



Ketogenic Diet Therapy for Adults with Epilepsy

Kelly Faltersack, MS, RD, CD

Clinical Nutritionist, UW Health

Elizabeth Felton, MD, PhD

Assistant Professor, Department of Neurology
University of Wisconsin – Madison



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Disclosures



- Kelly Faltersack, MS, RD, CD
 - Receiving an honorarium from Nutricia for this presentation
 - I have no conflict of interest for this talk
- Elizabeth Felton, MD, PhD
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Learning Objectives



- Identify adults who may benefit from ketogenic diet therapy
- Discuss evidence supporting the use of ketogenic diet therapy in adults
- Understand unique considerations for starting ketogenic diet therapy in adults (compared to children)
- Learn about tools to help adults be successful when starting ketogenic diet therapy

Overview



- What will be covered
 - Approach to managing ketogenic diet therapy in adults with epilepsy
- What will not be covered
 - Ketogenic diet basics
 - See 8/2016 webinar by Zahava Turner, RD, CSP, LD
 - In depth review of modified Atkins diet
 - See 5/2017 webinar by Stacy Bessone, RDN, LDN
 - Details about refractory epilepsy
 - See 12/2017 webinar by Dr. Arthur Partikian

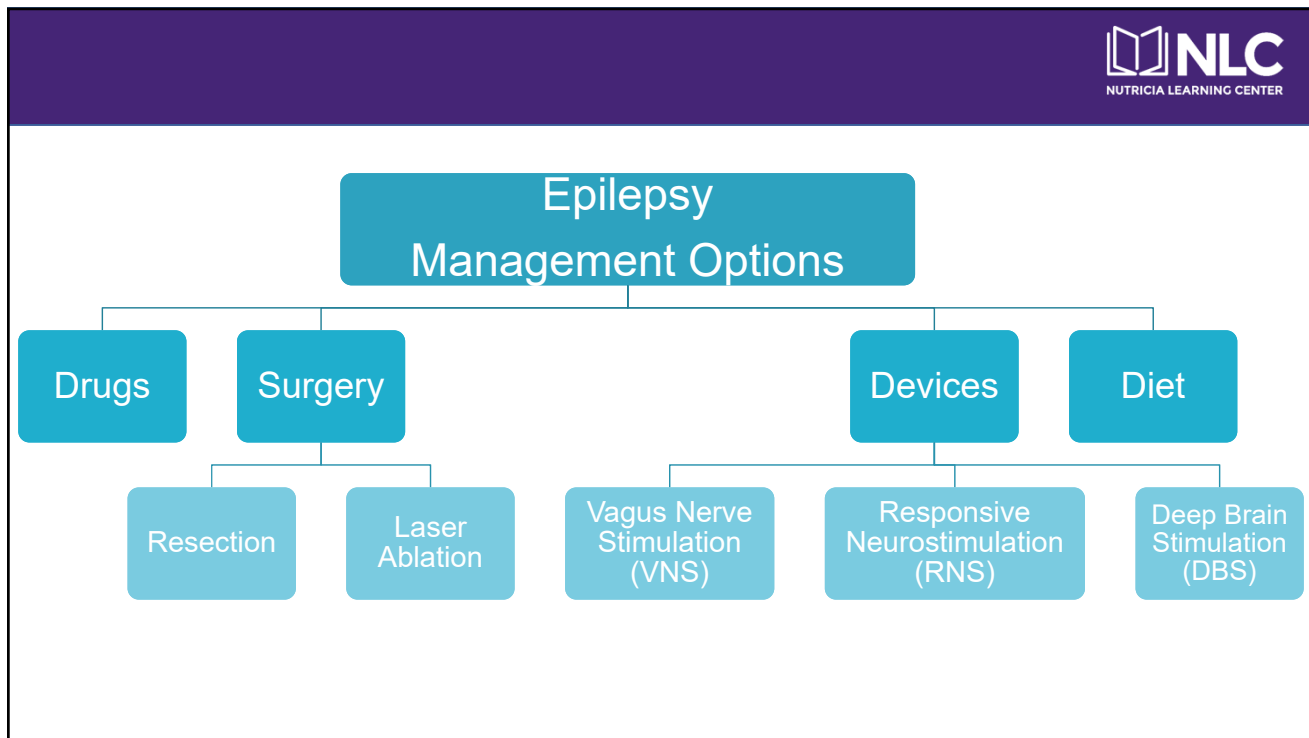


Brief Background

Epilepsy Statistics



- 4th most common neurological problem
 - After migraine, stroke, and Alzheimer's disease
- 1 in 26 will develop epilepsy
- Incidence in USA
 - 150,000 new diagnoses/year (48/100,000 people)
- Prevalence
 - 3 million adults and 470,000 children in USA
 - 50 million worldwide
- 30-40% poorly controlled



What is a Ketogenic Diet?

- High fat, low carbohydrate, moderate protein medical nutrition therapy
- Designed to mimic a fasting state and induce nutritional ketosis
- Metabolism is altered so that the body uses fat for energy instead of glucose



Ketones



- Liver breaks down fat into ketone bodies
- Ketones can be used by brain for energy
- Useful marker of compliance
- Patients can easily check at home

Ketone	Where measured	How measured
Acetoacetate	Urine	Urine ketone test strips
Acetone	Breath	Breath meter
β-hydroxybutyrate	Blood	Blood glucose/ketone meter

Nutritional Ketosis ≠ Ketoacidosis



Table 1. Blood levels during a normal diet, ketogenic diet, and diabetic ketoacidosis

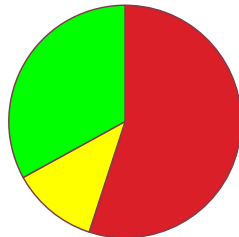
Blood Levels	Normal Diet	Ketogenic Diet	Diabetic Ketoacidosis
Glucose (mg/dl)	80-120	65-80	>300
Insulin (μU/l)	6-23	6.6-9.4	≅0
KB Conc (mmol/L)	0.1	7/8	>25
pH	7.4	7.4	<7.3

Table adapted from Paoli A. et. al. Eur J Clin Nutr. 2013.

Macronutrient Composition



Standard American



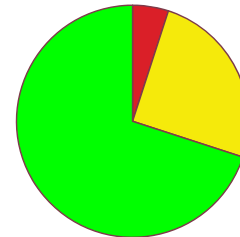
■ Carbohydrates
■ Protein
■ Fat

Classic Ketogenic



■ Carbohydrates
■ Protein
■ Fat

Modified Atkins Diet

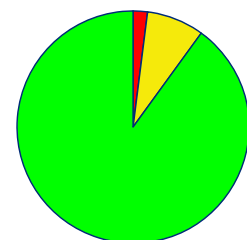


■ Carbohydrates
■ Protein
■ Fat

Classic Ketogenic Diet



- 90% of calories from fat!
 - Typically a 4:1 ratio
 - Fat (g) : carbohydrate (g) + protein (g)
- Use for adults receiving enteral nutrition
 - G-tube dependent
 - Inpatients in status epilepticus
- Often started in the hospital over 3-4 days
 - We have had success with slow outpatient initiation to lower ratios

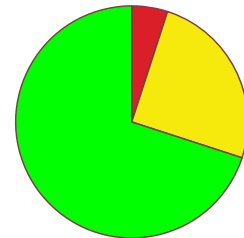


■ Carbohydrates
■ Protein
■ Fat

The Modified Atkins Diet (MAD) Kossoff 2003



- 10-20 grams net carbohydrates
(net = total carbs - fiber)
 - Adults: typically 20 g net carbs
 - Count carbs by using food labels
- No calorie or fluid restriction
- No need to weigh foods
- Easy to start as an outpatient



- Carbohydrates
- Protein
- Fat



Approach to Managing Ketogenic Diet Therapy in Adults

“Adults are not big children”

Dietary therapy DOES work for adults



- Early studies (1930s) showed efficacy in adults¹
- Most studies from 1980s and 1990s focused on efficacy in children
- More recent studies (2010s) again showing efficacy in adults^{2,3,4}
 - About 50% of patients have >50% seizure reduction
 - About 6-13% seizure free
- Compare that with adding another drug!
 - 1% seizure free on fourth drug regimen
- Other benefits beyond total # of seizure reduction

1. Barborka CJ. Arch Neurol 1930.
2. Payne NE, et. al. Epilepsia. 2011.

3. Kossoff EH, et. al. Epilepsy Behav. 2013.
4. Cervenka MC, et. al. Epilepsy Behav. 2016

Ketogenic Diet Therapy Clinics



- Pediatric
 - Most major academic medical centers
 - Commonly accepted, guidelines exist
- Transition
 - Increasing focus on pediatric to adult transition in neurology
 - Almost non-existent for ketogenic diet therapy
- Adult
 - Very few dedicated clinics with an adult neurologist and ketogenic dietitian focused on adults
 - Yet rapidly increasing patient interest

Kossoff EH, et. al. Epilepsia. 2018.

Adult patients who may be interested in ketogenic diet therapy



- Young adults on a ketogenic diet since childhood
- Drug resistant / medically refractory epilepsy patients
 - Not a surgical candidate
 - Surgical candidate, but not interested
 - Status post surgery, still having seizures
 - Acute super refractory status epilepticus
- Non-refractory epilepsy patients
 - Interested in lowering medication
 - Intolerant to medication side effects
 - Interested in “alternative” options
 - Interested in diet for other reasons and hoping for dual-benefit

UW Health Adult Epilepsy Dietary Therapy Clinic



- Multidisciplinary team
 - Adult neurologist / epileptologist
 - Registered dietitian nutritionists
 - Epilepsy nurses
 - Epilepsy pharmacists

UW Health Adult Clinic Workflow



- Referral by primary neurologist or PCP
- 1-hour clinic visit with MD and RD
- 2-hour education session with RD
 - Intensive instruction about the diet
 - Starter kit
- 1- and 3-month follow-ups, then every 3-6 months
- Quarterly cooking classes
- Patient continues to follow with their primary neurologist (if applicable)



Visit 1: Initial Consultation



- 1-hour visit with physician and dietitian
- Take a general epilepsy history
- Screening questions focused on adults
 - Coexisting medical conditions to consider *
 - Medications *
 - Plan for pregnancy *
 - History of eating disorder
 - Pre-existing food restrictions (allergies, gluten-free, vegetarian, vegan, low-FODMAP, organic, artificial sweetener avoidance, etc.)

Coexisting Medical Conditions



Medical Condition	Pre-ketogenic diet therapy	After starting ketogenic diet therapy
Type 2 Diabetes	<ul style="list-style-type: none"> Baseline HgBA1C and review of medications Make sure managing provider is on board 	<ul style="list-style-type: none"> Monitor blood sugar Improvement in glycemic control is common May require medication adjustment
Hypertension	<ul style="list-style-type: none"> If uncontrolled, need to address prior to starting ketogenic diet therapy 	<ul style="list-style-type: none"> Improvement in BP is common May require medication adjustment
Obesity	<ul style="list-style-type: none"> Establish weight goals Make it clear that weight loss is not primary focus 	<ul style="list-style-type: none"> Weight loss is common and can be motivating! Assess for losing weight too quickly
Hypercholesterolemia	<ul style="list-style-type: none"> If very elevated at baseline, proceed with caution 	<ul style="list-style-type: none"> Lipids often increase initially, then trend towards baseline by 1 year If elevated triglycerides – assess for low carnitine

Coexisting Medications



- Adults may be on medications that require additional monitoring
- Examples (focus on non-epilepsy medications):

Medication	Concern	Recommendations
Certain blood pressure medications, such as diuretics	Electrolyte disturbance (potassium, magnesium)	Check electrolytes 1 month after starting ketogenic diet therapy
Oral hypoglycemic, insulin, metformin	Hypoglycemia	Obtain blood glucose/ketone meter and monitor blood sugar, so med adjustments can be made
Olanzapine and other drugs that can increase lipids	Elevated lipids	Check lipid panel more often
Liquid or sublingual medications	Hidden carbohydrates	Convert to pill when possible Check carbohydrate content

Pregnancy



- Not enough evidence to know if ketogenic diet therapy is safe to continue during pregnancy
 - One case report with 2 patients
- We do not advise starting ketogenic diet therapy if considering pregnancy
- If a woman becomes pregnant
 - Need to weigh risks/benefits
 - Evaluate existing literature at that time

Van der Louw EJ et al. Seizure. 2017.

Visit 1: Initial Consultation cont.



- Discuss potential side effects
 - Important for patients to be aware of these
- Discuss potential benefits
- Review our clinic's experience offering ketogenic diet therapy to adults

Side Effects – Our Experience



Most Common	Occasional	Less Common
Constipation	Other GI side effects (e.g. bloating, diarrhea)	Renal stones
Weight loss	Dizziness / lightheadedness	Acidosis
	Hyperlipidemia	Weight gain
	Nutrient deficiency (e.g. vitamin D, carnitine)	Hair thinning or loss
	Change in menstrual patterns	Hypoglycemia

Beneficial Effects – Our Experience



Medical Conditions	Other
Decreased and/or less severe seizures	Able to go back to work
Weight loss	Improved concentration/focus
Improved blood pressure	More energy
Improved mood	Improved endurance

Visit 1: Initial Consultation cont.



- Patient receives folder
 - ▣ Intake form (includes 3-day food record)
 - ▣ Clinic flier and our business cards
 - ▣ Calendars to record seizures
 - ▣ Charlie Foundation informational handouts
- Baseline labs ordered
- Patient instructed to think about it, get labs, and return intake form

Baseline Labs



All patients	Select patients
Complete metabolic panel, Magnesium, Phosphorus	Selenium
Complete blood count	Zinc
Lipid Panel	Copper
Vitamin D	Vitamin B12, Folic Acid, MMA, Homocysteine
Carnitine (free and total)	Urine organic acids
Urinalysis	Serum amino acids
Urine pregnancy (women)	Urine stone risk panel
Anti-seizure medication levels	Hemoglobin A1C
	Beta-hydroxybutyrate (BHB)

Visit 2: Dietitian Education Session



- 2-hour outpatient education session
- We encourage anyone involved in food prep to attend
- Provide individualized education and resources

- “Keto starter kit” includes:

- Binder of educational materials
- Urine ketone test strips
- Recipe cards from our cooking classes
- *The Modified Keto Cookbook*
- Silicone molds for fat bombs
- Charlie Foundation pocket guide
- Product samples
- *The Ketogenic and Modified Atkins Diets: Treatments for Epilepsy and Other Disorders* (book)



Visit 3: 1 month check in



- 30-minute visit with MD and RD
- Fill out brief follow-up survey while waiting
- Check vitals, including weight
- Review seizure/ketone calendars
- Check labs (in certain circumstances)
- Focus on side effects, barriers, first impressions of efficacy and other benefits
- Ongoing education and troubleshooting
- Most important: provide encouragement!

Visit 4: 3-4 month check in



- 30-minute visit with MD and RD
- Similar to 1-month check in
- Review seizure/ketone calendars
- 3-month labs reviewed
- Decide at this point if they want to continue
- Subsequent visits every 3 months for the first year, then every 3-6 months

Cooking Classes



- Quarterly cooking classes in Learning Kitchen
- Informal support group for patients and families
- Learn cooking skills
- Try keto-friendly ingredients



The Learning Kitchen



Common Mistakes



- ❑ Eating too many carbs
- ❑ Not eating enough fat
- ❑ Eating too much protein
- ❑ Issue with ketone test strips

Challenges Faced by Some of Our Adult Patients



- ❑ Little experience reading food labels
- ❑ Little experience cooking
- ❑ Coexisting memory impairment
- ❑ Limited financial means to afford food
- ❑ Limited access to grocery stores
- ❑ Poor social support
- ❑ Need to cook separate meals for family
- ❑ Caregivers who are not on board with or don't understand ketogenic diet therapy
- ❑ Caregivers need to prepare and send food for work or day programs
- ❑ Social situations / eating out
- ❑ Vacations

Air Travel



- ❑ Airport security letter
 - Allowed to bring extra fluids and food through airport security
 - Allowed to bring an extra carry-on bag
- ❑ Tips
 - Patient should present letter and state "I need this for medical reasons"
 - Pack foods and oils in clear containers
 - Use clearly labeled unopened packages
 - Can bring baked goods
- ❑ Disclaimer: We are not able to guarantee this will work, but some of our patients who travel frequently have reported success!

Alcohol



- Limited amounts of low carbohydrate alcohol are okay
- Caveats
 - Only if no other contraindications
 - Will feel the effects of alcohol more quickly
 - Too much alcohol could compromise ketosis
 - Need to count carbs from alcohol



Expanding Use of Ketogenic Diet Therapy in Adults

Ketogenic Diet for Status Epilepticus



- Ketogenic diet therapy has been successfully used as an emergent, acute therapy in adults with status epilepticus
- Tips
 - Protocols and orders sets are important to prevent errors
 - UW Health Clinical Practice Guideline
 - No propofol in last 24 hours
 - Pharmacy assistance to remove dextrose from IV fluids and minimize carbohydrates in medications
 - Hypoglycemia is only treated if less than 50
 - Carbs are everywhere!
 - Even in personal care products

Cervenka MC et. al. Neurology. 2017.

Other Neurologic Conditions



- www.clinicaltrials.gov
- www.pubmed.gov



Ketogenic Diet Therapy in Adults Final Tips and Resources

What about recent trends/fads?



- Exogenous ketones
 - Increase BHB (acutely) but may not help with seizure control
 - May inhibit endogenous ketone production
- Cannabidiol (CBD) oil
 - Recently FDA approved for pharmaceutical use
 - Absorbed better with a fatty meal
- Fasting / Intermittent Fasting
- Mainstream Keto
 - Usually not equivalent to the medical nutrition therapy discussed in this presentation
 - Should ideally occur only after consultation and ongoing support from MD/RDN

Electronic Health Record - Tips



- Smart Phrases
- Best Practice Alerts (BPA)
- Order sets

Patient Resources



Resources:

- The Charlie Foundation: <https://charliefoundation.org/>
- *The Ketogenic and Modified Atkins Diets*. Kossoff EH et al. New York, NY: Demos Medical Publishing; 2016.
- Practice Paper of the Academy of Nutrition and Dietetics: Classic and Modified Ketogenic Diets for Treatment of Epilepsy. Roehl K, Sewak SL. *J Acad Nutr Diet*. 2017;117:1279-92.

Recipes:

- <https://www.uwhealth.org/epilepsy-seizures/epilepsy-services-ketogenic-diet-recipes/49959>
- <https://charliefoundation.org/category/recipes/>
- <https://www.ruled.me/>
- MyKetoPlanner <http://www.myKetoPlanner.com>
- *The Modified Keto Cookbook: Quick, Convenient Great-Tasting Recipes*. Martenz DM, Zupec-Kania, B. Springer Publishing Company; 2015.

Patient Resources cont.



Carbohydrate Counting:

- ❑ Calorie King: <https://www.calorieking.com/> (also available as a free mobile app)
- ❑ USDA National Nutrient Database
<http://ndb.nal.usda.gov/>
- ❑ Carb Manager mobile app
<https://www.carbmanager.com/>
- ❑ Chron-o-meter mobile app <https://cronometer.com/>

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Questions?

Kelly Faltersack, MS, RD, CD

Elizabeth Felton, MD, PhD

Adult Epilepsy Dietary Therapy Clinic
<https://www.uwhealth.org/ketogenicdiet>



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