A photograph of a dark, rocky tunnel with a road leading to a bright sunset over a lake and mountains. The text is overlaid on the image.

# Narcolepsy Idiopathic Hypersomnia

## Management Beyond Medication

Gina Dennis  
*aka Madcap Gina*

*Madcap*  
Narcolepsy

Certified  
Health  
Coach

FAMILY

WITH

NARCOLEPSY



# Legalese

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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 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.



# NARCOLEPSY & IH SYMPTOM MANAGEMENT

One “tool” in the toolbox is not enough.

*The more “tools”  
the better 😊*

# What If?

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What if some of our energy and wakefulness issues are diet and lifestyle-related?

What if the medications we take spend so much of their energy on our DIET AND LIFESTYLE-RELATED SYMPTOMS that they have less impact on narcolepsy & IH symptoms?

What if we lessened that hit to our already broken system?

**WHAT IF?**

# Think About It

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People **WITHOUT** a hypersomnolence disorder say things like:

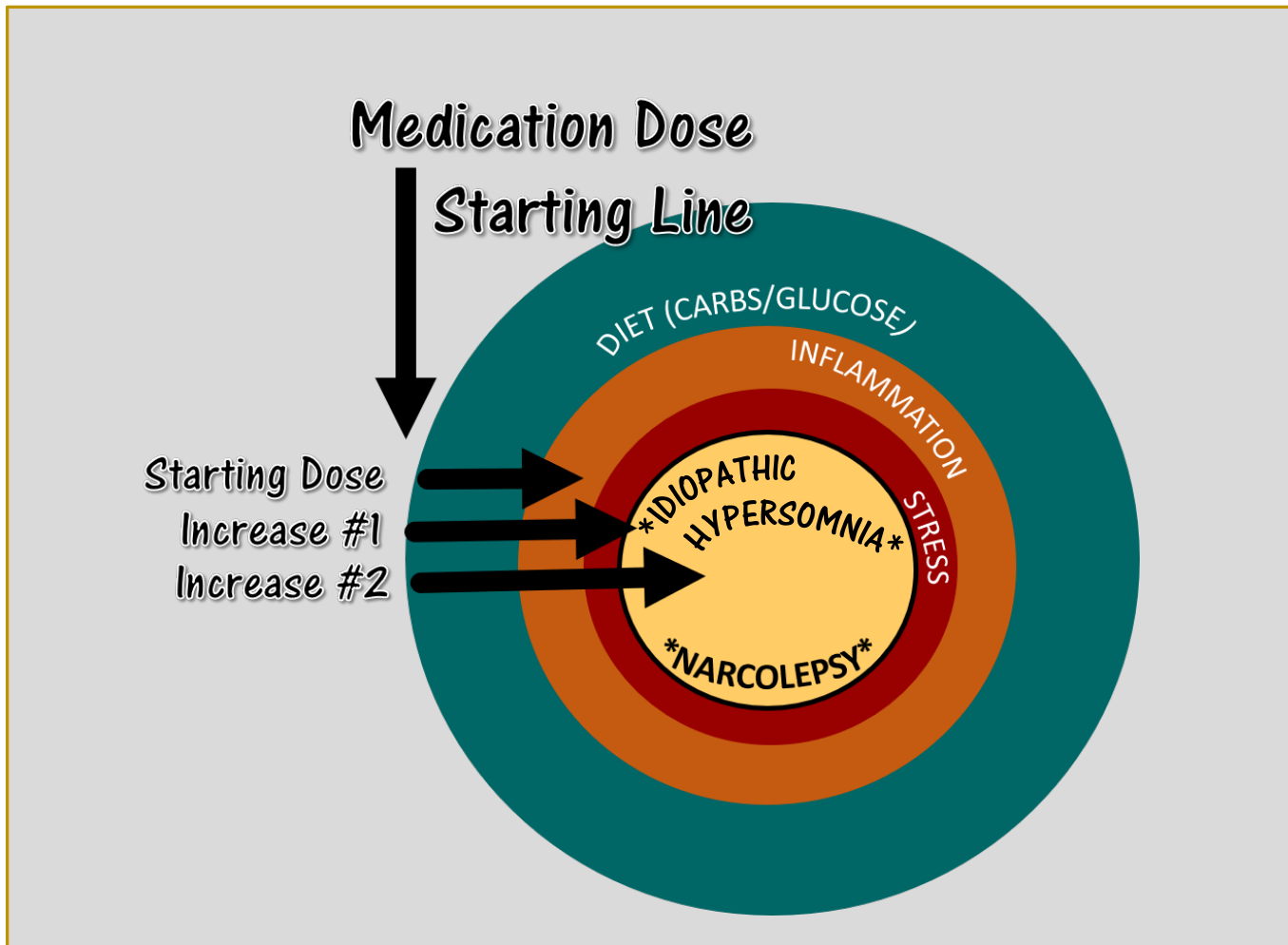
*Sleepy Tired Brain Fog No Energy Fatigued Lethargic Slept Poorly*

*We feel these effects so much more acutely.*

Why **ADD TO** our symptoms with our diet and lifestyle?



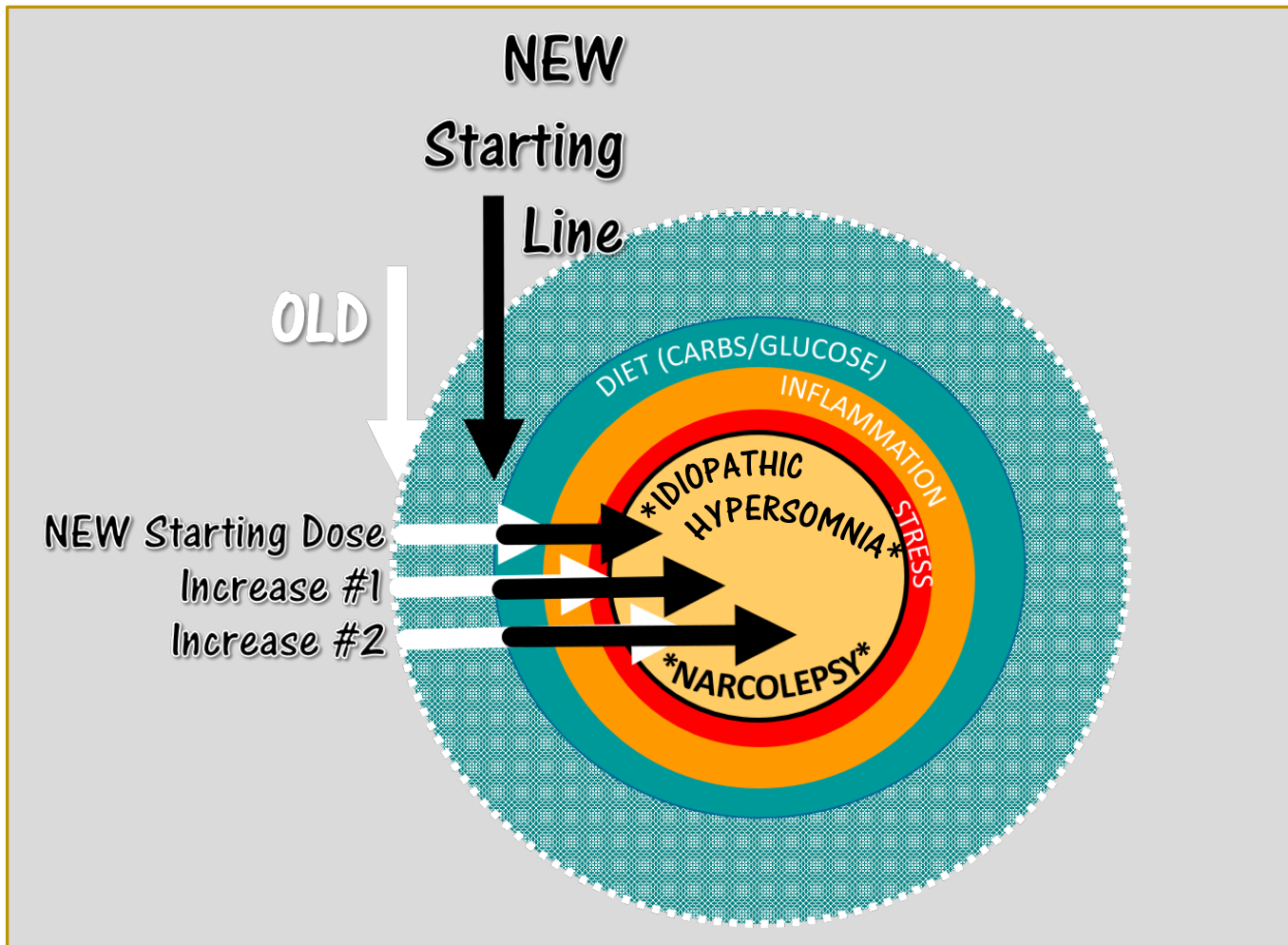
**Instead, do what we can to manage our symptoms beyond medication.**



## FULL IMPACT

- DIET (carbs/glucose)
- INFLAMMATION
- STRESS

MEDS HAVE TO WORK **HARDER** & HAVE TO REACH **FURTHER**  
TO ARRIVE AT THE CORE (NARCOLEPSY/IH)



## REDUCED IMPACT

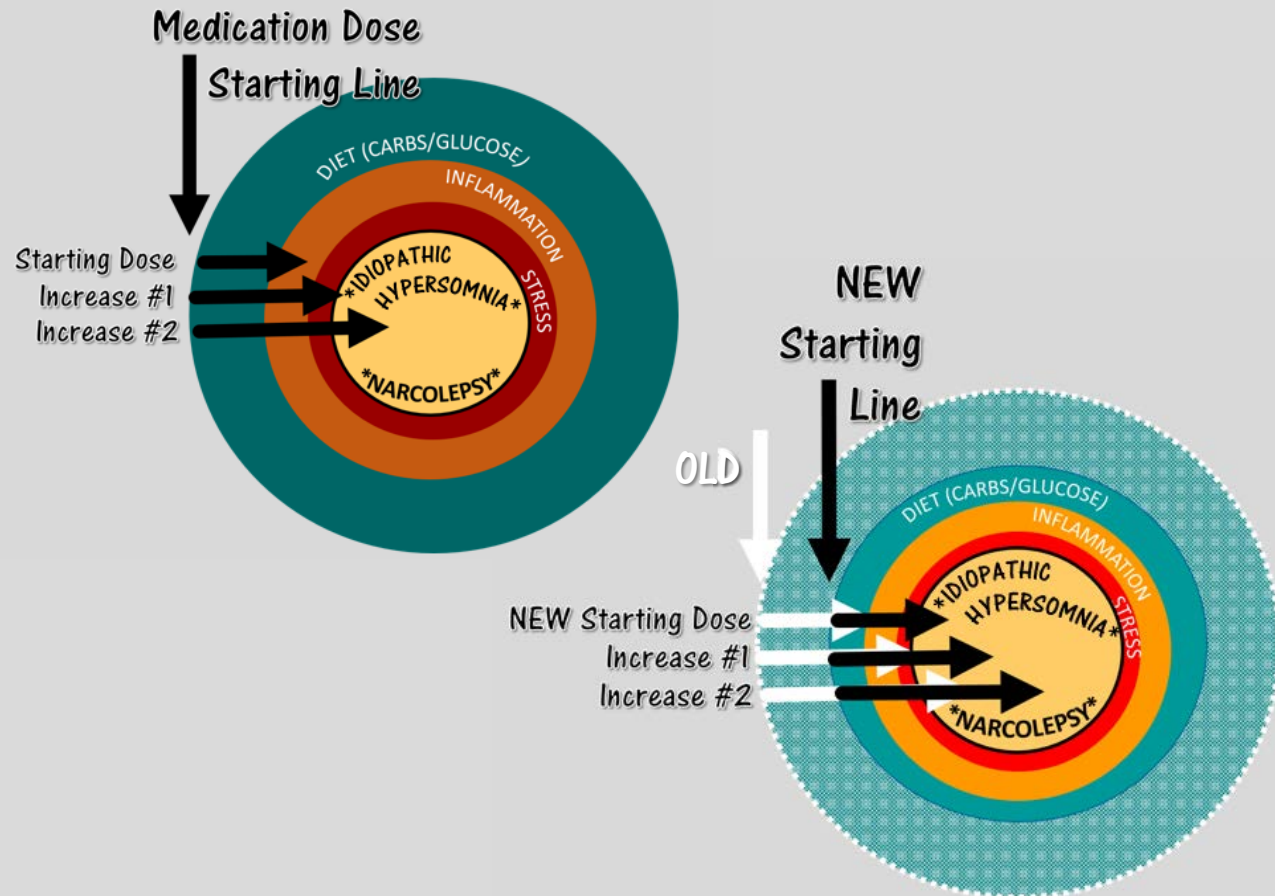
- DIET (carbs/glucose)
- INFLAMMATION
- STRESS

WHAT IF WE MOVE THE STARTING LINE CLOSER TO THE CORE???

WE REQUIRE *LESS* MEDICATION TO BE **JUST AS EFFECTIVE!**



# Let's Get Real



## **CURE:**

1. to restore health, so ~~ness~~, or normality
2. to bring about ~~ness~~ from
3. to deal with ~~ness~~ that eliminates or rectifies

## **MITIGATE:**

1. to cause to become less harsh
2. to make less severe or less painful

# Eeek!!!!

**Average person consumes  
300+ grams of carbohydrates a  
day!**

For a diet to NOT impact the  
sleep/wake system

you need to get somewhere

***LESS THAN 100 grams of carbohydrates  
per day.***



Diet

Inflammation

Stress

# CARBS... aka Glucose

To be crystal clear, all the bread, pasta, cereal, potatoes, rice, fruit, dessert, candy, and sodas we consume will raise our blood glucose levels and impact our energy and wakefulness.



***Eat carbs and go **nighty night**.***

Diet

Inflammation

Stress

# Diets Galore!!!!

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**Low Carb / Atkins**

**Paleo / Primal**

**Mediterranean**

**South Beach**

**Keto/Ketogenic**

**Carnivore**

**Whole 30**

**Low Glycemic**



Diet

Inflammation

Stress

# The Amazing KETONE (via diet or supplement)

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- Optimizes cognitive function and improves memory
- Has a **STRONG**, positive impact on brain fog
- Increases non-REM sleep
- Increases energy

**Oxybates = GHB (*gamma-hydroxybutyrate*)**

**KETONES = BHB (*beta-hydroxybutyrate*)**

Diet

Inflammation

Stress

# Exogenous Ketones

- Once a day only
- NEVER at the same time as Oxybate dosing OR within 6 hours of Oxybate dosing
- Start SLOW (half the recommended dose then build up to full dose as needed)
- Cheap brands are NOT SAFE
- SAFE brands are:
  - Perfect Keto
  - Pruvit/Keto OS



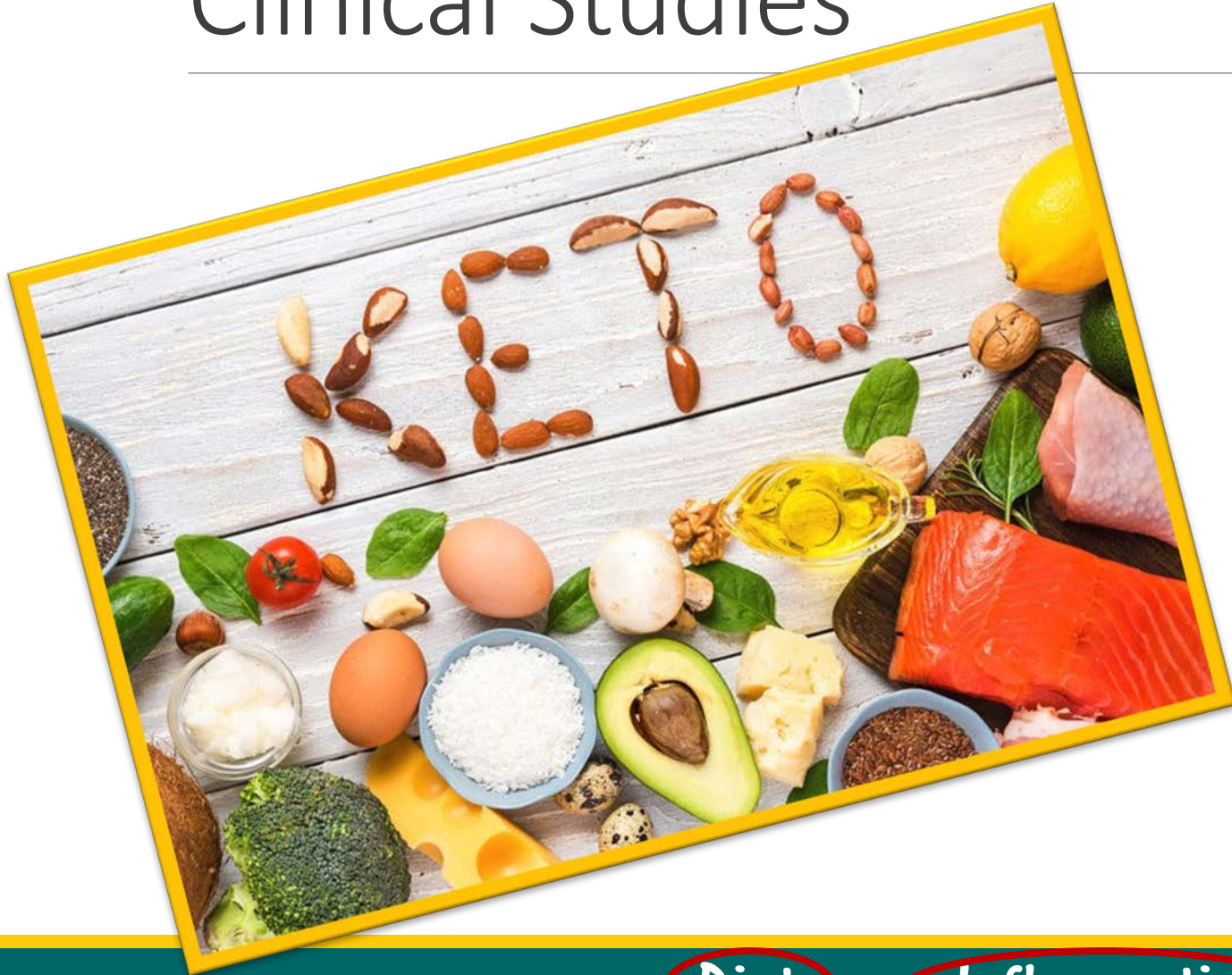
Diet

Inflammation

Stress

# Clinical Studies

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**AUSTRALIA**

**Netherlands**

**Germany**

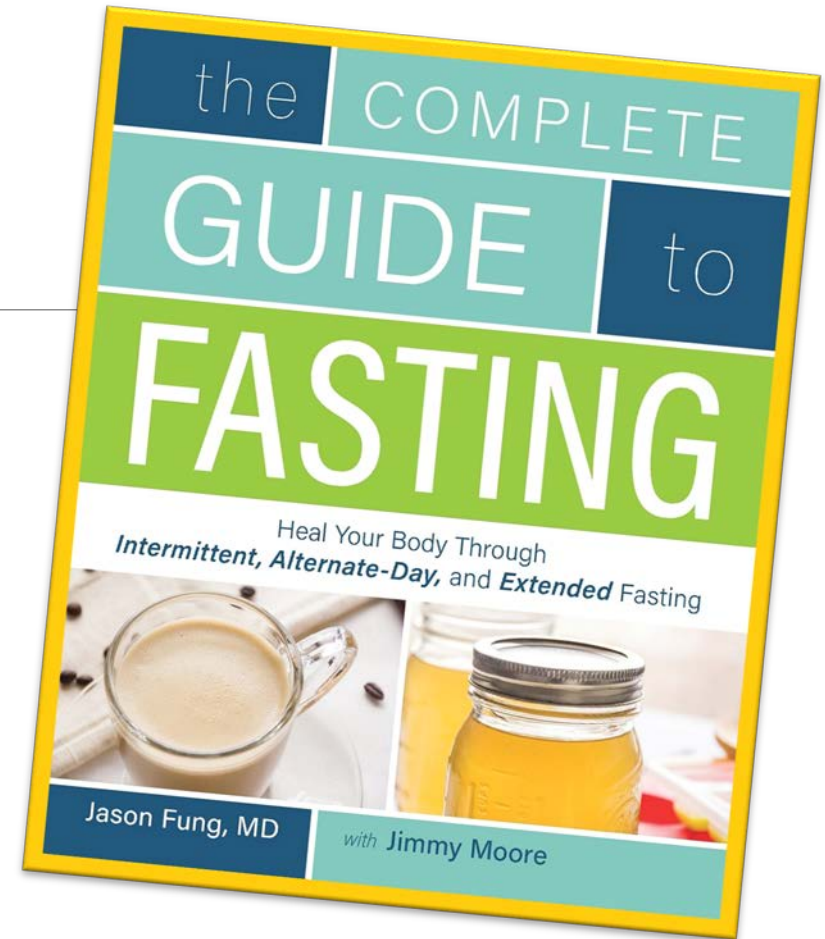
**Diet**

**Inflammation**

**Stress**

# Fasting and Food Timing

- Fasting: Can be a few hours all the way to several days
  - No need to be drastic
    - Fast from after dinner till lunch the next day
    - Extend it to not eating till dinner
- *“Stay awake by staying just on the edge of hunger” – Mali Einen*
- Eat only protein and fats during the day and then eat all the carbs at dinnertime.



By Dr. Jason Fung

Diet

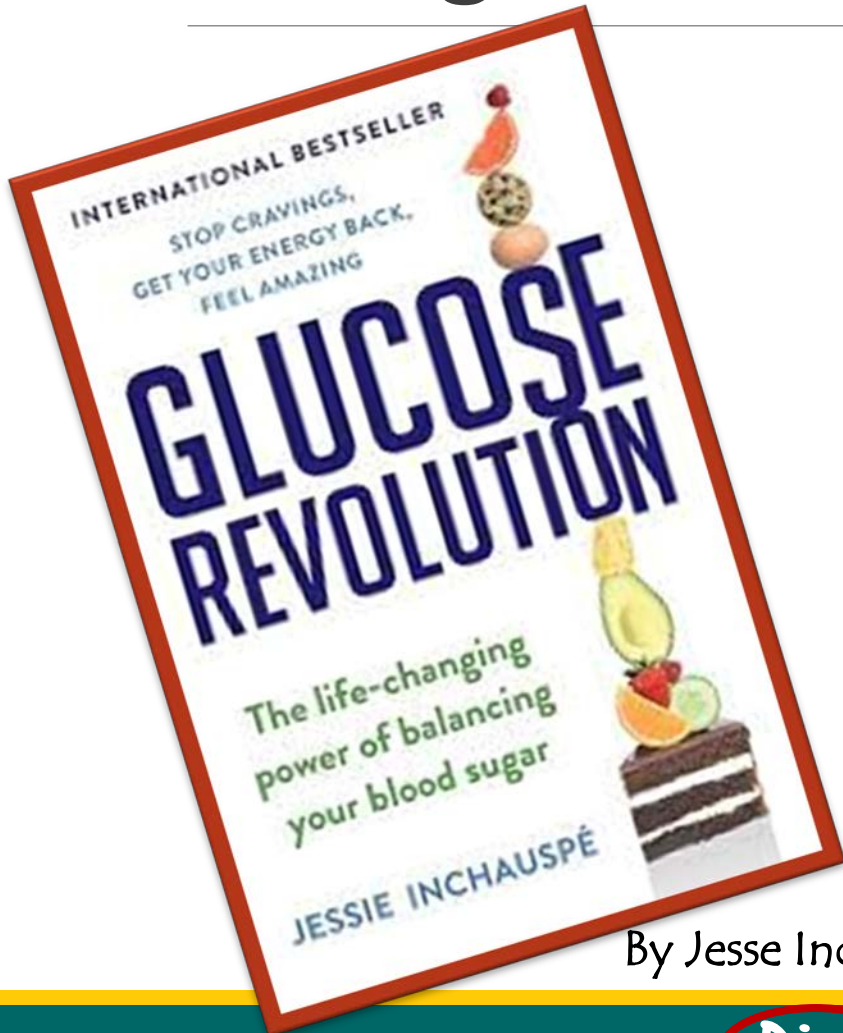
Inflammation

Stress



# Eating Food in a Certain Order

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By Jesse Inchauspe'

**By eating in a certain order you can reduce the impact of food on your energy levels and wakefulness.**

1. Eat above-ground veggies first. SALAD!
2. Next eat your protein and fats
3. Finally, eat the carb-y bits like corn, potatoes, bread, pasta, dessert

Diet

Inflammation

Stress

# Sleep Hygiene

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## Wake & Sleep on Schedule

- The body CAN be trained to fall asleep and to wake up at the same time every day
- Wake up and go to sleep at the same time each day... YES, even on weekends
  - Social Jetlag
  - Vary times only by an hour



Diet

Inflammation

Stress

# Sleep Hygiene

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## Naps

- The body CAN be trained to fall asleep and to wake up at the same time every day... even for NAPS
- Take your naps at the same time every day and for the same amount of time
- Try to nap in the same place each time
- DO NOT FIGHT the need to nap

Think of your nap as a medication...

Same TIME, Same DOSE, *DO NOT SKIP IT!*



Diet

Inflammation

Stress

# Sleep Hygiene



## Light Control

- Light sensors in the eyes that are sensitive to color tone
  - Color of the light tells the brain to be AWAKE or to be ASLEEP
- DAYTIME
  - Get direct sunlight within a few hours of waking (No contact lenses, glasses/sunglasses)
  - Use a UV lightbox
  - Get outside multiple times a day
- NIGHTTIME
  - Within 3 hours of bedtime, BLOCK blue-light from devices
    - F.LUX, night-mode on phones/tablets, blue-light blocking apps
    - Blue-light blocking glasses

Diet

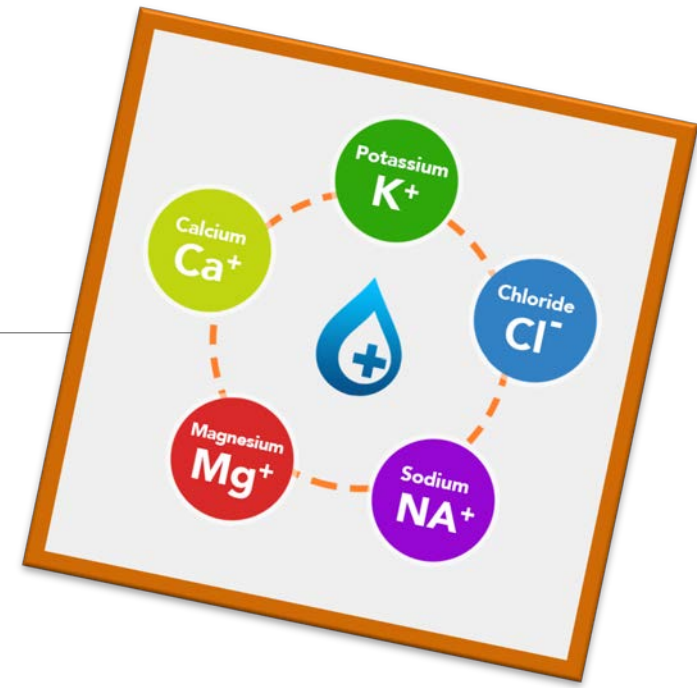
Inflammation

Stress

# Low Electrolytes

Can mimic some of our narcolepsy/IH symptoms

***Narcolepsy/IH meds can cause depletion***



- Magnesium
  - Muscle cramping, twitching/*restless leg*
- Potassium
  - Weakness, *feeling tired*, muscle cramps, *confusion*, etc
- Sodium
  - *Fatigue*, weakness, headaches, *difficulty concentrating*

Diet

Inflammation

Stress

# A Note About Oxybates

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- SODIUM!!!
  - Recommended daily amount is approx. 2300mg
  - Potassium is needed to draw off excess sodium
    - Side effects of low potassium = weakness, feeling tired, muscle cramps, confusion, etc
- Lumryz = 1640mg at max dose
- Xyrem = 1640mg at max dose
- Xywav
  - LOWER sodium
  - Contains other electrolytes = Magnesium & Potassium



# Stress From All Directions

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- Constant connection
- Busy, hectic lives
- Financial
- Commute to work/school
- Family/friends
- Lack of movement
- No spare time, no time for self-care



Diet

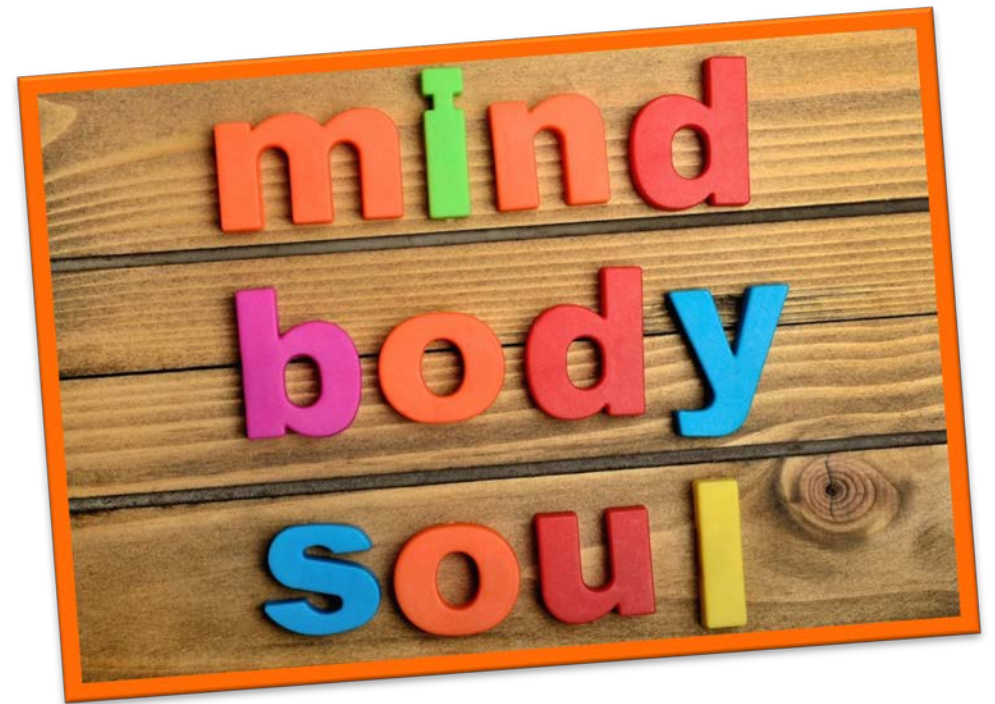
Inflammation

Stress

# Mind, Body, & Soul

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- Meditation / Gratitude / Journaling
- “Unplug” i.e. Social Media Vacay
- Exercise / Movement
- Friendships / Family
- Self-Care



Diet

Inflammation

Stress



# Medication & Supplements

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Are you taking them as directed?

- With or without food?
- AM or PM?
- Contraindications?

[www.drugs.com](http://www.drugs.com)

Google:

“What time of day should I take \_\_\_\_\_?”

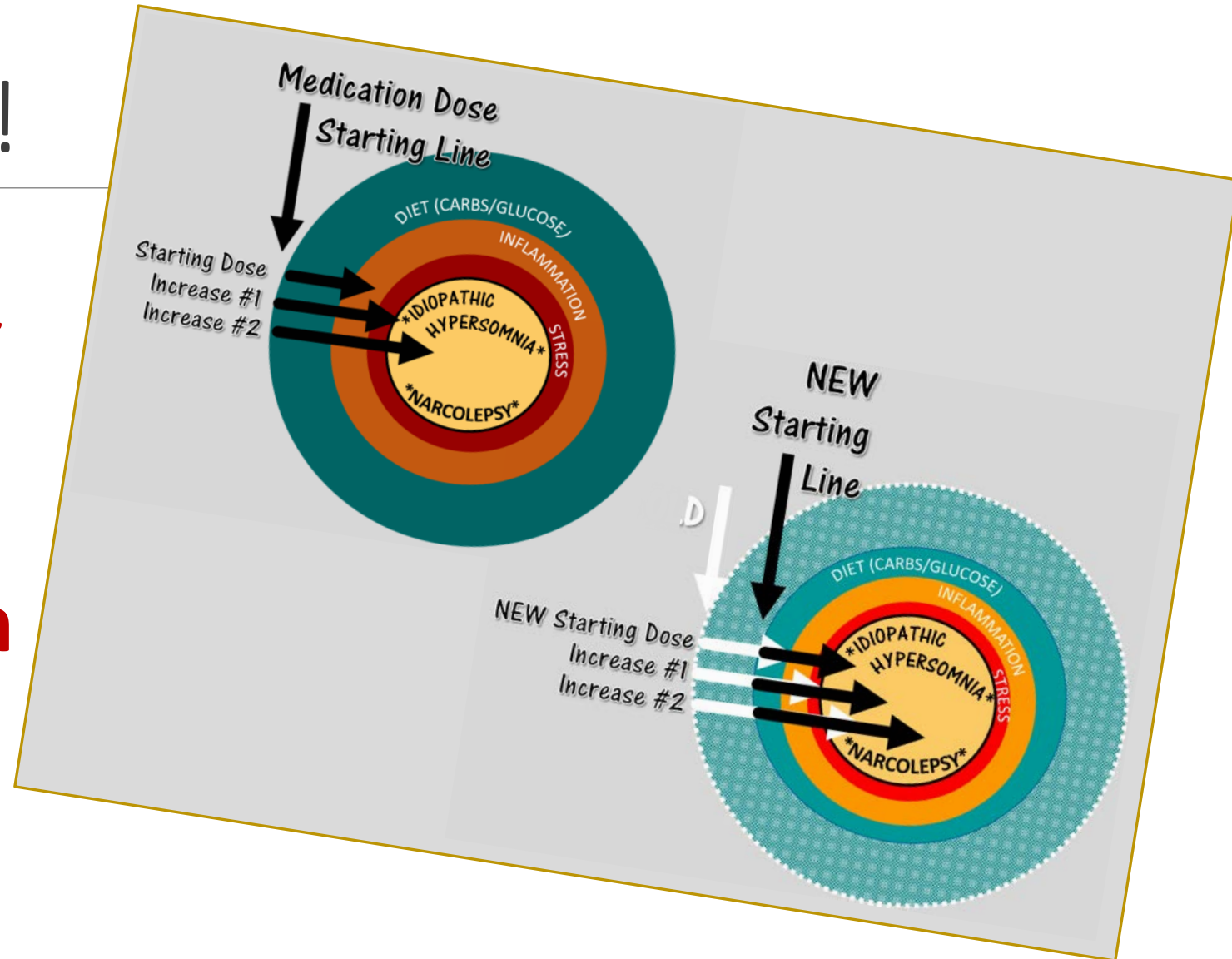
“Should I take \_\_\_\_\_ with or without food?”



# Quick Reminder!

***EACH change you make could affect your meds!***

**Be sure to have a step-down plan in place with your doctor.**



# Ugh

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# The Need for a “Slow & Steady” Approach

*Make too many  
changes at once and  
you won't know which  
one works!*

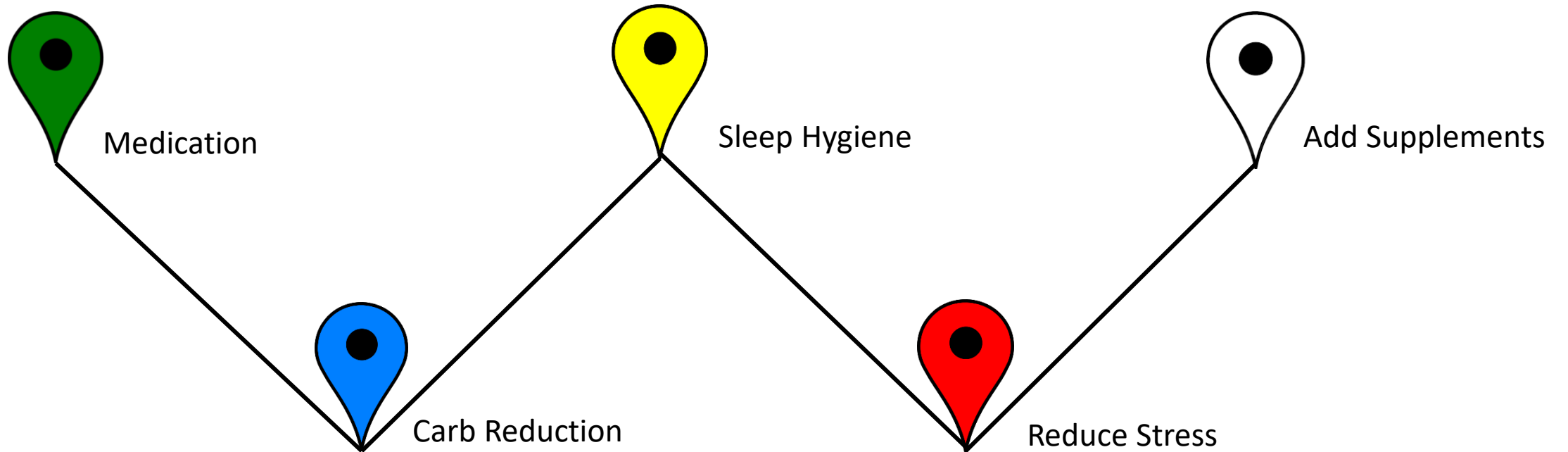
ONE change at a time

Keep a journal to track  
results



# Point A to Point B and So Forth

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# The Madcap Route

**BREAK. IT. DOWN.**

Make a list of **EVERY TOOL**

Number it from **EASIEST** to **HARDEST**

Break the **HARDEST** ones into even smaller steps

Start with the **EASIEST** one

**MASTER** it, *THEN* move on

*You don't have to go **FAST**, you just have to **GO!***

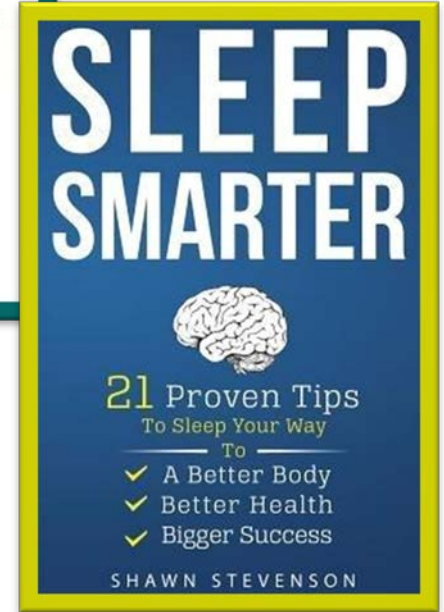
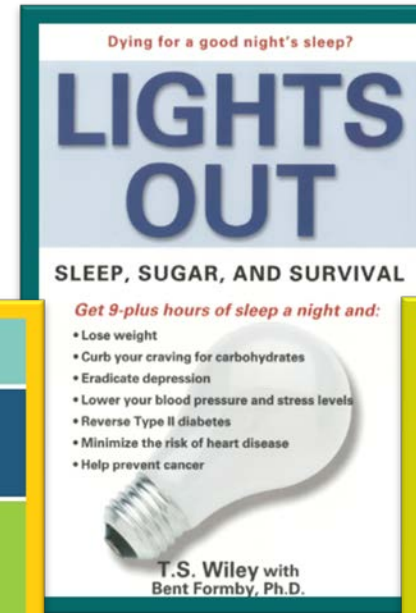
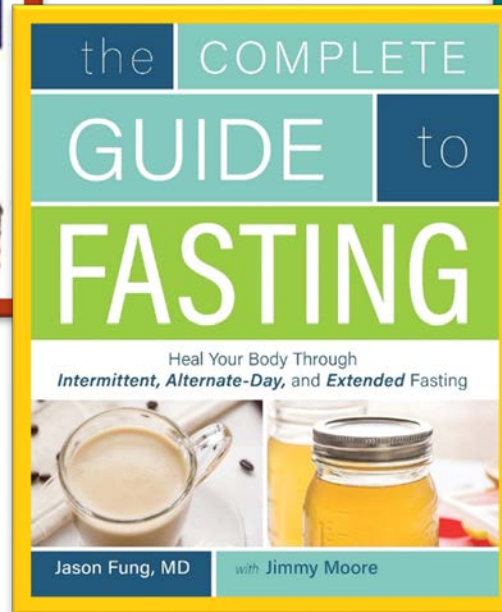
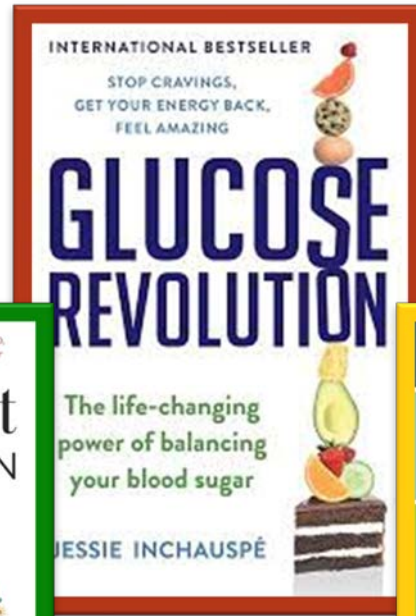
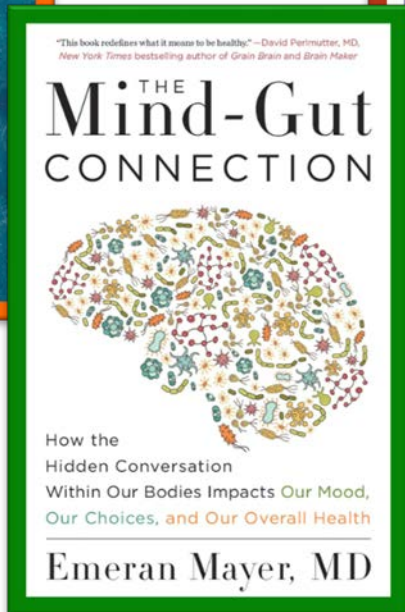
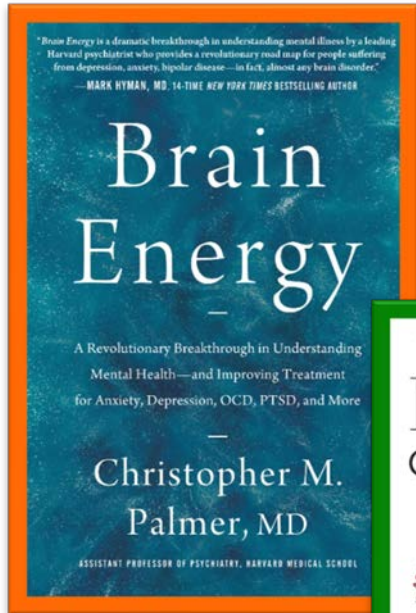


# A 30,000 Foot View of the Science-y Stuff

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# More Info





# More Info

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5000 Members Strong

**Fat Fueled and Awake**

MADCAP KETO FOR NARCOLEPSY & IDIOPATHIC HYPERSOMNIA

# Playing Devil's Advocate

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10%

**Average awake time for PWN & PWIH = 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%?*

# Where to Find Me

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# Madcap NARCOLEPSY

*With Gina Dennis, aka Madcap Gina*

[www.madcapnarcolepsy.com](http://www.madcapnarcolepsy.com)

[madcapnarcolepsy@gmail.com](mailto:madcapnarcolepsy@gmail.com)



Q&A

The image features the text 'Q&A' in a dark blue, stylized font. The 'Q' is a circle with a vertical line through its center and a short tail. The ampersand is a thick, curved shape. The 'A' is a solid triangle with a horizontal bar. Below the text is a soft, light blue reflection. The entire graphic is set against a white background with a dark teal horizontal bar at the bottom.