# LIFE AFTER DIAGNOSIS

live your bestlife

Improving overall health and wellbeing and how that can have a positive impact on managing Idiopathic Hypersomnia symptoms

Part Two

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This is part two of a three part presentation and discussion on 'Improving overall health and wellbeing and how that can have a positive impact on managing Idiopathic Hypersomnia symptoms'.

In part one of our series, we delved into the important topic of self-care. We discussed what that means and how it can positively impact your wellbeing. We also explored the concept of acceptance, which can be a transformative milestone you may not even realise you need to reach. We discussed the effects of stress and effective methods for minimising its impact with practical tips on achieving that goal.

In part two of our series we explore healthy eating, including hydration and how making different choices can have a positive impact on our symptoms and our ability to manage them. Additionally, we look at medication management and discuss ways to harness its full potential.

Our third session focuses on sleep, the important role of morning sunlight including the impact of melatonin and, cortisol, the consequences of Vitamin D deficiency and also physical activity and the benefits of Mindful Movement.

Links to all 3 of the pdf's that relate to this series can be found here: <u>https://www.hypersomnolenceaustralia.org.au/single-post/life-after-diagnosis-live-your-best-life</u>

DISCLAIMER - The content of this presentation and our Living with IH discussions is for information purposes only and is not a substitute for professional medical advice. Any concerns you may have about your health should be discussed with your doctor.



I started part one of this series by saying that I know making lifestyle changes isn't easy. I acknowledge that everyone is different, including the severity of our symptoms, our response to medication and the level of support we may receive. I also acknowledge that lifestyle changes can not only be difficult to initiate, they are often difficult to maintain, it can seem impossible. Even the thought of making changes can be overwhelming - I know because I spent many years thinking that way myself.

I have, through years of research and, trial and error, identified some things that I know can make symptoms worse or certainly more difficult to manage. **By sharing what has proven effective for me and others, I aim to inspire hope.** I believe that, although it's not easy, it is possible to optimise the positive potential of living with Idiopathic Hypersomnia (IH).

### Two important things first.

Firstly, I didn't just stumble upon the changes I have made. I've spent many years researching and learning about sleep disorders, health and wellbeing. I have listened to many people with sleep disorders and I have spoken to numerous doctors, researchers and health professionals.

But I'm not a doctor, so please speak to your doctor/s before implementing any changes to your lifestyle that will impact your health. Also, because making lifestyle changes isn't easy, you may need the assistance of a specialist therapist. If necessary, ask your doctor for a referral to one of these health care professionals.

And secondly, I am the happiest and healthiest I have ever been but I still have Idiopathic Hypersomnia with long sleep and, sleep inertia and sleep drunkenness. Making lifestyle changes has not magically made my IH symptoms disappear. Research suggests IH reaches its peak in young adulthood and generally remains stable, that is, it doesn't get worse.

So why do people find some days, weeks or even months more difficult than others?

Aside from the people who have other medical and/or psychological conditions which can account for or contribute to their symptoms, **the most likely reason IH can appear to have worsened is because the person's ability to manage their symptoms is compromised by other external factors they are not taking into consideration.** For example, in part one we talked about the impact that chronic stress can have on us, particularly our cognitive ability. Other factors include: what we eat; our level of physical activity; sleeping patterns and hydration.

Why can Idiopathic Hypersomnia appear to have worsened?	
SOME CONTRIBUTING FACTORS	
<ul> <li>Chronic stress can have a huge impact on cognitive function</li> </ul>	<ul> <li>Poor diet - particularly one that is high in sugar/carbohydrates</li> </ul>
<ul> <li>People with chronic illness are at a greater risk of developing depression and anxiety</li> </ul>	• Other medical or mental health conditions we may not be aware of or may not be taking into consideration
• Tolerance to IH medication	• Inflammation
Your ability to manage your symptoms can be compromised by other factors you may not be taking into consideration	



Lifestyle changes are behavior modifications or habit changes that encourage positive changes in your life.

I know that it's difficult to create positive habits when your brain is in a constant fog and threatens to shut down and sleep all the time – that's when you can get your brain to wake up in the first place! So, it's definitely a constant work in progress for me. I have good and bad days. The important thing is that you don't give up on yourself. Some days are a complete write off for me where I literally scrap the whole day completely and start again tomorrow. So don't be too hard on yourself if you too have to completely write a day off and start again tomorrow. The important thing is that you give yourself the time to re-group and then try again.

Making positive changes can create lasting effects on your personal wellbeing. The foods you eat, the amount of sleep you get and your exercise habits can all influence your weight, hormone health, level of pain, inflammation and impact the severity of your IH symptoms and your ability to manage them.

#### BEHAVIOUR MODIFICATIONS OR HABIT CHANGES THAT ENCOURAGE POSITIVE CHANGES IN YOUR LIFE

- Adequate Sleep
- Healthy Eating
- Physical Activity
- Stress Management
- Hydration Habits
- Healthy Exposure to Sunlight

Making changes to these habits can create lasting effects on your personal wellbeing and have a positive impact on the severity of your IH symptoms and your ability to manage them.

### Healthy Eating - Effects of Carbohydrates

It is indisputable that common nutrient deficiencies and poor health manifest as low mood, anxiety, poor concentration, irritability, fatigue/tiredness, and sleep disturbances. But when looking for the cause of your symptoms, how many doctors asked you what you eat *and* explained to you the consequences of certain foods on the symptoms you were experiencing? Did they discuss with you how simple changes to your diet can have a positive impact on your symptoms?

When consumed, carbohydrates are generally quickly absorbed into the bloodstream as glucose, which is sugar. This causes a spike in blood sugar levels, and consequently, a surge in energy. Yet, just as carbohydrates are quickly absorbed, your blood sugar will also fall rapidly, leading to feelings of tiredness, fatigue, weakness, irritability, and brain fog – symptoms that people with IH can do without!

# That afternoon crash you experience is probably not solely caused by your hypersomnia hitting you when your medication wears off – it is also likely to be due to the carbohydrates/sugar you have consumed earlier in the day.

To regulate blood glucose levels, the hormone insulin is released from the pancreas. However, insulin prompts excess carbohydrates to be stored as fat and elevates the risk of developing health issues such as obesity, insulin resistance, and type 2 diabetes. Therefore, the best way to regulate blood sugar levels is to greatly reduce your carbohydrate intake and, replace

it with a healthier alternative. More on this below.

Carbohydrates are quickly absorbed into the bloodstream as sugar



- Steep rises in blood sugar will lead to sharp drops
- This can lead to feelings of tiredness, fatigue, weakness, irritability and brain fog
- Increased risk of developing other health issues including Type 2 Diabetes, Insulin resistance, Obesity





# A diet containing fewer than 100 grams of carbohydrates per day can assist in stabilising blood sugar levels, mitigating the detrimental effects of sudden spikes, including the subsequent dramatic crash.

Protein, fats and fiber help to slow down the digestion of carbohydrates and delay their absorption into the blood. This helps to prevent spikes in glucose levels after eating. So, eat these first, before your carbs.

For those interested in losing a bit of weight or who would like to maintain their weight...

Protein is more satiating than carbohydrates. When following a diet that is higher in protein and healthy fats you feel satisfied sooner, ie; you don't have that constant hunger and the never ending grazing that we tend to do on a diet that is higher in carbohydrates (industrial seed oils can also affect hunger, see below for more information).

I generally consume no more than 20-25gms of carbohydrates a day. Some days I consume less and some days I consume a little more, but never more than 50gms. Less than 20-25gms of carbohydrates a day is considered being on a 'keto diet'\*. I don't consider it a diet though; it is simply a lifestyle change.

\*Your body is likely to enter ketosis on a diet of less than 25gms of net carbs a day. See below for more information about the importance of staying hydrated and replenishing electrolytes.

It is important to remember that **all** carbohydrates you eat and drink are converted into sugar in the body. That includes glucose, fructose (a.k.a. fruit sugar), sucrose (a.k.a. table sugar), and lactose (a.k.a. dairy sugar).

### **HEALTHY EATING - REDUCE CARBS**

- All carbohydrates are converted into sugar in the body
- Consuming fewer than 100 grams of carbs per day can assist in stabilising blood sugar levels mitigating the effects of sudden spikes, including the subsequent dramatic crash
- Eat protein, fats and fiber first to help slow down absorption of carbs
- **Protein is more satiating than carbs.** When following a diet that is higher in protein and healthy fats you actually eat less because you feel satisfied sooner

Once consumed, all carbohydrates end up as sugar in the body.



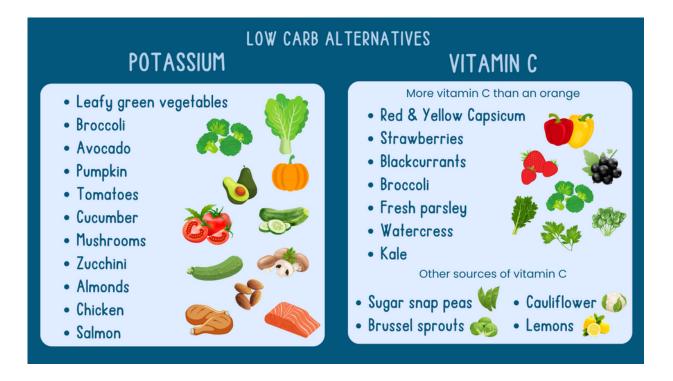
# APPROX. NET GRAMS OF SUGAR/CARBS IN:

- One large apple: 26 🧲
- One mango: 45 🧐
- One large orange: 18
- One medium pear: 18
- One cup of pineapple: 16 🔮
- One cup of grapes: 25 §
- One Banana: 25

\*'Net' grams of sugar/carbs is the total grams of carbs less the amount of fibre and sugar alcohol. You may be surprised to know how much sugar there is in the fruit you consume.

There are 6 teaspoons of sugar in 25 grams of carbs. For reference, there are 22 grams of sugar/carbs in a Krispy Kreme glaced doughtnut and 25.9 grams of sugar/carbs in a can of Sprite. That doesn't mean you are better off eating a Krispy Kreme doughtnut!

While these fruits are high in sugar they are also high in various essential vitamins and minerals, including vitamin C and potassium. Below are some lower carb alternatives:



### \*Understanding net carbs

Net carbs are all the carbohydrates in food that can be absorbed and used by the body for energy. In contrast, total carbs include all types of carbohydrates, including fibre and sugar alcohols, which are not fully absorbed by the body.

In America, nutritional labels include fibre in the total carbs, so you have to deduct the fibre from the total carbs to get net carbs. Meanwhile, in Australia, fibre is listed separately from carbs on nutrition labels, meaning that the carbs shown are always net carbs.



It is important to note that when you reduce carbohydrates you need to replace them with a healthier alternative, ie: protein and fat.

Fat has been demonised over recent years but there are good fats and bad fats. Certainly the trans fats found in margarine and vegetable oils should be avoided, but there is no evidence that saturated fat is associated with cardiovascular disease.

Industrial seed oils are highly processed oils derived from the seeds of various plants such as soybeans, corn, rapeseed (the source of canola oil), cottonseed, and sunflower seeds. They are commonly referred to as vegetable oils but there is absolutely nothing 'vegetable' about these oils. How exactly are they industrial? Hexane, bleach and other horrific processes. Watch <u>here</u>.

Industrial seed oils are not "heart healthy" or otherwise beneficial for our bodies and brains. In fact, despite organisations like The Heart Foundation suggesting these harmful oils are "better for you", there is quite a bit of research that suggests quite the opposite, that they are contributing to chronic inflammation and disease. Here's why:

#### **Processing and refinement**

Industrial seed oils are <u>highly processed</u>, which involves high heat, chemical solvents, mechanical pressure and deodorisation. This processing causes the fatty acids to oxidise, which creates byproducts that are harmful to our health. It can also lead to the formation of trans fats, which are also harmful to health.

### Inflammation - Omega-6 to Omega-3 ratio

Industrial seed oils are high in omega-6 fatty acids and low in omega-3 fatty acids (some seed oils have an omega 6 to omega 3 ratio as high as 75:1!) Scientists believe an imbalance in the consumption of these fatty acids act like toxins as they accumulate in body fat and can lead to an increased risk of inflammation. Inflammation from excessive consumption of industrial seed oils contributes to many conditions for which we normally blame cholesterol and saturated fats, including type 2 diabetes, obesity, Alzheimer's, cancer, auto-immune disorders, heart disease, inflammatory bowel disease and can cause chronic pain and fatigue.

- When you are insulin resistant (a sign of metabolic damage caused by seed oils) body fat doesn't get released into the bloodstream efficiently, making you hungry.
- Inflamed body fats are not able to produce energy efficiently. This makes us hungry and reduces our energy levels.
- People who are metabolically damaged feel hungry when they shouldn't, and end up eating more calories than they need.
- We assume that people gain weight with age because their metabolism slows down, but it is more likely that it is damaged over time by seed oils.

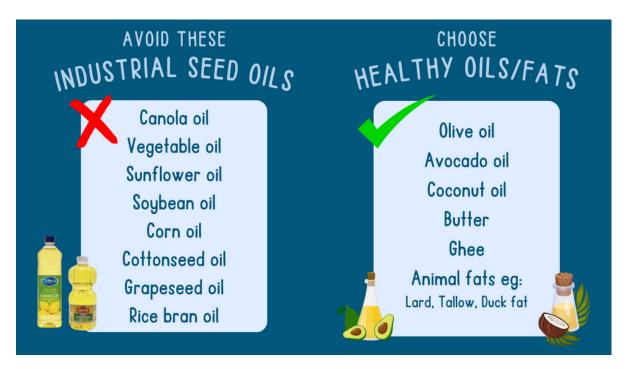


#### Industrial seed oils are void of nutrients and full of damaging free radicals

Industrial seed oils use damaging processing techniques which strip away all nutrients and leave us with an oxidised fat that causes free radicals in the body. Free radical damage plays a major part in the development of chronic and degenerative illness such as cancer, autoimmune disorders, aging, cataract, rheumatoid arthritis, and cardiovascular and neurodegenerative diseases.

#### Industrial seed oils are not suitable for cooking

Industrial seed oils should not be used for cooking because omega-6 fatty acids, especially linoleic acid, create harmful byproducts when they're heated. These destructive effects occur within minutes of being heated and are exacerbated when oils are reheated.



Industrial seed oils are hidden in many, if not most, processed foods like sweet and savoury biscuits and crackers, salad dressing, chips, sweets, muesli bars, pasta sauces, nut milks, margarine and even a lot of 'butter' so you would almost certainly be consuming more than you realise.

Avoid 'butter' that contains vegetable oil, emulsifiers, preservatives, flavours or colours etc. These nasties are typically found in 'butter blends' (typically referred to as 'spreadable' butter).





Butter that is good for you should not contain anything more than cream (churned from milk) and salt.

# Always check food labels



# Healthy Eating - In a nutshell

- Cut out all added sugar
- Reduce carbohydrates and increase protein
- Avoid ultra processed foods. Eat fresh as much as possible
- Avoid seed/vegetable oils and foods made with these oils - check labels!
- Consume healthy fats
- Stay hydrated

### Sweeteners

If you use sweeteners, it is important to know that some are better than others. Look for **natural sweeteners** like Stevia, and Monk Fruit Extract (be wary of blends\*) and **non insulin spiking** sugar alcohols like Erythritol and Xylitol.

\*Many artificial sweeteners such as Sucralose are sold as 'blends' eg: Splenda and Equal. Avoid sweetener blends containing Dextrose or Maltodextrin.

Monk fruit and stevia are both low glycemic index (GI) sweeteners and should have little or no effect on a person's blood sugar levels.

Non insulin spiking sugar alcohols provide fewer calories (about half to one-third less calories) than regular sugar. This is because they are converted to glucose more slowly, require little or no insulin to be metabolised and don't cause sudden increases in blood sugar.

### Avoid insulin spiking sugar alcohols:

- Sorbitol
- Lacitol
- Glycerol
- Mannitol
- Isomalt

Insulin spiking sugar alcohols can cause a spike in your blood sugar which will inevitably result in a crash.

Your small intestine doesn't absorb sugar alcohols well, so fewer calories get into your body. But because sugar alcohols aren't completely absorbed, excess consumption can lead to gas, bloating, and diarrhoea.

Definitely avoid Maltitol and Maltodextrin. Both are highly processed and have a high glycemic index (GI) value. Maltodextrin's GI value is twice as high as ordinary table sugar!



Electrolytes are essential minerals—like sodium, magnesium, and potassium—that are vital to many key functions in the body.

Dehydration can cause electrolyte imbalances. People with IH are particularly susceptible to dehydration and therefore electrolyte imbalances.

This is due to;

1. Medications. Firstly, they can cause you to focus on one specific task, at the detriment of others, so you just forget to drink water.

### How much water should you drink every day?

It is recommended that you drink 240mls every hour for the first 10 hours that you are awake.



How much of that should be electrolyte replenishing water will depend on the amount of sodium, potassium and magnesium in your diet.

Secondly, they (all amphetamine-based drugs and modafinil) are diuretics, which means they can dehydrate you by making you urinate more. Learn more about amphetamine-based medications <u>here: "Why is my dex</u> <u>not working"</u>

2. Sleeping for long periods and/or not taking care of our hydration needs because we often neglect our wellbeing due to being too tired to even notice the effects of that. We often just attribute it all (negative effects) to IH but, it's not always IH, all of the time.

Dehydration and electrolyte imbalances cause many of the symptoms people with IH experience, including: headaches, dizziness and light-headedness, cognitive dysfunction (confusion, trouble following a conversation, forgetfulness, etc), and feeling tired or fatigued. It can also cause irregular or fast heart rate, muscle cramps, muscle spasms or weakness, nausea, and vomiting.

I can (and I know others can too) experience all that with sleep drunkenness, but nausea and vomiting are not directly related to sleep drunkenness.

For many years, there have been days where I don't feel like I shake the 'sleep drunkenness' at all. Fortunately, this has improved since switching to a low carb lifestyle (and intermittent fasting) which includes making sure that I'm regularly replenishing my electrolytes.

I have now added a bottle of electrolyte-replenishing water to my morning routine (read more about my morning routine and other 'tips' <u>here</u>). I'm still horizontal and half-asleep when I take my first dose of medication in the morning. Then, I continue to sleep for another hour or so before attempting to wake up for the final time. I then start drinking the electrolyte water as soon as I can when I wake up, even before I am properly up (ie: vertical and out of bed).

It is still extremely difficult for me to wake up but adding the electrolyte water has helped with the morning nausea and headaches. The length of the 'sleep drunkenness' has reduced slightly too, provided I keep my fluids and electrolytes up throughout the day and keep my carbs down.



# Signs of Dehydration

- Cognitive impairment
- Low energy/Mood
- Tiredness/Fatigue
- Low blood pressure
- Heart palpitations
- Muscle cramps
- Headaches
- Dizziness/Confusion
- Nausea

# Signs of Electrolyte Imbalances

#### Magnesium

 Muscle cramps, restless legs, low appetite, nausea, fatigue and weakness

#### Sodium

• Headaches, difficulty concentrating, confusion, loss of energy, drowsiness and fatigue

#### Potassium

• Fatigue, tiredness, confusion, muscle weakness and cramps

Reducing carbohydrates in our diet can have a positive impact on our overall health and wellbeing. If you consume less than 25gms of carbs a day, your body is likely to enter ketosis, which means that it will use fat for fuel, rather than glucose, the main energy source in a predominately carb diet. Since your body retains less water whilst on a ketogenic low-carb diet, lots of electrolytes will be flushed out of your system. People who are new to a low-carb diet may neglect the need to replenish the electrolytes that are washed out of their body.

# This imbalance of electrolytes can cause fatigue, headaches, light-headedness, dizziness and muscle cramping - often known as 'keto-flu'.

Here are the recommended electrolyte intake guidelines, whilst on a low carb/ketogenic diet (thanks to <u>Keto</u> <u>for Beginners Australia</u>):

**Sodium: 5000-7000mg spread throughout the day**. This is usually best taken as broth, sole water (pink Himalayan salt water), or simply putting some salt on the tongue and swigging down with water.

**Potassium: 1000-3500mg per day**. Spinach, Broccoli, Avocado, Pork, and 'Lite-Salt' are great sources of Potassium.

**Magnesium: 300-500mg per day**. Avocado, Spinach are great sources of this, but it can still be difficult to get enough. Magnesium oxide is poorly absorbed by your digestive tract but. Magnesium Citrate tablets are a great option. If you suffer from loose stools as a result, you may benefit from trying magnesium glycinate, malate or taurate.

For more information about starting a low carb lifestyle check out Keto for Beginners Australia. Start with their <u>FAQ</u>.



I started intermittent fasting years ago by accident. Your diet and the timing of both your food and medication intake can have an impact on the effectiveness of Dexamphetamine (Dex) and other amphetamine based medications, eg: methylphenidate (Ritalin) and lisdexamfetamine (Vyvanse) etc. I will come back to this in more detail later. But, with this in mind, it was just easier for me to fast during the day. It definitely helped me to not build up a tolerance to my medication because I was using less of it; because my medication wasn't being negated by food and drinks I would normally consume during the day. Then, while learning about living low carb (a ketogenic lifestyle), I learned about the health benefits of intermittent fasting. What I learned was that is was a win/win for me!

I never set out to loose weight. When I started to combine intermittent fasting with living low carb, quite by accident, I lost over 20 kilos – almost in a blink of the eye (there was no effort involved because I wasn't even trying). I won't share my before and after photos again (you can see them in the PDF of the first presentation). The reason I shared them in the first presentation is because they don't just show that I have lost weight, they show that I had not only become overweight, but that I was visibly unhealthy. I mean unhealthy aside from IH; BUT my poor health was impacting the severity of my IH symptoms and the way I was able to manage them.

Intermittent fasting (IF) is an eating plan that switches between fasting and eating on a regular schedule. Research shows it can benefit heart health, brain health, reduce inflammation, improve cell repair processes, reduce the risk of cancer and is used in cancer treatment, and weight loss – because it helps to burn fat. This happens because IF prolongs the period when your body has burned through the calories consumed during your last meal and begins burning fat. Incidentally, this is why the idea of lots of small meals during the day for weight loss doesn't work, and it's not good for insulin resistance either. Research has also shown that IF can help prevent — or even reverse — some forms of disease, including type 2 diabetes.

There are several different ways to do intermittent fasting, but they are all based on choosing regular time periods to eat and fast. For instance, you might try eating only during an eight-hour period each day and fast for the remainder. Or you might choose to eat only one meal a day (OMAD) 3 days a week (and eat normally on the other days). There are many different intermittent fasting schedules.

I choose to fast for 16 hours and I give myself an 8 hour window to eat, although I usually only eat one meal a day and maybe one small snack.

# INTERMITTENT FASTING IS AN APPROACH TO EATING THAT ALTERNATES BETWEEN PERIODS OF FASTING AND EATING

### **Benefits of Intermittent Fasting**

- Heart health
- Brain health
- Reduce inflammation
- Improve cell repair processes
- Reduce risk of cancer/cancer treatment
- Weight loss (helps burn fat)



If you take amphetamine based medications eg: dexamphetamine (Dex), methylphenidate (Ritalin) or lisdexamfetamine (Vyvanse) etc, your diet and the timing of both your food and medication intake can have an impact on the effectiveness of these medications.

Your body needs both acid-forming and alkaline-forming foods, so eating a balanced diet is important. However, acidic and acid forming foods (including vitamin C supplements) decrease the absorption of amphetamine medication, reducing its effect. These foods tend to make urine more acidic too. This increases the rate by which amphetamine medication is released from the body, which also reduces its effectiveness. Normally around 30% of all amphetamine medication you take is excreted in the urine. However, highly acidic urine (around pH 4-5) will result in as much as 75% of the amphetamine medication being eliminated from the body! That would make a huge difference to the effectiveness of amphetamine medication. Whereas a low acid or alkaline urine (around pH 8) will result in less than 5% of amphetamine medication being eliminated via your urine.

There are MANY reasons why you may struggle more one day compared to another. Unless you eat and drink exactly the same things at exactly the same times every day, the pH of your urine, could be one of them.



### If you are taking your amphetamine medication with your morning coffee (or tea) STOP!

These medications are also more effective when you are hydrated, so drink plenty of water (not soft drinks, fruit juice or caffeine drinks as these are all highly acidic) and do not take it with food.

# You should aim to take these medications at least 45 mins before food and at least 2 hours after food.

Always speak to your doctor first about how to maximise the effectiveness of your medication. Remember to tell all of your treating doctors which medications you take (don't assume they know). Amphetamine medication interacts with various vitamins/minerals and medications, including some popular antidepressants, so if your doctor doesn't offer information, please ask.

HYPERSOMNOLENCE

Information from our "Why is my dex not working" factsheet.

# It's also important to delay that first cup of coffee (or tea) for at least 90-120 minutes after waking.

People who take amphetamine based medications should do this anyway, assuming they take a dose of medication upon awakening.

Coffee can make you feel more awake in part because of the way that it interacts with adenosine— a molecule that inhibits alertness and causes us to feel sleepy. As the day goes on, adenosine builds up in the brain, it is then cleared out while we sleep. But the chemical residue doesn't just disappear the moment we wake up. It takes a while (about 90 minutes) for the effects to clear naturally.



Caffeine <u>blocks adenosine receptors in the brain</u>, but it's important to remember that caffeine doesn't actually clear adenosine. This is why consuming coffee doesn't really "get rid" of your tiredness if you have not had enough sleep - it just starves it off until later, typically causing you to crash.

By waiting 90-120 minutes before consuming caffeine you give your body time to wake up naturally. You can help it out by hydrating, getting some sun, and moving around to get your morning cortisol flowing (more about this is <u>part 3</u>).

This can result in your first cup of coffee producing a more noticeable feeling of alertness (due to the more natural adenosine buildup). It could also help reinforce your natural sleep-wake cycles. If you start drinking caffeine later in the morning, you'll be less likely to feel an energy dip around lunch time. This can help you avoid drinking caffeine too close to bedtime.

Also, our body naturally makes cortisol, a hormone that wakes us up. This starts as soon as we open our eyes. When we delay caffeine intake by 90-120 minutes, we allow the body to wake up naturally and produce cortisol without interfering with its natural rhythm. I discuss our body clock, melatonin and cortisol in more detail in <u>part 3</u>.



## Links to all 3 of the pdf's that relate to this series can be found here:

https://www.hypersomnolenceaustralia.org.au/single-post/life-after-diagnosis-live-your-best-life



HYPERSOMNOLENC

While looking beyond the symptoms of Idiopathic Hypersomnia and what could be causing them, or at least contributing to them and making them more difficult to manage, I found myself going down a rabbit hole that lead me to where I am today.

I learned that, in order to maintain a well-balanced, healthy lifestyle, it's important to give the same level of care and attention to all four "Pillars of Health"; sleep, mindset, exercise and nutrition. If one or more of these pillars are not in place, it will have a negative impact on the others.

However, I quickly realised that sleep is very rarely part of the 'health and wellbeing' discussion, so I set out to change that. I decided to organise the <u>Sleep Health & Wellbeing Expo</u> and the <u>Idiopathic Hypersomnia & Narcolepsy Education Day.</u> Both were the first of their kind in Australia, so it wasn't easy. Unlike mindset (mental health), exercise and nutrition, sleep is not treated with the same respect. Despite the findings of the <u>Federal Parliamentary Inquiry into Sleep Health in Australia</u> that acknowledged attitudes needed to change and recommended that more awareness and education was needed, I couldn't get funding or support from the State or Federal Government for either event.

"We have known the importance of sleep for decades yet for many reasons, sleep health has not received the attention it deserves within our community and in the health programs run by state and federal governments. In part this is because there are still many who think that it's a sign of 'toughness' and a badge of honour to be able to get by on less sleep. The reality is that such an approach does harm — in some cases with very serious consequences."

Mr Trent Zimmerman MP, Chair of the Committee that oversaw the inquiry into Sleep Health in Australia. This quote is from the <u>report, 'Bedtime reading'</u>.

Fortunately I was able to call on a fantastic bunch of medical and health professionals to speak at the expo and the education day. There were 6 speakers at the education day including Prof Yves Dauvilliers and <u>15</u> <u>speaker sessions</u> at the expo - there would have been more, only I couldn't fit them in! Each of the speakers generously volunteered their time (some came from interstate at their own cost) and I am immensely grateful.

I will be forever thankful to Dr James Muecke AM MBBS (Hons) who personally inspired me to make positive changes resulting in my improved health and wellbeing, and who guided me in my research on the benefits of low-carb living, and the risks associated with seed oils and ultra-processed foods.



Dr Elizabeth (Liz) Machan , Dr James Muecke, Michelle Chadwick



Prof. Ron Grunstein, Michelle Chadwick, Fiona Mobbs, Dr David Cunnington, Dr Sara Winter, Prof. Yves Dauvilliers joined us live via video

And I am grateful for the unwavering support and guidance of Prof Ron Grunstein AM MBBS, MD, PhD, FRACP, a world-renowned pioneer in sleep research and clinical practice in Australia.

Furthermore, I am honoured to have connected with Dr. Elizabeth (Liz) Machan (Cayanan) BAppSc (Hons I) PhD, ESSAM AEP, whom I first met at a clinical trials network meeting in 2017, involving researchers from the Woolcock Institute of Sleep Medicine and the University of Sydney. It is a privilege to collaborate with Liz as part of a team conducting a '*Keto Study – A novel dietary approach to manage symptoms of narcolepsy and idiopathic hypersomnia*,' slated to commence later in 2024. Additionally, I am thrilled to be involved in a study led by Dr. Sara Winter PhD BPsychSc (Hons I), focusing on co-designing *Cognitive Behavior Therapy for Hypersomnia* (*CBT-H*) that we also hope will start in 2024/2025.



There are many references and resources that I have learnt from. The following are an example of some of the ones I found particularly helpful.

**If you're not into reading, watch the documentary** <u>'Fat Fiction'</u>. It opened up a world of knowledge to me and started my journey down the rabbit hole!

#### Other great documentaries:

The Magic Pill, Fat, the follow up Fat 2, and The Big Fat Fix





It was hard to choose an example of the great books I have read, but here is a selection.



#### The Big Fat Surprise: Why Butter, Meat & Cheese Belong in a Healthy Diet by Nina Teicholz

Nina Teicholz is a New York Times bestselling author and investigative science journalist and leader in nutrition reporting who is challenging the conventional wisdom on dietary fat-particularly, whether saturated fat causes heart disease and whether fat really makes you fat. Similar to the eye-opening impact of the documentary 'Fact Fiction,' Nina's work lead me on my journey to find answers about my health. Nina's book, and her work in general, has provided me with valuable insights into the food industry and its influence on research findings, as well as how this shapes institutions responsible for public health education. Learn more about Nina's work <u>here and here.</u>



#### Fat Lot of Good by Dr Peter Brukner

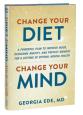
Like most doctors, Peter Brukner was trained to believe that drugs and surgery are the answers to all medical problems – including the epidemics of obesity, diabetes, and other 'modern illnesses' that are threatening our healthcare system and the life expectancy of future generations. For years he was dismissive of any 'alternative' diets or lifestyle changes.

But that all changed when facing the double threat of obesity and diabetes himself, he had a shocking realization that overturned a lot of the medical 'truth' he'd taken for granted: our dietary guidelines and food pyramid have no scientific basis. So he switched to a low-carb, healthy fat lifestyle – and dropped 13 kilos, lowered his insulin levels, and drastically improved his liver function in just three months.

In *A Fat Lot of Good*, Dr. Brukner busts the dietary myths we've been living by for decades and gives you all the information you need, in as simple a way as possible, to live a longer, healthier, and – more importantly – more enjoyable life.

Dr Brukner is a specialist sports and exercise physician. He is the current team doctor of the Australian cricket team. He is a Professor of Sports Medicine at Latrobe University and a founding Executive Member of the Australasian College of Sports Physicians, he served two terms as President and played a key role in establishing sports medicine as a medical specialty in Australia. He is the co-founder of the public health campaign <u>SugarByHalf</u> and is committed to the challenge of improving the nation's health with improved diet and increased physical activity. Learn more about Dr Brukner's work <u>here</u> and <u>here</u>.





Change Your Diet, Change Your Mind: A powerful plan to improve mood, overcome anxiety and protect memory for a lifetime of optimal mental health by Dr Georgia Ede

Dr Georgia Ede is a Harvard-trained psychiatrist specializing in nutrition science, brain metabolism, and mental health. This book is a comprehensive guide that shows you how to combine the surprising truth about brain food with the cutting-edge science of brain metabolism to optimize your mental health. Learn more about the book and Dr Ede's work <u>here.</u>

This is a new book on my reading list. I discovered this after reading Dr Chris Palmer's book Brain Energy, Revolutionary Breakthrough in Understanding Mental Health - And Improving Treatment for Anxiety, Depression, OCD, PTSD and More. https://brainenergy.com



# End Your Carb Confusion: A Simple Guide to Customize Your Carb Intake for Optimal Health by Dr Eric Westman

This is a good place to start for people new to low carb living, but it also has some good reminders for those already on their low carb journey. If you've spent years doing "all the right things" but you're still dealing with excess weight, diabetes, PCOS, heartburn, joint pain, fatigue, skin problems, or other issues, *End Your Carb Confusion* is the GPS you need to help you navigate your way from frustrated

and disappointed to empowered and successful. This book gives you the information you need to start reclaiming your health —no complicated and confusing scientific gobbledygook, only exactly what you need to understand how you got to where you are (hint—it's not your fault!) and, more important, how to get to where you want to be. Learn more about Dr Westman's work <u>here</u>.



# Big Fat Lies: How the diet industry is making you sick, fat & poor and Sweet Poison by David Gillespie

David is an Australian speaker and the author of several books on a range of topics including toxic people and the teen and adult brain. I have mentioned a few of his books on nutrition here but there are more. Learn more about David's work and other books <u>here</u>.

"Diets and exercise won't help us lose weight. Vitamins and minerals are a waste of money and sometimes downright dangerous. Sugar makes us fat and sick. And polyunsaturated fat gives us cancer and works with sugar to give us heart disease. My books exist because I desperately hope that with a little knowledge we can all vote with out feet and change the rules of the game before the game kills us."- David Gillespie

David Gillespie's book *The Sweet Poison Quit Plan* can help you learn how you to break your addiction to sugar.



### Toxic Oil: Why Vegetable Oil Will Kill You & How To Save Yourself by David Gillespie

Everything you believe about fat is wrong.

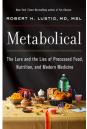
Polyunsaturated oil - everyone knows it's good for you, right? Wrong!

And we all know artery-clogging, cholesterol-forming saturated fat is bad for you, don't we? Wrong again!

In his previous book *Big Fat Lies*, David Gillespie showed that these 'truths' are in fact myths, based on poor research and bad evidence. In *Toxic Oil*, David reviews the latest evidence on why vegetable oil will kill you. He shows us how to avoid it and leads us through the supermarket, explaining how to read food labels and which products to buy. In the recipe section, you'll discover how to make versions of delicious meals and snacks that are difficult to buy without seed oil.

'Vegetable oil', which isn't made from vegetables at all, but manufactured from seeds, has systematically replaced saturated fats in our diets over the past one hundred years, but our rates of obesity, heart disease, diabetes and cancer are higher than ever." - David Gillespie





# Metabolical: The Lure and the Lies of Processed Food, Nutrition, and Modern Medicine by Dr Robert Lustig

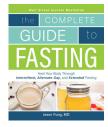
The New York Times bestselling author of *Fat Chance: The Hidden Truth About Sugar, Obesity and Disease* explains the eight pathologies that underlie all chronic disease, documents how processed food has impacted them to ruin our health, economy, and environment over the past 50 years, and proposes an urgent manifesto and strategy to cure both us and the planet.

Dr. Robert Lustig is a pediatric neuroendocrinologist and professor emeritus of Pediatrics, Division of Endocrinology at the University of California, who has long been on the cutting edge of medicine and science. He challenges our current healthcare paradigm, which has gone off the rails under the influence of Big Food, Big Pharma, and Big Government.

"The six cellular pathways to longevity are the same pathways to chronic metabolic disease:

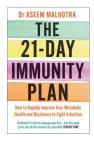
- Glycation
- Oxidative stress
- Inflammation
- Mitochondrial dysfunction
- Insulin resistance
- Membrane instability

And none of these pathways are druggable, except maybe inflammation, and that may be downstream of the other five." - Dr Robert Lustig. You can learn more about Dr Lustig's work <u>here</u>.



# Complete Guide To Fasting: Heal Your Body Through Intermittent, Alternate-Day, and Extended by Dr Jason Fung

Dr. Jason Fung is a Canadian nephrologist. He's a world-leading expert on intermittent fasting and low carb, especially for treating people with type 2 diabetes. He has written a number of best-selling health books. He also co-founded the Intensive Dietary Management program. You can learn more about Dr Fung's work <u>here.</u>



# The 21-Day Immunity Plan: How to rapidly improve your metabolic health and resilience to fight infection by Dr Aseem Malhotra.

A simple, clear, scientifically proven plan to boost metabolic health and help our immunity, by one of the world's most influential cardiologists.

Dr Malhorta is also the co-producer of the documentary "The Big Fat Fix". Learn more about Dr Malhotra's work <u>here</u>.



#### The Salt Fix: Why the Experts Got it All Wrong and How Eating More Might Save Your Life by Dr James DiNicolantonio

A leading cardiovascular research scientist and doctor of pharmacy upends the low-salt myth, proving that salt may be one solution to - rather than a cause of - the chronic disease crisis.

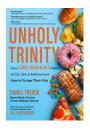
Also check out *The Immunity Fix* and *The Longevity Solution: Rediscovering Centuries-Old Secrets to a Healthy, Long Life* co-authored with Dr Jason Fung. Learn more about Dr DiNicolantonio's work <u>here</u>.





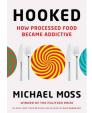
#### The Case for Keto by Gary Taubes

Gary Taubes is another well respected heavy weight in this space. He is an investigative science and health journalist and co-founder of the non-profit Nutrition Science Initiative. He is the author of Rethinking Diabetes (2024), The Case for Keto (2020), The Case Against Sugar (2016), Why We Get Fat and What to Do About It (2011) and Good Calories, Bad Calories (2007), published as The Diet Delusion in the UK. Learn more about Gary's work <u>here.</u>



# UNHOLY TRINITY: How Carbs, Sugar & Oils Make Us Fat, Sick & Addicted and How to Escape Their Grip by Daniel Trevor

Never before has a population gotten so fat and sick so fast. What's happening? Join heart attack survivor turned wellness warrior, Daniel Trevor, as he sheds light on the self-inflicted diseases of our time. Discover the truth about Big Food, Big Pharma, and Big Medicine, where financial interests often overshadow your health and well-being. UNHOLY TRINITY has been endorsed by some of the most prominent physicians, scientists, and health writers in the world, including a Dr Lou Ignarro winner of the Nobel Prize in Medicine. Learn more about Daniel Trevor's work <u>here</u>.



## Hooked, how processed food became addictive by Michael Moss.

From the Pulitzer Prize-winning investigative reporter and number one New York Times bestselling author of *Salt Sugar Fat* comes a "gripping" (The Wall Street Journal) expose of how the processed food industry exploits our evolutionary instincts, the emotions we associate with food, and legal loopholes in their pursuit of profit over public health. Learn more about Michael's work <u>here</u>.



The <u>Keto for Beginners Australia</u> website is also a good resource. It's a good idea to go straight to their <u>FAQ page</u>. They also have a Facebook group you can join.

### Links to all 3 of the pdf's that relate to this series can be found here:

https://www.hypersomnolenceaustralia.org.au/single-post/life-after-diagnosis-live-your-best-life

