

THE MADCAP

Miss Adventures OF A NARCOLEPTIC

One narcoleptic's adventures out of narcolepsy and into life

Diet for Narcolepsy

***A Science-y View
from 30,000 Feet***



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What Madcap Madness is This?

The Madcap MissAdventures of a Narcoleptic is a website dedicated to guiding people with narcolepsy toward dietary and lifestyle changes to mitigate their symptoms. Throughout this site, you'll find humorous adventures and practical advice, as well as easy to follow diet and lifestyle tips and tricks.

About the Madcap Miss (a.k.a. Gina Dennis):

- Gina was diagnosed with narcolepsy in 2004 at age 32
- When medication quit working she changed to a gluten free/low carb diet (July 2011) to help mitigate symptoms
- Gina's mom and son have narcolepsy and started the diet in December 2011 and July 2012 respectively

With diet Gina, her mom, and her son have a **70-90% reduction in narcolepsy symptoms**



Join the Madcap Miss as she shows you a path OUT of narcolepsy and INTO life!

Madcap Miss

A stylized blue signature logo for the Madcap Miss.

(a.k.a. Gina Dennis)

Diet for Narcolepsy: A Science-y View from 30,000 Feet (Part 1 – Orexin)



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.

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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. 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).

But here's an interesting thing, orexin is *also* involved in your digestive processes and glucose control. 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*

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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.
- 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.
 - 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.
 - 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.
 - 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.
 - 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.

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- Yummmmm. 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.*** 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

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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.

Your Madcap Miss



(a.k.a. Gina Dennis)

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Diet for Narcolepsy: A Science-y View from 30,000 Feet (Part 2 – Carbohydrate Control)



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.

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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.
3. Lowering blood glucose levels turn orexin ON.

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)
 - Does not raise glucose levels (Hello ON switch!)
 - Amino acids, found in protein, trigger orexin cell activity
 - Eating protein prompts the brain to manufacture serotonin, norepinephrine, and dopamine...these help to boost energy and mental clarity
 - Protein makes you feel full
- 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

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- 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
- 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

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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
- *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

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!

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Diet for Narcolepsy: A Science-y View from 30,000 Feet (Part 3 – The Gut Connection)



Finally! Part 3 to this series is here! This third and final post is all about the GUT connection to diet for narcolepsy. How in the world does your *gut* have anything at all to do with narcolepsy since narcolepsy is in the *brain*? Well I'm here to enlighten you and I think you'll be astonished at just how strongly some of our narcolepsy symptoms are tied to some of the issues we can have when our gut is not healthy.

Just as a reminder, this three 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. Once you've been on the diet for a bit and the narcolepsy fog has lifted enough for you to think straight, we'll go into much greater detail and dig deeper into the science-y stuff. As always,

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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.

In Part 1, you learned the basics of orexin. We looked at orexin's common functions and what turns it on and off. Remember? The ON/OFF switch. Then in Part 2, you learned how diet can not only help with keeping orexin ON when you need it but also how it can turn it OFF when you don't. And now Part 3 – The Gut Connection...let's get to it!

PART 3 – THE GUT CONNECTION

Think your inability to regulate sleep, anxiety, depression, fatigue, memory failure, brain fog... just to name a few... are solely narcolepsy related? Mmmm, perhaps not *solely*. It may be an issue in the gut. Yep, the GUT. Let's take a look at the gut in a whole new way and discover how what we eat has a direct impact on our BRAINS and thus our SLEEP, as well as feeling healthy and well overall.

When I was in elementary school, we were taught that all things “gut” were the Digestive System. The mouth all the way to the anus was about digesting food. But guess what? It is soooooooooo much more (I could do a page of O's here).

Did you know there are other names for the gut? The newest term is the Second *Brain*, or more formally known as the Enteric *Nervous System*. *Brain. Nervous.* Those words imply something other than digestion, don't they? Then there's this whole other part of the gut called the microbiome which is a community of trillions of bacteria that live within the gut and, when working properly and are healthy, help us live healthy lives (*since they are located in the gut and are a part of the Second Brain, I'm going to lump it all together in this*

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post as the GUT in an effort to keep you from going cross-eyed with too many new terms).

Before we dive into the things the gut does that we usually think of as brain/Central Nervous System tasks, let's refresh on what we originally thought of when the Digestive System was mentioned. Put simply, we ingest approximately 25 tons of foreign matter from the outside world through our mouths during our lifetime and the gut has the monumental task of breaking it down for us. When the gut breaks down the food we eat, it pulls vitamins and minerals out and passes them through the small intestine's walls and on into the bloodstream. Our blood then transports these items to the rest of our body. Any unnecessary leftovers and waste are then shuttled further into our Digestive System and are eventually expelled via our activities in the bathroom. That's super basic, but there it is in a nutshell. It's pretty much just a processing and recycling operation.

But our gut is also a major part of our Nervous System and thus the new title of Enteric Nervous System/Second Brain. Every single inch of it is embedded with neurons from the spinal cord that sense the area and coordinates the activity.

BONUS INFORMATION: There are even orexin receptors in the intestines that sense orexin.

An integral part of our Nervous System is its little messengers. These messengers are neurotransmitters and they influence learning and memory, mood and emotion, appetite and satiety, and even *sleep and wakefulness*. Guess where a whopping 95% of these are made? In our gut! Molecules like serotonin and dopamine for example. I want you to get a feel for how important it is that so many neurotransmitters are made in the gut but I can't dig deeply into the uses of *all* the neurotransmitters, there's just not enough space in this

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post. So let's at least take a look at serotonin because there's this thing it does that's is pertinent to narcolepsy. Serotonin is a building block for melatonin, which helps us sleep. With so much serotonin being made in the gut, it means there's 400 times more melatonin made there than is made in the pineal gland of the brain. Wow.

Beyond the gut producing 95% of our neurotransmitters, did you know that new research is showing that our gut stimulates production of chemicals called cytokines as well? These are important for inducing sleep, particularly deep, non-REM sleep. Are you beginning to see the importance of gut health? Ha! We've just hit the tip of the iceberg folks.

Orexin is also a critical molecule in the Second Brain because the nerves in the intestines sense orexin... remember I said earlier that there are orexin receptors in the gut? Orexin triggers the movements that push the food through our body. So if your orexin levels are low, your digestive system slows down.

And *then*, as if the gut didn't have enough to do, it is also our LARGEST immune organ in the body. Our gut houses 70-80% of our immune system and is our FIRST line of defense aimed at killing and expelling foreign invaders like bacteria, viruses, and toxins. Our intestinal lining is only ONE cell layer thick so we have lots of good bacteria in there coating our intestinal wall (this is our microbiome) and this bacteria is the first in line to protect us.

Well, all that I've said thus far has been about a *healthy* gut. What can make it UNhealthy and what are the consequences of an unhealthy gut? Take a deep breath... now again... okay, let's dig into it the ugly bits.

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Simply put, today's typical diet of foods high in refined carbohydrates, sugar, and processed foods is killing the good bacteria in our guts and causing inflammation. This leads to something called Leaky Gut (ew...) and that nastiness leads to a whole host of other issues far worse than the thought of our guts leaking. Our bodies begin to freak out and then it starts attacking itself. We stop being able to fully absorb nutrients. In the end we wind up sick and tired and unhealthy. But I can't leave you right here without an explanation of some sort so get a bib or something and we'll dive into the icky-ness that is the Leaky Gut.

Earlier I said that in a healthy gut the cells lining the intestinal wall, and the microbiome coating it, act as a barrier that allows only properly digested vitamins and minerals to pass through the small intestine's walls. Now, usually, the spaces in the intestinal wall that things pass through are sealed pretty tight but when the gut is irritated by some external trigger, these spaces loosen and begin to "leak" larger items (undigested food) into our blood. Thus the term "Leaky Gut." Well these larger particles are deemed as invaders and the immune system freaks out and launches an attack. If you let the stuff leak out for too long and it happens too frequently the body starts mistaking your own cells as foreign invaders and BAM! You have an autoimmune issue brewing. Leaky Gut also causes an imbalance in the microbiome, causes reduced nutrient absorption, can cause digestive and neurological distress, and all those lovely things a healthy gut does for us is thrown into chaos.

And guess what happens to orexin production when the immune system starts to fight the good fight? *It is drastically curtailed.* Remember the on/off switch we talked about in Part 1 and 2? Well this immune response due to Leaky Gut is just as effective when it comes to turning OFF our orexin cells. Nighty night.

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Hmmm...what *are* these pesky things that irritate the gut and cause an imbalance? There's lots but we are going to focus on food since the series is about narcolepsy and diet. We'll dig into the other things at a later date.

There are two things that seem to consistently trigger symptoms in narcoleptics via the gut:

1. Carbohydrates (this includes sugar)
2. Wheat (specifically, a protein found in wheat called *gluten*)

So let's talk about these triggers...

Oh those gloriously yummy carbohydrates and sugars. They not only directly reduce orexin production as I explained in Part 2 (the OFF switch), but they also alter the gut's microbiome...you remember, those bacteria that are creating more neurotransmitters than our brain does? Well those wonderful neurotransmitters are created by the *good* bacteria. Every gut also has some *bad* bacteria and these baddies LOVE sugar. They eat it and multiply. Pretty soon they take over and the microbiome shifts to the dark side. We end up with more of the bad and less of the good. All of a sudden we have issues thinking and sleeping and feeling...all those good things that neurotransmitters do can't be done because we don't have enough good bacteria making them.

And yeah, wheat/gluten... it's in all the yummys too. Besides gluten being a known neurotoxin, when we eat something gluten-y, like bread and other flour-y products, it goes through our stomach and when it arrives in the small intestine it triggers the release of a chemical called zonulin. Zonulin signals the intestinal walls to open wide. Leak, leak, leak...out go toxins, microbes, food particles, etc. into the bloodstream and interior tissues where they aren't supposed to be and BAM! That immune response we just talked about starts.

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And remember what I said happens when the immune response is triggered? *It is drastically curtailed.* Um, hello!?! OFF switch.

You know, it's been really tough to organize this post in a way that makes sense to someone looking at these connections for the first time. The primary difficulty comes from the fact that they are all interconnected. There isn't just one effect. The nerves and microbes and food all interact with each other and very often amplify each other's actions. If we aren't aware of these other functions of our gut we can get stuck in a sleep inducing cycle without even trying. One wrong move and it can all snowball out of control.

But it's not all gloom and doom. If we control our carbohydrates to keep orexin in the ON position for wakefulness, we also keep control over our carbohydrate/sugar loving bad microbes. This keeps the bad ones at bay while the good ones thrive and produce all the good neurotransmitters. When we reduce carbs, we naturally reduce all the gluten-y yummys like bread and other flour-y products since they are high carb foods. If we eliminate gluten altogether, we can heal that Leaky Gut and stop the inflammatory response in our body that is curtailing our orexin production. And to bring things full circle, a low carb diet has been shown to have an anti-inflammatory effect as well as help tighten the spaces in the intestine's lining. We are now aware of the other functions of our gut and that scary, out of control snowball that we talked about in the previous paragraph? It gets halted in its tracks before it can do more damage.

Well! That's it! Part 3 wraps up my thoughts on the science behind the diet my family and I have adopted to mitigate our narcolepsy symptoms. Can you see why all the information that I've laid out to you in the three posts was compelling enough for us to make changes in our diet AND can you see why it's

working for us? I hope you'll stay with me for future posts because now we get to talk about HOW to make all this part of your daily life. Please stay with me because ***I've got a roadmap for you that you'll be able to navigate even in your sleepest moments.*** See you soon!

Your Madcap Miss



(a.k.a. Gina Dennis)

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MORE INFO: Dr. David Perlmutter has several books out there that dive deeply into the connection between the gut and the brain. In his first book, *Grain Brain*, he focused on the destructive nature of grains on our brain health but he also spent time talking about how carbohydrates can hurt it as well. THEN in his second book, *Brain Maker*, he dove into the microbiome and how the Standard American Diet, as well as some of today's common medical practices, have set up the brain for reduced function and disease. VERY interesting reads should you decide to take a deep dive into the connection between the gut and your brain. But wear your parachute folks, because these books are more techy and science-y than my 30,000 foot view series.

Madcap Narcolepsy, LLC Disclaimer

*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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