



Medical Ketogenic Diet Myth Busting



Presented By:

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2



Disclosures

- Consultant, Keto Ambassador for Nutricia North America
- Consultant, Scientific Advisory Board for Cerecin

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3

Objectives



- Assess **diet initiation methods** for the medical ketogenic diet
- Distinguish factors that go into **choosing an appropriate enteral formula** for patients on the medical ketogenic diet
- Explain ways to **dispel myths** regarding the medical ketogenic diet to patients and professionals

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Myth #1

All patients should start the KD inpatient

All patients should start the KD outpatient

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Fact Check



Dietary Element	LGIT	MAD	MKD	CKD
Carbohydrate (excluding fiber)	10% of kcals GI < 50	10-20 g/day	15-30 g/day or 5% of kcals	4% of kcals
Fat	60% of kcals	Ad lib (LCT)	60-80% of kcals	90% of kcals
Protein	30% of kcals	Ad lib	Ad lib	6% of kcals
Food Measurements	Weighed; Household	Visual	Weighed; Household	Weighed
Ketone Testing	Urinary	Urinary	Urinary and blood	Blood
Prescribed ketogenic nutritional products	No	Initiation Only (LCT)	Yes (LCT/MCT)	Yes (LCT)

Martin-McGill KJ, Lambert B, Whiteley VJ, et al. Understanding the core principles of a 'modified ketogenic diet': a UK and Ireland perspective. J Hum Nutr Diet. 2019;32:385-90.

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Fact Check



Inpatient support

- Classic KD
- Controlled environment
- Time for RD to teach management
- Insurance coverage for pt
- Monitoring
- Connections to services

Consensus statement:

80% of centers surveyed begin the classic KD in the hospital

Kossoff EH, et al. Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International Ketogenic Diet Study Group. *Epilepsia Open*. 2018;3:175-92.

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Fact Check



Classic Ketogenic Diet Initiation Options

Diet	Rapid Start	Gradual: Ratio Increment	Gradual: Meal by Meal
Initiation Time	3-5 days	1-8 weeks or longer	1-3 weeks
Supervision	Hospital	Home	Home
Method	1. 1:1 Day 1 2:1 Day 2 3:1 Day 3	Begin at 1:1 ratio for all meals. Increase ratio by ½ step weekly	Week 1: goal ratio 1 meal Week 2: goal ratio 2 meals
	2. Start with 3:1 or 4:1 with increasing keto meals daily	Stop at the ratio that yields the best outcome	Week 3: goal ratio for 3 meals and all snacks

Zupec-Kania B, Vanatta L, Johnson M. *Ketogenic Diet Therapies for Neurological Disorders Pocket Guide*. 3rd ed The Charlie Foundation for Ketogenic Therapies; 2021.

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9

Fact Check



Outpatient support

- MAD / LGIT / MKD
- Comfortable environment for pt
- RD teaching by video or email
- Insurance coverage
- Flexible monitoring
- Patient driven

Consensus statement:

92% of centers surveyed said an outpatient protocol can be used

Kossoff EH, et al. Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International Ketogenic Diet Study Group. *Epilepsia Open*. 2018;3:175-92.

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Fact Check



The experts agree – all diet options are valid
There is no wrong answer and no wrong diet

Fully consider:

- Your patient/family
- Your keto center and set up

Kossoff EH, et al. Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International Ketogenic Diet Study Group. *Epilepsia Open*. 2018;3:175-92.

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Discuss



- Pandemic related shift in practice
- Is this the best practice?
- Is the hospital admission necessary?
- What am I concerned about?
- Are there patients that always start inpatient?

Kossoff EH, et al. Ketogenic diet therapy provision in the COVID-19 pandemic: Dual-center experience and recommendations. *Epilepsy Behav.* 2020;111:107181.

Wirrell EC, et al. Care Delivery for Children With Epilepsy During the COVID-19 Pandemic: An International Survey of Clinicians. *J Child Neurol.* 2020;35:924-33.

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12

Discuss




CASE STUDY

Chloe
10 years old
GT fed blended diet

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Myth #2

Enteral nutrition formula change for starting ketogenic diet is a simple, easy change.

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Fact Check

Enteral Meal Choices

- Milk-based protein commercial formula
- Whey-based protein commercial formula
- Blenderized: commercial meal pouch
- Blenderized: real food, homemade blend
- Customized modular formula mixture

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Fact Check



Milk-based protein commercial formula

- Designed to be nutritionally complete
- Well tolerated and efficacious
- To be used under strict medical supervision
- Easy to use for any keto diet version and all feeding options

Ashrafi MR, et al. The efficacy of the ketogenic diet in infants and young children with refractory epilepsies using a formula-based powder. *Acta Neurol Belg.* 2017;117:175-82.

Coppola G, et al. Ketogenic diet for the treatment of catastrophic epileptic encephalopathies in childhood. *European Journal of Paediatric Neurology.* 2010;14:229-34.

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Fact Check



Whey-based protein commercial formula

- Tolerability and adverse effects = Vomiting, diarrhea, constipation, acidosis, growth
- Efficacy = diet response
- In line with other evidence for those on ketogenic formulas
- Found to be both well-tolerated and efficacious

Wheeler CE, et al. Efficacy and tolerability of a whey-based, medium-chain triglyceride-enhanced ketogenic formula in children with refractory epilepsy: A retrospective study. *Seizure.* 2021;91:29-33.

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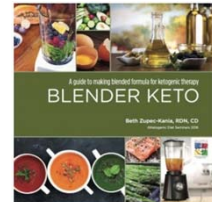
17

Fact Check



Blenderized

- Huge benefit in reducing volume, although increase in free water
- Food allergies or digestive issues
- Commercial blend versus Home blend
- Variety of nutrient-dense, whole food ingredients supporting Dietary Guidelines for Americans
- GI tolerance and microbiome



<https://charlifoundation.org/store/>

Bennett K, et al. Blenderized Tube Feeding: Health Outcomes and Review of Homemade and Commercially Prepared Products. *Nutr Clin Pract.* 2020 Jun;35(3):417-431.

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Fact Check



- Formula supplements can aid in administering KD to both orally and enterally-fed patients
- More diet responsive
 - 67-90% rate (v 31.5-70% for oral)
- Lower dropout rate

Benefits of KD formula:

- Palatable
- Easy to adjust ratio
- Lower risk of error
 - Preparation
 - Calculation
- Compliance

➔ improved efficacy & outcome

Sampaio LPB, et al. The use of a formula-based ketogenic diet in children with refractory epilepsy. *Arq Neuropsiquiatr.* 2017;75:234-7.

Wheeler CE, et al. Efficacy and tolerability of a whey-based, medium-chain triglyceride-enhanced ketogenic formula in children with refractory epilepsy: A retrospective study. *Seizure.* 2021;91:29-33.

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19

Discuss



When choosing a keto formula consider:

- ➔ Allergies / Sensitivities
- ➔ Previous formulas tolerated
- ➔ Insurance coverage
- ➔ Ability of caregiver to manage feeds (and keto center)
- ➔ Family choice

Do not underestimate the importance of a good bowel regimen!

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Myth #3




I want to give my patient (my child)
a “natural” alternative
to anti-seizure medications.

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Fact Check





Multiple Possible Side Effects

Constipation	Growth	Acidosis
Nausea Vomiting Reflux	Increased Lipids	Vitamin Deficiency

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Fact Check

- Charlie Foundation –Super Foods handout
 - Found in Tool Kit in KetoDietCalculator

Spinach	Flavonoids and antioxidants, vitamins A, B2, C, K, magnesium, manganese, folate, iron, calcium & potassium	Eating raw is the best method to preserve nutritional value. Steaming or quick sautéing are second best.
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- Includes information on prebiotics and probiotics
- Great handout for both professionals and patients

<https://ketodietcalculator.org/ketoweb/ketodocs/handouts/Professional/9.%20SuperFds%20Pre%20Probiotics.pdf>

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23

Discuss



- Start this conversation slowly, more abrupt with HCPs
- Ask what side effects the child had with medications
- Find something to agree on or empathize with them
- Use that “in” to make known the KD has side effects, too
- Find foods they can’t live without and try to fit it in

- Would love to hear how you handle this in your keto centers!

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Myth #4



Once you are on
the medical ketogenic diet,
you can never stop it.

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Fact Check



Glut1 Deficiency Syndrome (Glut1DS)

- KD is first line
- Should be continued into adolescence/adulthood
- Balance long term adverse effects of KD with current state
- Target BHB 2-5 mmol/L
- Unclear how long diet management should be continued

Klepper J, et al. Glut1 Deficiency Syndrome (Glut1DS): State of the art in 2020 and recommendations of the international Glut1DS study group. *Epilepsia Open*. 2020;5:354-65.

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26

Fact Check



Discontinuation


- 75% of patients will respond within 14 days
- Consensus group agreed that a fair assessment for response would be 3.2 months (SD 1.3 mo)
- Certainly, if sz worsen after 1-2 weeks, diet can be stopped
- Transition to MAD/LGIT for some
- Short duration of diet for others

Kossoff EH, et al. When do seizures usually improve with the ketogenic diet? *Epilepsia*. 2008;49:329-33.

Kossoff EH, et al. Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International Ketogenic Diet Study Group. *Epilepsia Open*. 2018;3:175-92.

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Fact Check

Reasons to discontinue the KD:

- ▶ Seizure freedom (23%)
- ▶ Prolonged KD use w/ limited continued benefit (23%)
- ▶ No efficacy (20%)

Slower Wean

Had achieved significant seizure reduction (>50%) → Longer duration of KD → Were having fewer monthly seizures


Faster Wean

Completely unsuccessful sz control → Shorter duration of KD → Were having same/more seizures

Worden LT, Turner Z, Pyzik PL, et al. Is there an ideal way to discontinue the ketogenic diet? Epilepsy Research. 2011;Apr 30.

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Fact Check

- 26 patients who had KD 1st and then either KD or MAD 2nd
- Most of the patients restarted diet due to seizures (65%) or recurrence after seizure freedom (19%)
- 77% of the group had $\geq 50\%$ seizure reduction with the 1st diet and 50% reduction with the 2nd diet

Identical response	Worsened response	Improved response
14 patients (54%)	9 patients (35%)	3 patients (16%)

Kossoff EH, Doerr SC, Winesett SP, et al. Diet Redux: Outcomes from Reattempting Dietary Therapy for Epilepsy. J Child Neurol. 2016.

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Discuss



Think about how you can prep your patient and team.



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30

Conclusion



- I hope this Myth Busting discussion has helped you to think or re-think how you handle certain questions or presumed thoughts about the medical Ketogenic Diet
- Hope you have learned something new today
 - Diet initiation options
 - Enteral formula options
 - Side effects and weaning of the diet
 - Resources, handouts and solid scientific evidence for what we do and to back up the decisions we make

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31

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32



Questions and Answers

Please enter your questions into the Q&A box on the right-hand side of your screen

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33




www.ketohope.org



- Keto Friends – connects new keto families to experienced ones for educational and emotional support
- Another opportunity for quality professional support and education

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34




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35