Welcome to Part 2 of the series Diet for Narcolepsy: A Science-y View from 30,000 Feet where I’m sharing with you the reasons, as scientifically as a layman can get, behind the diet my family and I follow.

This 3 part series is meant to be a high level overview of how I’ve interpreted the science and applied it to the diet my mom, my son, and I follow, thus the “30,000 Feet” part of the title. Later on, after you’ve been on the diet for a bit and the fog has lifted enough for you to think straight, we’ll go into much greater detail and dig deeper into the science-y stuff. My hope is that in this series I’ll have provided you with enough solid and concise information that you can share it with your doctor, family, and friends in order to gain their support in your endeavor.

Be sure you’ve read the first post in this series, Diet for Narcolepsy: A Science-y View from 30,000 Feet – (Part 1 – Orexin), since I’m building on that information here in this post.

Let’s dive right in!

**PART 2 – CARBOHYDRATE CONTROL**

In my last post we talked about orexin and I revealed the three pieces of information that blew my mind and made me realize that the idea of mitigating narcolepsy symptoms via diet actually had real potential. Those three items were:

1. What we eat causes our blood glucose levels to go up and down.
2. High glucose levels turn orexin OFF. (1)
3. Lowering blood glucose levels turn orexin ON. (2)

On. Off. Glucose. Glucose is the switch... So how do we control the ON/OFF switch?

First, we need to understand what glucose is, right? Food is made up of three things called macronutrients: carbohydrates, proteins, and fats. When you eat, the body digests the macronutrients. Bear in mind that *every type of carbohydrate you eat* is eventually converted to a simple form of sugar known as **glucose**. Some carbohydrates (certain vegetables and a few fruits) convert more slowly and have less of an effect on your blood glucose levels. But other carbohydrates like all the bread, pasta, cereal, potatoes, rice, fruit, dessert, candy, and sodas you eat and drink (otherwise known as sugars and starches) eventually wind up as glucose and will significantly raise your blood glucose levels. *(Portions of this paragraph were taken from the site Mark’s Daily Apple, it was worded so well that I just had to use it.)*

You now have a basic understanding of what glucose IS and that the foods we eat, specifically the carbohydrates that we eat, raise it. To be *crystal clear*, “all the bread, pasta, cereal, potatoes, rice, fruit, dessert, candy, and sodas you eat and drink” will raise your blood glucose and **turn your orexin OFF**. Voila! We see our OFF switch in all its glory. It’s just that simple folks.

Now, please recall that *low* levels of glucose in the blood will allow your orexin cells to be in the ON position. And since part of what this website is about is using diet to help keep orexin ON, we should probably talk about that right? Low levels of glucose can be accomplished by eating protein and fat, and being careful with carbohydrate consumption. The main type of diet that does this is called a *Low Carbohydrate* diet.

Each macronutrient is a fuel for the body. If you limit one (carbohydrates) your body will burn the other two (protein and fat). And there are some truly lovely benefits for people with narcolepsy when we use the other two to function:

- **Protein**
  - Blocks glucose (meaning that when you do eat carbohydrates you minimize the effect they have when you pair them with protein) (3)
  - Does not raise glucose levels (Hello ON switch!) (4)
  - Amino acids, found in protein, trigger orexin cell activity (5)
  - Eating protein prompts the brain to manufacture serotonin, norepinephrine, and dopamine...these help to boost energy and mental clarity (6)
  - Protein makes you feel full (7)

- **Fat** *(OMG FAT! Hold your horses and keep an open mind. I’m referring to *good* fats and we’ll break all that down at a later date)*
  - Makes you feel full and satisfied (8)
  - Certain vitamins, notably A, D, E, and K, require fat to get absorbed properly in the body making dietary fat necessary to transport these “fat-soluble” vitamins (9)
When reducing carbohydrates and providing dietary fat, the liver uses the fat as fuel rather than storing it away for later use (this is called ketosis and I’ll talk about that in a minute)

Has been shown to help brain functions like memory, speaking ability, and motor skills

Omega-3 oils/fats promote neurogenesis (the birth of new brain cells) and communication between neurons.

That’s the basics of what a Low Carbohydrate diet can do for people with narcolepsy... but what if I told you that you could take a Low Carbohydrate diet a step further and truly maximize what it can do for you? You’re asking “If Low Carbohydrate diets help keep the orexin switch ON during the day, what else do I need?” What if, by going a step further, you could ADD in some more benefits?

I’m referring to a Ketogenic diet. The Ketogenic diet is just a Low Carbohydrate diet with a few changes. Ketogenic diets get more of their calories from dietary fat than they do from protein and carbohydrates. This diet also drops the carbohydrate intake down to around the 20% of caloric intake mark. By dropping the carbohydrate intake to such a low amount, being moderate in protein intake, and getting the bulk of the calories from fat, this diet switches the body to being a fat burner instead of a sugar (glucose) burner. When the body makes the switch it is called ketosis and means that the body is producing something called ketones.

Why are ketones a benefit to people with narcolepsy? Ask and you shall receive:

- Ketones increase non-REM sleep
- Ketone production is a natural physiologic state induced during prolonged states of decreased glucose availability. So by default, when in ketosis, your glucose levels are very low, keeping the orexin in the ON switch longer.
- Ketosis increases the number of energy producing mitochondria in cells and improves their efficiency, thereby giving you more expendable energy
- Ketones help optimize cognitive function and improve memory, this may be due to the anti-inflammatory effects of ketones on the immune response
- Since you aren’t eating carbohydrates, you aren’t producing insulin and crashing your blood sugar. This reduces food cravings.

Those are some pretty nice reasons to take the diet to the Ketogenic level, eh? Well check this out: A study performed in 2004 took 9 people with narcolepsy and put them on a low carbohydrate/ketogenic diet. The 8 subjects that finished the study showed the following results:

- The total score on the Narcolepsy Symptom Severity Questionnaire decreased by 18% after 8 weeks
- The Sleepiness Subscale score decreased by 22%
- The Sleep Attack Subscale score decreased by 13%
- The Sleep Paralysis Subscale score decreased by 24%
Decreased, decreased, DECREASED folks.

Here’s something else to think about. Over the last four years, I’ve been involved with two groups on Facebook whose members are people with narcolepsy and use diet (in some form or another) and lifestyle changes to mitigate their narcolepsy symptoms (the Gluten Free Narcolepsy and the Keto PWN Facebook groups). We’ve noticed that when medicated people with narcolepsy get into ketosis they do not need their standard dosages and need to either reduce the dose or eliminate the medication altogether. Hmmm...interesting. So what could be happening here?

As it turns out, many of the drugs prescribed to narcoleptics alter glucose metabolism and induce ketosis:

- Amphetamines suppress hunger, induce hypoglycemia, and promote ketosis (20) (21)
- Gamma-hydroxybutyrate (a.k.a. Xyrem) is a modified version of a common metabolic ketone (beta-hydroxybutyrate) and promotes the metabolism of fat instead of carbohydrates (22) (23)

Inducing these effects using diet seems a viable mechanism to reduce the necessity for drugs that do the same thing... but without the side effects. Food for thought isn’t it?

Whew! Are you cross-eyed? No? Great! It means I did my job and condensed down all that super complicated information into something easy to understand. But we aren’t finished with all the science-y stuff just yet. Stay tuned for Part 3 where I’ll dive into the gut...not literally, ew! We’ll just look at gut health and why I feel it is an integral part of this diet for narcolepsy. See you soon!

**Your Madcap Miss**

(a.k.a. Gina Dennis)

For more information on the cognitive effects of ketones:

REFERENCES:

1. Sleepiness after glucose in narcolepsy  
2. Hypothalamic orexin expression: modulation by blood glucose and feeding  
   http://diabetes.diabetesjournals.org/content/48/11/2132.short
3. Activation of central orexin/hypocretin neurons by dietary amino acids  
4. Protein: metabolism and effect on blood glucose levels  
5. Activation of central orexin/hypocretin neurons by dietary amino acids  
6. Precursor control of neurotransmitter synthesis  
7. Dietary protein – its role in satiety, energetics, weight loss, and health  
8. Scientist Discover Why a Low GI Meal Makes You Feel Full  
   http://www.sciencedaily.com/releases/2009/03/090317201139.htm
9. Avocado Consumption Enhances Human Postprandial Provitamin A Absorption and Conversion from a Novel High B-Carotene Tomato Sauce and from Carrots  
   http://jn.nutrition.org/content/early/2014/06/04/jn.113.187674
10. Omega-3 fatty acids  
    http://umm.edu/health/medical/altmed/supplement/omega3-fatty-acids
11. n-3 fatty acids: role in neurogenesis and neuroplasticity  
12. Acute effects of the very low carbohydrate diet on sleep indices  
13. The Ketogenic Diet: Uses in Epilepsy and Other Neurologic Illnesses  
    http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2898565/
14. The ketogenic diet increases mitochondrial uncoupling protein levels and activity  
15. The therapeutic implications of ketone bodies: the effects of ketone bodies in pathological conditions: ketosis, ketogenic diet, redox states, insulin resistance, and mitochondrial metabolism

16. The fat-fueled brain: unnatural or advantageous?

17. The ketone metabolite B-hydroxybutyrate blocks NLRP3 inflammasome-mediated inflammatory disease
   http://www.nature.com/nm/journal/v21/n3/full/nm.3804.html

18. Reactive hypoglycemia

19. Diet therapy for narcolepsy

20. Studies of the hypoglycemic effect of D-amphetamine in aggregated mice

21. Amphetamine-Like Analogues in Diabetes: Speeding towards Ketogenesis
    http://www.hindawi.com/journals/crie/2015/917869/

22. Central and peripheral metabolic changes induced by gamma-hydroxybutyrate

23. Glucose and fat metabolism in narcolepsy and the effect of sodium oxybate: a hyperinsulinemic-euglycemic clamp study
Let me be totally up front here...I AM NOT A DOCTOR, nor am I a nutritionist, OR have any, ANY formal training in such things. I am just a person with narcolepsy and with family members with narcolepsy. I also happen to use dietary and lifestyle changes to mitigate my narcolepsy symptoms and have been experimenting with these changes since July 2011. I have successfully maintained a high level of narcolepsy symptom management since that date as have my family members. This website contains our personal stories, failures, and experiments. In this website I will share with you the information that I have found most credible and some practical ideas for mitigating narcolepsy symptoms. I beg you to check with your doctor before initiating any of the dietary changes I speak of, especially if you are taking any medications.

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