

Diet for Narcolepsy

MY FAMILY'S AWAKENING

Presented by Gina Dennis (a.k.a. Madcap Miss) - 2016 Narcolepsy Network Conference - Orlando, Florida USA

My “FWN”

FAMILY
WITH
NARCOLEPSY



The “Before” Picture



Finding Diet

I used to be a
ZOMBIE,
and now I'm not.

h sores brain fog skin ras



Zombie
research
institute



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Legalese

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 then, as have my family members. This presentation contains our personal stories, failures, and experiments. In this presentation 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.

The Basics of Our Diet

Low Carbohydrate - between 20-80 net carbs per day (Carbs - Fiber = Net Carbs)

- Moderate fruit intake - Mostly berries
- Low glycemic veggies
- Protein

High Fat

- Avocados
- Olive oil
- Nuts and nut oils
- Real butter

Gluten Free

- Limited gluten free replacement products



A 30,000 Foot View of the Science-y Stuff



Science-y Stuff

Orexin

*I see orexin as an **ON/OFF** switch*

What we eat causes our blood glucose levels to go **up and down**

High glucose levels turn orexin **OFF**

Low glucose levels turns orexin back **ON**

ON. OFF. Glucose is the switch.

How do we control the **ON/OFF switch?**



Science-y Stuff

Carb Control

Glucose = Carbohydrates & Sugar



To be crystal clear, all the bread, pasta, cereal, potatoes, rice, fruit, dessert, candy, and sodas we consume will raise your blood glucose levels and *turn your orexin OFF*.

Eat carbs and go *nighty night*.

Science-y Stuff

The Gut Connection

Enteric Nervous System **Second Brain**

- Every single inch of the gut is embedded with neurons (we even have orexin receptors in the gut)
- 95% of our neurotransmitters are made in the gut
 - Serotonin is a building block for melatonin and our gut has 400% MORE melatonin in it than the brain does
- 70-80% of our immune system is in the gut
- Nutrients are pulled from food and pushed through the gut lining into bloodstream
- Leaky Gut caused by Gluten
 - Tight junctions in the intestine open up and leak out foreign bodies (undigested food) into our blood
 - This leads to an immune response and orexin production is drastically curtailed
- Too many carbs/sugar and the gut's microbe balance gets skewed and we stop producing all those lovely neurotransmitters



STOP the damage!

Diet for Narcolepsy Benefits to PWN

Low Carb and **Gluten Free**

Carbohydrate Consumption is Reduced

- Controls blood glucose levels
- Keeps orexin in the **ON** position
- Less sugar in the gut means the gut is better able to stay balanced to produce neurotransmitters

Protein

- Does not raise glucose levels
- Amino acids trigger orexin cell activity
- Prompts creation of neurotransmitters (helps boost energy and mental clarity)

Fat

- Vitamins A, D, E, and K require fat to be absorbed into the body properly
- Has been shown to help brain functions like memory, speaking ability, and motor skills
- Helps promote neurogenesis (birth of new cells) and communication between neurons

Diet for Narcolepsy Benefits to PWN (continued)

Low Carb and **Gluten Free**

Ketones

- Tightens junctions in the intestine, reducing Leaky Gut
- Increase non-REM sleep
- Increases energy
- Optimizes cognitive function and improves memory
- Has an anti-inflammatory effect on the immune response
- Reduces food cravings

Gluten Free

- Stops release of zonulin and thereby stops Leaky Gut
- No Leaky Gut = No immune response
- Naturally reduces carbohydrate consumption

A “Healthy” Diet vs. Diet for Narcolepsy

Breakfast



American Heart Association

Smoothie

- ½ cup frozen berries (raspberries)
- ½ frozen banana
- ¼ cup orange juice
- ¼ cup nonfat, sugar free vanilla yogurt



Diet for Narcolepsy

Smoothie

- ½ cup frozen berries (raspberries)
- 2 tablespoons flax seeds
- ¼ cup unsweetened almond milk
- ¼ cup full fat coconut cream
- ½ ripe avocado
- Stevia to taste

A “Healthy” Diet vs. Diet for Narcolepsy

Breakfast



American Heart Association

29 net carbs

19 grams Sugar

5 grams protein



Diet for Narcolepsy

8 net carbs

5 grams sugar

8 grams protein

21 grams of carbs MORE!

A “Healthy” Diet vs. Diet for Narcolepsy

Lunch



American Heart Association

Open-Face Tuna Melt with Oven-Baked Sweet Potato Chips

- ½ medium sweet potato
- ¼ tablespoon canola oil
- ¼ teaspoon ground black pepper
- ½ can light tuna in water
- ½ tablespoon low-fat mayonnaise
- ½ teaspoon chopped red onion
- ¼ teaspoon herbs
- ¼ teaspoon lemon juice
- 1 slice whole-wheat bread
- ¼ medium sliced tomato
- ½ cup shredded reduced fat cheddar cheese



Diet for Narcolepsy

Open-Face Tuna with Oven-Baked Sweet Potato Chips

- ½ medium sweet potato
- ¼ tablespoon olive oil
- ¼ teaspoon ground black pepper
- ½ can light tuna in water
- ½ tablespoon regular mayonnaise
- ½ teaspoon chopped red onion
- ¼ teaspoon herbs
- ¼ teaspoon lemon juice
- 1 romaine lettuce boat
- ¼ medium sliced tomato
- ½ cup shredded cheddar cheese

A “Healthy” Diet vs. Diet for Narcolepsy

Lunch



American Heart Association

31 net carbs

11 grams sugars

24 grams protein



Diet for Narcolepsy

19 net carbs

7 grams sugar

20 grams protein

12 grams of carbs MORE!

A “Healthy” Diet vs. Diet for Narcolepsy

Dinner



American Heart Association

Grilled Chicken with Vegetables
and a Whole Wheat Dinner Roll

- 1 teaspoon herbs
- ¼ tablespoon lemon juice
- ½ teaspoon olive oil
- 1 boneless skinless chicken breast
- ¼ small zucchini
- ¼ small red bell pepper
- ¼ small eggplant
- 1 small whole wheat dinner roll



Diet for Narcolepsy

Grilled Chicken with Vegetables
NO Dinner Roll

- 1 teaspoon herbs
- ¼ tablespoon lemon juice
- ½ teaspoon olive oil
- 1 boneless skinless chicken breast
- ¼ small zucchini
- ¼ small red bell pepper
- ¼ small eggplant
- 2 tablespoons butter

A “Healthy” Diet vs. Diet for Narcolepsy

Dinner



American Heart Association

19 net carbs

2 grams sugars

28 grams protein



Diet for Narcolepsy

3 net carbs

2 grams sugars

25 grams protein

16 grams of carbs MORE!

A “Healthy” Diet vs. Diet for Narcolepsy

TOTAL



American Heart Association

79 net carbs

32 grams sugars

57 grams protein



Diet for Narcolepsy

30 net carbs

14 grams sugars

53 grams protein

49 grams of carbs MORE!

A “Healthy” Diet (for PWN)???



Baked Lay’s (24 net carbs!)

Whole Grain Cranberry Walnut Muffin (30 net carbs!)

Low Fat Vanilla Ice Cream (22 net carbs!)

Whole Grain Flour Tortilla (14 net carbs!)

Luna Protein Bar (16 net carbs!)

Whole Grain Cheerios (17 net carbs!)



It's Just Common Sense

If there's a food that messes with our sleep, our wakefulness, our memory, our mental focus/function,
WHY EAT IT?

Why **ADD** to what narcolepsy already does to us?



The “After” Picture - Kathy

I have been delivered from the pit of my despair.

Delivered from that cold dark place where death and life had the same meaning.
That place where no joy could be found and all hope was buried in the hard ground.

I have been embraced by the sun’s warmth and carried into the light of life.

I have lifted mine eyes and seen the beauty that is the brightness of a new day.

The “After” Picture - Glenn



COLLEGE!!



262 miles
89 hours & 47 minutes





The "After" Picture - Gina



Easy Peasy Changes You Can Make NOW

Eat more meat and veggies

Put the bread down

Reduce or eliminate sugary drinks

Add in more FAT

- Avocados
- Olive oil
- Nuts
- Real butter

CHALLENGE



Rate sleepiness from 1-10
(10 is worst)

EAT.



**How
do you
*FEEL?***

Playing Devil's Advocate

10%

Average awake time for PWN = 10 hours per day

10% MORE = 1 hour per day

7 hours per week

30 hours per month

365 hours per year

What would YOU do with 10%?

How To Get More Information



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