mays) oil, ozokerite, petrolatum, beeswax, ethylhexyl palmitate, paraffin, stearyl alcohol, carnauba (copernicia cerifera) wax, BHT

### **Tropical Traditions Unscented Lip Moisturizer**

(for those who have allergies or are sensitive to fragrance)

Ingredients: Organic virgin coconut oil, organic beeswax, organic virgin palm oil

### **Tropical Traditions Coconut Lip Moisturizer**

Ingredients: Organic virgin coconut oil, organic beeswax, organic virgin palm oil, organic coconut oil flavor





## Ketogenic Diet – Supplies List

- Keto Mojo Meter**
  - Blood ketone testing meter available on Amazon for \$44.99
- Urine ketone test strips**
  - These are available over the counter and are most often stored with diabetes supplies in pharmacies, grocery stores, and drug stores
- Your child’s favorite plate, bowl, cup or bottle, and utensils**
- Supplements advised for your child**
  - Please check with your child’s dietitian for recommendations before you buy any supplements.  
  
You may look online for coupons at [www.caltrate.com/coupons](http://www.caltrate.com/coupons) and [www.centrum.com/register-for-your-coupon](http://www.centrum.com/register-for-your-coupon)
- All medicines your child is taking right now**
  - Keep them in their original bottles with pharmacy labels
- Pill crusher**
- Small rubber spatula**
- Optional: vanilla extract, liquid Stevia, and low-carb toothpaste**
  - You may check the Charlie Foundation Resource Low-Carb/Carb-Free Lists at: [www.charliefoundation.org/resources-tools/resources-3/low-carb](http://www.charliefoundation.org/resources-tools/resources-3/low-carb) for more details on which products are approved for use on the ketogenic diet. Talk with your child’s care team if you have questions.

# Ketogenic Diet – Resources

## Modified-Atkins Diet

You may find more details online at these sites:

- Atkins for Seizures: <http://atkinsforseizures.com>
- Carley's Carbless Kitchen: <http://carleyscarblesskitchen.com/>
- Modified Ketogenic Diet Therapy Booklet from the Charlie Foundation (Book): [www.charlifoundation.org/store-home/media-videos-books/item/1017-modified-ketogenic-booklet](http://www.charlifoundation.org/store-home/media-videos-books/item/1017-modified-ketogenic-booklet)
- CalorieKing Carb Counter (Book): [www.calorieking.com/products/books](http://www.calorieking.com/products/books)

## Parent and Patient Support Groups

You may find more details online at these sites:

- The Charlie Foundation: [www.charlifoundation.org](http://www.charlifoundation.org)
- Matthew's Friends: [www.matthewsfriends.org](http://www.matthewsfriends.org)
- The Carson Harris Foundation: [www.carsonharrisfoundation.org/](http://www.carsonharrisfoundation.org/)
- Dravet Syndrome Foundation: [www.dravetfoundation.org/](http://www.dravetfoundation.org/)
- Glut-1 Deficiency Foundation: [www.g1dfoundation.org/](http://www.g1dfoundation.org/)
- Anita Kaufmann Foundation: [www.akfus.org/](http://www.akfus.org/)
- Atkins for Seizures: <http://atkinsforseizures.com>
- Citizens United for Research in Epilepsy (CURE): [www.cureepilepsy.org/](http://www.cureepilepsy.org/)
- The Intractable Childhood Epilepsy (ICE) Alliance: [www.ice-epilepsy.org/](http://www.ice-epilepsy.org/)
- Lennox Gastaut Syndrome Foundation: [www.lgsfoundation.org/](http://www.lgsfoundation.org/)
- Angelman Syndrome Foundation: [www.angelman.org/](http://www.angelman.org/)
- Carley Eissman Foundation: <http://carleyeissmanfoundation.org/>
- International League Against Epilepsy (ILAE): [www.ilae.org/](http://www.ilae.org/)

Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products, services or the content or use of any third party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these Sites. Use of the links provided on this or other sites is at your sole risk.

# Glossary

**Antiepileptic drug (AED):** Medicine used to help control seizures.

**Calorie:** A way to measure the energy found in food.

**Carbohydrate:** One of 3 main nutrients (along with protein and fat) that gives the body calories (energy). Carbohydrates include starches and sugars.

**Carnitine:** A nutrient found in most cells in your child's body. Carnitine helps move fatty acids into the cell so your child's body can make energy.

**Cholesterol:** A type of fat found in your child's body. Your child's liver makes some cholesterol. It can also be found in foods such as eat, fish, eggs, butter, cheese, and milk. Cholesterol levels can be checked in your child's blood.

**Constipation:** A change in your child's bowel movement and stool pattern. Your child's stool may be harder and painful to pass.

**Dietitian:** An expert in diet and nutrition.

**Electrocardiogram (ECG or EKG):** A test that shows the electrical activity of your child's heart.

**Electroencephalogram (EEG):** A test that shows the electrical activity of your child's brain.

**Epilepsy:** 2 or more unprovoked seizures. Unprovoked means the seizure was not related to fever, injury or electrolyte imbalance.

**Excess ketosis:** When your child's body makes too many ketones. Signs of excess ketosis are nausea, fast and shallow breathing, reddened face, vomiting, and extreme sleepiness.

**Fat:** One of 3 main nutrients (along with protein and carbohydrate) that gives the body calories (energy). There are many different types of fats. Some fats are better for your child than others.

**Fiber:** A type of carbohydrate that your child's body does not digest. It is naturally found in plant foods.

**Glucose:** The main type of sugar in the blood that gives your child's body energy.

**Gram:** A unit to measure mass or weight.

**Gram scale:** A scale that measures food or formula in grams.

**Hyperglycemia:** High blood sugar. Signs of high blood sugar are increased urination, extreme thirst, and unexplained weight loss.

**Hypoglycemia:** Low blood sugar. Signs of low blood sugar are pale skin, sweating, dizziness, nausea, and extreme sleepiness.

**Ketogenic diet (KD):** A high fat, adequate (enough) protein, low carbohydrate diet. KD should only be done under medical supervision. KD is mostly used to treat hard to control seizures.

**Ketones:** Ketones are made when fat breaks down in the liver. Your child's body can use ketones for energy instead of glucose. Ketones can be checked in your child's blood or urine. Ketones seem to help with seizure control.

**Ketosis:** Large amount of ketones in your child's body. Ketosis happens when your child's body uses fat for energy instead of glucose.

**Kidney stones:** Small mineral deposits that can form inside your child's kidneys. Kidney stones can block the flow of urine.

**Lethargic:** More drowsy than usual or having less energy than usual.

**Long chain triglycerides (LCTs):** The main type of fat found in foods.

**Medium chain triglycerides (MCTs):** A type of fat found in a small number of foods such as coconut oil. Your child's body uses MCTs differently than other fats. MCTs are more ketogenic. Large amounts of MCTs can cause abdominal discomfort, diarrhea, or vomiting. Your child's dietitian will help you add the right amount of MCTs to your child's diet.

**Modified Atkins diet (MAD):** A more liberal version of the ketogenic diet. MAD should only be done under medical supervision. MAD is about a 1:1 ratio.

**Net carbohydrates:** To measure net carbohydrates, take away the grams of fiber from the total grams of carbohydrate.

**Neurologist:** A doctor who is an expert of the nervous system. A neurologist will manage your child's diet treatment for epilepsy.

**Protein:** One of 3 main nutrients (along with fat and carbohydrate) that gives the body calories (energy). Protein is important for your child's growth.

**Ratio:** The amount of fat compared to the amount of protein and carbohydrate combined. A 4:1 ratio has 4 grams of fat for every 1 gram of protein and carbohydrate combined.

**Recipe:** Instructions for preparing your child's meals or formula.

**Seizure:** Abnormal electrical discharges in the brain.

**Urine ketone testing strips:** Test strips used to check for ketones in your child's urine.



# Modified-Atkins Diet Post Test

1. Why does your child need to be on the diet? \_\_\_\_\_

\_\_\_\_\_

2. What does the body use for energy on the diet? \_\_\_\_\_

3. When the diet begins, how long will you try it for? \_\_\_\_\_

4. Which macronutrient is restricted on the diet? \_\_\_\_\_

5. Circle the foods below that are carbohydrates:

Bread      Chicken      Banana      Olive oil      Egg      Ranch dressing

Salmon      Cereal      Avocado      Milk      Black beans      Butter

Beef      Potato      Rice      Sour cream      Crackers      Bacon

6. List 5 fat sources: \_\_\_\_\_

\_\_\_\_\_

7. List 3 carbohydrate-free beverages besides water: \_\_\_\_\_

\_\_\_\_\_

8. List 3 symptoms of hypoglycemia: \_\_\_\_\_

9. How is hypoglycemia treated? \_\_\_\_\_

10. List 3 other possible side effects of the diet: \_\_\_\_\_

\_\_\_\_\_

# Nutrition Facts

8 servings per container

**Serving size** 2/3 cup (55g)

**Amount per serving**

**Calories** 230

**% Daily Value\***

**Total Fat** 8g 10%

Saturated Fat 1g 5%

*Trans Fat* 0g

**Cholesterol** 0mg 0%

**Sodium** 160mg 7%

**Total Carbohydrate** 37g 13%

Dietary Fiber 4g 14%

Total Sugars 12g

Includes 10g Added Sugars 20%

**Protein** 3g

Vitamin D 2mcg 10%

Calcium 260mg 20%

Iron 8mg 45%

Potassium 235mg 6%

\* The % Daily Value (DV) tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.

12. What is the serving size of this food?

\_\_\_\_\_

13. How many grams of **total** carbohydrates are in a serving of this food?

\_\_\_\_\_

14. How many grams of **net** carbohydrates are in a serving of this food?

\_\_\_\_\_

15. If your child ate 1 1/3 cups of this food,

how many net carbohydrates would they

have eaten? \_\_\_\_\_