USING KETOGENIC DIETS IN OLDER CHILDREN AND ADOLESCENTS

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About the Ambassador
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Stacey has been a pediatric dietitian for almost 20 years. She is currently a dietitian at the Neuroscience Institute, Department of Neurology at Johns Hopkins Medicine All Children's Hospital in St Petersburg, Florida. Her practice is devoted exclusively to all forms of the Ketogenic diet, both inpatient and outpatient. Stacey routinely provides presentations to physicians and residents, and has spoken nationally on the classic ketogenic diet. She has a passion for the diet and educating others to increase awareness of dietary therapies as a viable treatment option for epilepsy and other neurological disorders.

Objectives

- Interpret the latest research for older children, adolescents and adults on the ketogenic diet

- Compare and contrast the use of variations of the ketogenic diet in older children, adolescents and adults

- Define and describe obstacles of older children, adolescents and adults on the ketogenic diet and ways to address them

Ketogenic diets- They are not just for kids anymore

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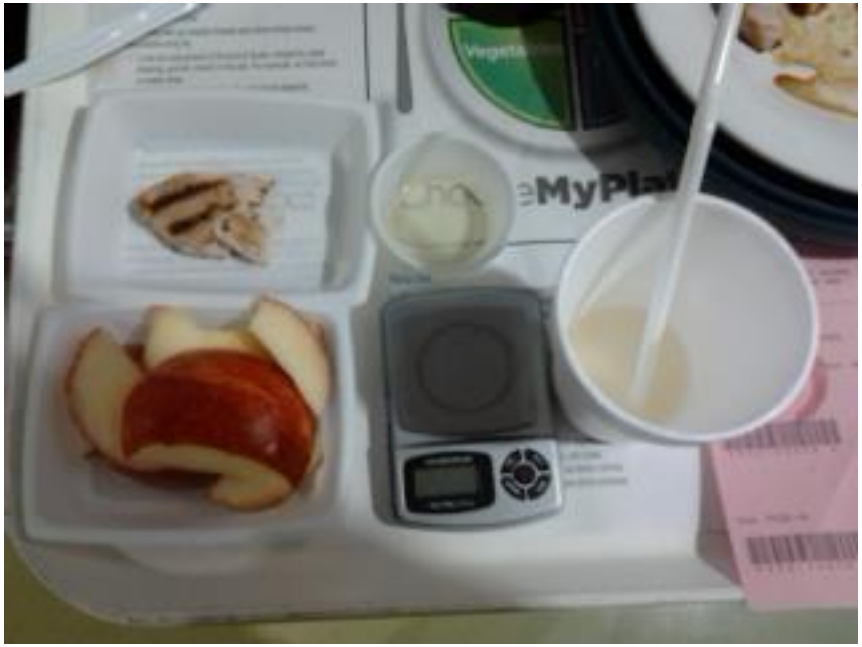

Felton EA, Cervenka MC. Dietary therapy is the best option for refractory nonsurgical epilepsy. Epilepsia, 2015. Vol 56 (9);1325-1329.

- Diet therapy in general is more widely accepted and older patients are initiating diet therapy
- KD therapy may be more available and less expensive then drugs and can be initiated quickly with predictable side effect profiles
- There is ample data showing efficacy of KD's in children through adults at about 50% responder rates
- Dietary therapy tends to have less compliance in adolescents and adults (1-88% CKD and 0-63% MAD) however a drug pre panel study had a drop out of 41.5% for 3 years
- Can possibly help with comorbid conditions such as type 2 diabetes and obesity

Kossoff et al. What are the minimal requirements for the ketogenic diet services in resource- limited regions? Recommendations from the ILAE task force for dietary therapy. Epilepsia, 2015 Vol 56 (9); 1337-1342

- History states that diet therapy requires a large team and for resource poor countries this is not feasible (and sometimes remote areas in general)
- A physician is mandatory for all diet therapies and a RD is required for CKD (but not for alternative diets)
- CMP for baseline labs and Lipid monitoring there after
- Multivitamin and calcium supplements are required and infants require ketogenic formula
- Low risk (no comorbidity patients) can be initiated out patient with availability to contact medical diet team in an emergency
- Patients >15 YO should only be initiated if there is the potential of enrollment in an adult diet center. Adult issues include driving and pregnancy

Ye et al. Efficacy of and patient compliance with the ketogenic diet in adults with intractable epilepsy: a meta- analysis. J Clin Neurol 2015;11(1):26-31

- Multiple resources were evaluated using STATA to determine efficacy and compliance for KD's in adults
- 12 studies with 270 patients determined:
  - Efficacy of all combined, CKD and MAD were 42%, 52%, and 34%
  - Compliance of all combined, CKD and MAD were 45%, 38% and 56%
- Concluded that compliance with adults was more difficult in the CKD but better in the less restrictive MAD with efficacy being the opposite, better in CKD and less in MAD
- Diet therapy is a promising complementary therapy for adults with intractable epilepsy

Payne et al. The ketogenic and related diets in adolescents and adults- a review. Epilepsia.

2011 vol 52 (11) :1941-1948.

- Ketogenic diets have evolved to provide variations that are more liberal so many older children and adults may opt for diet therapy
- Compliance hurtles remain higher is adolescents and adults. Response rates in adults are similar to that of children across all diets Discontinuation is usually due to lack of efficacy.
- Onset of efficacy was seen rapidly (in summary - 4 days to 2 months in non-comparable studies)in adolescents and adults
- Ketone production did not correlate with seizure reduction. Some patients (Barborka, 1930) never achieved ketosis but had reported benefits. (alertness and energy)

Cervenka et al. The impact of the Modified Atkins Diet on lipid profiles in adults with epilepsy. Nutritional Neuroscience. 2016;19 (3):131-137.

- Prospective study evaluating lipid profiles in >17 year old adults started on MAD, diet naïve, initiated at 20 grams carb/day. Fasting lipid panels were obtained at day 1 clinic visit.
- 33 patients were on MAD for a minimum of 6 months at data analysis- 27 pts 1 or more years, 12 for 2 or more years.
- Results demonstrated patients on MAD for 3 months to >2 years had initial increases in LDL and total cholesterol over the first 3 months, but those levels normalized there after on continued diet therapy

Cervenka et al. The impact of the Modified Atkins Diet on lipid profiles in adults with epilepsy. Nutritional Neuroscience. 2016;19 (3):131-137.

Plasma level (mg/dl)	Baseline (n = 37)	1 month (n = 8)	3 months (n = 30)	6 months (n = 13)	12 months (n = 9)	24 months (n = 5)
Total cholesterol	190 (55)	204 (43)	205 (55)	200 (35)	188 (42)	166 (22)
LDL	117 (40)	130 (40)	130 (46)	131 (35)	115 (38)	97 (28)
HDL	57 (25)	60 (25)	62 (22)	56 (15)	59 (19)	57 (13)
TG	86 (42)	61 (20)	77 (34)	85 (47)	68 (31)	60 (30)

n= # patients with fasting Lipid panel at f/u time point

Schoeler NE, Cross JH. Ketogenic diet therapies in adults with epilepsy: a practical guide. Pract Neurol 2016;0:1-7.

- Most controlled data for the diet(s) is demonstrated in children leaving a lack of controlled studies in adults. (not performed due to the assumption of poor compliance and fear of side effects in adults)
- Diet tolerability has not been compared between children and adolescents/adults. Available papers describe side effects that are similar to that of studies in children. (including Cervenka 2015). Risks, benefits and obstacles should be discussed
- MAD is described as the most suitable for adults (due to ease of measuring and lack of protein restriction) but both CKD and MAD can be offered or adjustments such as addition of MCT oil to MAD can make better results achievable.

Schoeler NE, Cross JH. Ketogenic diet therapies ion adults with epilepsy: a practical guide. Pract Neurol 2016;0:1-7.

- "Ketogenic diet therapies are one of the few treatments that allow patients a feeling of empowerment over their condition; clinicians should work with patients to promote flexibility and independence while still ensuring safety and adherence"
- There is no consensus on how to discontinue diet therapy. Adults with a good response may be apprehensive in discontinuing. If seizure frequency increases , weaning may need to be slowed or discussion may need to occur on continuing diet therapy
- Note: in UK the same laws are applied to discontinuing/changing diet therapy as to changing AE medications.

Kossoff et al. Diet Redux: Outcomes from reattempting dietary therapy for epilepsy. J Child Neurol. 2016 Mar 9. pii: 0883073816636225.

- 26 patients treated with the CKD reinitiated diet therapy (either CKD or MAD) 6 months or greater apart
- Mean age for 1st attempt at diet therapy was 5.6 years old with the 2nd attempt 11.5 years old
- 77% vs 50% pts had a >50% seizure reduction from attempt 1 and attempt 2 of diet therapy. CKD and MAD had equal efficacy on the second attempt.
- Feasible to reinitiate the diet. This evaluation of patients may provide a suggestion of likelihood of response for counseling patients

DECIDING WHICH DIET IN THE OLDER CHILD OR ADOLESCENT

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FACTORS TO CONSIDER

Consider: Age

- Have they had a long history of eating what they want?
- Are they younger and may have better results with a CKD instead of MAD?
- Have they been on diet therapy before?

Consider: Diet history

- Are they picky eaters?
- Are they big eaters?
- Do they eat a lot of carbohydrates?

Consider: Do they eat PO or are they tube fed

- Any patient that is tube fed should be recommended to be on the CKD
- MAD/LGIT/MCT via tube with blenderized foods
- What if they are both tube fed and eat by mouth?

Consider: What is their Diagnosis?

Epilepsia, **(*):1–14, 2008
doi: 10.1111/j.1528-1167.2008.01765.x

SPECIAL REPORT

Optimal clinical management of children receiving the ketogenic diet: Recommendations of the International Ketogenic Diet Study Group

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Diagnoses with probable benefit from KD

- Refractory Epilepsy- when 2-3 anti-epileptic drugs (AEDs) have failed
  - (~30% of patients with epilepsy are classified as refractory)
- Glut 1 Transport Deficiency
- PDHD
- Doose (myoclonic astatic epilepsy)
- Tuberous Sclerosis
- Rett Syndrome
- Dravet (severe myoclonic epilepsy of infancy)
- Infantile Spasms
- Tube fed or formula fed patients

Diagnoses with suggested benefit from KD

- Mitochondrial respiratory chain complex defects
- Landau-Kleffner syndrome
- Lafora body disease
- Lennox Gastaut Syndrome
- Sub acute sclerosing panencephalitis (SSPE)
- Refractory status epilepticus (F.I.R.E.S.)

Consider: What is the education level of the family and the patient

- Many older children may have to be responsible for some of their own meals.

- Can the family grasp the concept of counting carbs or would they benefit from a menu based diet like the CKD?

- Would they be better with a low ratio CKD instead of MAD or LGIT?

Consider: Resources

- Can they purchase a scale?
- Can they afford some of the common CKD food like heavy cream and butter?
- Do they have a computer to look things up? Can they email for follow up?
- Do they have support from the family? Both parents, grandparents, siblings?

IMPLEMENTING THE DIETS IN OLDER CHILDREN AND ADOLESCENTS

Implementing the diet- Tube feedings

- May need a lower ratio to meet protein needs- 3:1, 2:1 or lower due to required hypocaloric intakes- use Liquigen® (MCT) or coconut oil
- Suggest diluting formula and increasing strength of feed as tolerated
- Issues tolerating MCT oil. Start slow. Take with formula
- Any comorbidities?
- Fiber?

Implementing the diet- CKD PO

- Realistic intake goals for fat- show them what a meal looks like
- If possible, have patient participate in menu planning
- Portable scale
- Use App (MyKetoPlanner) so patient has access and can/help make their own menus

Implementing the diet- MAD

- Have patient participate in consultation
- Provide websites and social media sites to help support
- If able, email with patient, have patient do their own food log- create investment
- Have patient make menus for quick meals and for certain restaurants
- Use low carb websites/Pinterest for meal ideas
- Follow up
- DRIVING!!!

Cervenka MC, Terao NN, Bosarge JL, et al. E-mail management of the modified Atkins Diet for adults with epilepsy is feasible and effective. *Epilepsia.* 2012;53(4):728-32.

- 3 month prospective study enrolling 22 patients to start a 20 gram MAD diet via email only
- 21 patients reached ketosis, 16 at least 40mg/dl. 21 were on diet at 1 month and 14 at 3 months
- After 1 month, 41 % had >50% seizure reduction, 5% with >90% seizure reduction
- After 3 months, 27% had >50% seizure reduction, 14% with >90% seizure reduction
- Evaluated food records revealed patients were on about a 1:1 ratio, mean email # was 6 (1-19), weight loss was most common side effect
- Concluded that MAD diet can be done via email for adult patients when there is limited physician and RD access

Concerns

- Eating out/ Compliance
- Social pressure/ Compliance
- Family history of heart disease/lipidemia
- Willingness to drink and take vitamin/mineral supplement

Lightstone et al. Reasons for failure of the ketogenic diet. J of Neurosciences Nursing. 2001;33(6):292-295.

- 46 children over a 2 year period were evaluated as to why they discontinued the diet
- The main reasons ages 6-12 and >12 year old included- to regimented (caregiver issues) patient refuses to eat foods, cheating
- D/C for lack of efficacy was much greater (7) for ages <6 than the other 2 groups of older children

What we can take away from Lightstone paper ?

- Keep it as simple as possible
- Make it as flexible as possible
- Get as much buy in from the patient as possible- suggest foods that they like to eat- not what the caretaker or the RD picked out.
- Cheating doesn’t mean you have to quit- empower them as much as possible to keep going

What has changed since 2001? Lightstone study

- More flexible versions of the diet available- MAD, LGIT
- Technology improvements- Pinterest, internet sites with recipes, blogs
- Improved low carb food product choices.(low carb flours, convenience foods are available in supermarkets)
- Availability of keto products and recipes using them (KetoCal recipes, actual keto chefs), MCT oil
- Well trained facilities that can screen patients properly for the diet and adjust diets to help them with success

Case Study #1

- 9 year old, TF, LGS
- On Pediasure then started Ketocal 4:1
- Had 75% reduction of seizures but increased abdominal girth, severely constipated, readmitted for constipation and abdominal pain
- Switched to 3:1 powder (no fiber) , fine after 24 hours
- Continues with 75% seizure reduction

Case study #2

- 9 year old F, PO with Autism, dialeptic/absence seizures, 100's/day
- Picky eater
- Started MAD at 15 grams carb/day
- Incorporated MCT oil
- Seizures reduced to 3-5/day
- Started 2:1 CKD menus, increased to 3:1
- Seizure free, talking more, doing well in school

Case study #3

- 18 year old , Myoclonic jerks, In HS, plays Lacrosse
- Diet recall was >3000 kcals/day
- Started at 20 to 25 grams/day, no protein restrictions, high fat, 2 gram carb snacks before practice
- Increase to 30 then 35
- Noticed better attention, no jerks on some days
- Eventually no jerks- WANTS TO DRIVE

Case #4

- 9 year old, Doose (MAE), previously on keto diet 3:1
- Was seizure free on diet but discontinued diet due to complaints of strictness and cost
- Seizures came back
- 2 years later, initiated MAD 10 grams increased to 15 grams carb/day
- Seizure free

Summary

- Research is available to support the use of KD's in older children (even adults)
- Clinical considerations should be made when choosing a diet (compliance, diagnosis, development)
- Practical considerations may help with success (resources, motivations, available technology)

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THANK YOU!

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