People, people, people. This 3 part series of posts has been HARD to write. Here I am, attempting to share with you the reasons, as scientifically as a layman can get, behind the diet my family and I follow, with nary a shred of professional schooling in either medicine or nutrition. Seriously folks, all I have are my experiences and the experiences of my family, our successes and our failures. But it is our experiences and the fact that we've been highly successful at this that gives me enough confidence to share the science-y things I've found with you.

You see, when I found out about using diet to mitigate narcolepsy symptoms, it took me months and months of reading, and re-reading, and !OMG! RE-READING till just enough of the information filtered through my narcolepsy fogged brain to make sense. My hope is that these posts will condense the science-y parts down to a level that can penetrate through even the most extreme of narcolepsy fogs.

This 3 part series will be a high level overview of how I've interpreted the science and applied it to the diet my family 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 and family/friends in order to gain their support in your endeavor.

So let’s get to it shall we?
PART 1 - OREXIN

In everyone, orexin is a biochemical that regulates alertness and promotes wakefulness. (1) Whether we have Type 1 narcolepsy (a.k.a. narcolepsy with cataplexy) or Type 2 narcolepsy (a.k.a. narcolepsy without cataplexy), we ALL have issues with alertness and wakefulness (i.e. excessive daytime sleepiness and sleep attacks). (2, 3, 4)

But here’s an interesting thing, orexin is also involved in your digestive processes and glucose control. (5, 6, 7) And this, my friends, is where it gets interesting and where I feel diet comes into play.

At its most basic level, orexin is all about food and eating. Here’s how a day in the life of the orexin neuron is supposed to play out For today’s purposes, this will be enough about orexin. But keep in mind that there are other important things about it that we’ll dive into at a much later date.

- Light dawns with the sunrise and hits the retina sending impulses to the brain that get orexin up and running. (8)
- Since you’ve not eaten through the night your blood glucose levels are low. This turns the orexin production up (in other words, it flips the on switch) in order to help you go find and prepare something to eat. This translates in a few different ways and has several effects associated with alertness/wakefulness:
  - High orexin levels means you are awake since consciousness is pretty important when finding and preparing food to eat. (9)
  - Orexin affects mood by stimulating the dopamine and serotonin reward systems. So the idea of food makes you happy and you feel motivated to go eat. (10, 11)
  - Orexin affects energy by stimulating the Locus Coeruleus (LC). More orexin fibers go to the LC than any other place in the body. The LC is a brain region that regulates overall activity level and sensitivity by releasing adrenaline. More orexin equals more adrenaline equals more energy. Meaning you have the energy to go find food, prep it, and eat it. (12)
  - Orexin affects memory by stimulating the hippocampus which is involved in geospatial and emotional memory. This helps you remember where food is, how to prepare it, etc. (13)
  - Also important in finding and preparing food is the fact that orexin affects cognitive function by stimulating the prefrontal cortex which is responsible for attention and calculation. This area enables you to plan where to go and how to get there, what to do in case of adverse events. (14)
- Yummmm. Orexin helped you go get something to eat, sooo….you eat. And then the flip side of the process begins. As you digest the food your glucose levels rise and the orexin production reduces in output and turn off.
- Flash forward a few hours and your blood glucose levels drop, you get hungry, and the whole thing starts up again.
- When the sun begins to set and it starts to get dark your retina senses a lessening of light and starts sending impulses to the brain that reduce the levels of orexin. You get sleepy and go to bed.
The sun rises and the whole thing starts again.

Sigh...that’s what’s supposed to happen, right? But in narcoleptics things get all out of whack. And if yours is out of whack don’t you want to do what you can to get it to work better, more efficiently? Would you keep doing things that throw it further out of whack than it already is? No, I don’t think you would.

Ok, so what do we do to un-whack it? Hidden in that long description of what orexin does were three very important bits of info that we as narcoleptics need to know:

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

Please read that section just one more time. Basically, FOOD turns orexin on and off. ON and OFF folks. (15) I don’t know about you, but this was mind blowing for me.

So now that you know that food affects orexin are you more curious about how a diet can help with making the most of the orexin you have? Good. In Part 2 I’ll dive into some of the science-y things that I think apply to why a low carbohydrate diet (and variations thereof) can help you control glucose orexin’s on/off switch. And then in Part 3 I’ll dive into the gut (not literally, ick!) and discuss why its health is so important to us and is an integral and important part of the diet my family and I follow.

Whew! That was a lot of super technical information and honestly, I tried to keep it as short and sweet as possible. I hope you stay with me as we dive into more detail in Parts 2 & 3.

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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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