The Long Covid Survival Guide - (Healing from CFS / EBV / POTS / MCAS / PEM / Dysautonomia)

If this helps you, please consider subscribing to my healing frequencies YouTube channel: https://www.youtube.com/@Anjali.Healing432 - music to heal & recover.. Thanks! ~ Anji Kaizen

TREATMENTS & PROTOCOLS

Sick of being sick? Me, too. I spent the first part of my healing journey with Long Covid / Long EBV / MCAS / CFS / POTS / PEM / Dysautonomia & Leaky Gut looking for a silver bullet that would solve my problems - a single "cure" for what ailed me. I went to many specialists (therapist, ENT, cardiologist, pulmonologist, allergists, herbalists, acupuncturists, GI Doctor, etc) thinking "maybe THIS one can fix me!" and nope. None of them did. Everyone said "you look normal, but you're obviously struggling. We just don't know why." That wasn't good enough for me. So, I've been doing a ton of research to heal my body. Here's what I've learned.

Please read this document in order. Everything builds on the previous chapter.

You should not rely on any information contained in this Guide and related materials in making medical, health-related or other decisions. Please consult a doctor or other health professional

NAVIGATE: Open Doc Tabs to the left to find different headings & navigate the guide. I advise you to read the whole thing first, then jump around as needed for your healing.

(Resources, Health Hacks, Recommended Reading & Practitioners at bottom of doc)

PLEASE NOTE: Nothing in this post is to be taken as medical advice. Your experiences may differ from mine, as each body is unique. I highly recommend finding a good Functional Medicine Dr in your area to work with you as you heal. If you have an ACUTE infection with COVID or EBV, focus on resting & DO NOT start an exercise protocol without medical supervision. I am not a doctor, just someone who is obsessed with getting healthy again. And I have tried many diets. And pills. And supplements. But only a few things actually worked for me or made any noticeable difference. And here they are:

1. AVITAMINOSIS: Addressing Vitamin & Mineral Deficiencies

No wonder I felt so god awful for so long. I had several deficiencies: my vitamin D, vitamin B, iron, ferritin, potassium & magnesium levels were all alarmingly low. Ask your Doctor for a full blood work panel, specifically the ones listed above. There seems to be a correlation between these deficiencies & long covid patients. Once you address your deficiencies, your body can truly start to heal itself, it just needs the right vitamins & nutrients! Vitamin D is especially important because it helps your body regulate immune function, sleep, and energy levels.

Recommended Labs to Request: full blood panel, thyroid panel, total iron binding capacity & ferritin levels. If you have MCAS, also check your Zinc & Copper. These are what my Functional Medicine Dr ordered for me: CBC, CMP, zinc, copper, hs-CRP, homocysteine, fibrinogen, vitamin D, folate, B12, EBV Panel IgG and IgM, selenium, anti-TPO, anti-TG, GGT, iron panel including ferritin.

Note: if all of your labs come back normal, you may want to get further testing for tick borne diseases or heavy metals, or mold toxicity. These can all exacerbate Long Covid symptoms.

One of my practitioners described Long Covid as "pouring gasoline on low burning flames" of whatever health issues you may have already had. That's why so many people can have such different symptoms & experiences. Long Covid is full body inflammation that affects over eleven different systems in the body, which is why you must focus on healing the body as a whole instead of hyper-fixating on every symptom. For me, my symptoms were: gut dysbiosis, bloody stools, brain fog, tinnitus, severe fatigue, PEM, dizziness, chest pains, shortness of breath, confusion, heart racing, throat tightness, heat intolerance, lack of sweating, histamine intolerance, dissociation, panic attacks, anxiety and muscle aches. Addressing my deficiencies, my diet, my lifestyle, mindset, and adding supplements improved my overall and total body health significantly. I'll address those below.

2. MACROS: Meeting Basic, Caloric Needs

Before we get into diet, you need to figure out your daily caloric, metabolic and energetic needs. Download the Cronometer app for free & calculate that right now before we go any further. Then, add an extra 15% calories to account for the amount of inflammation in your body that's taking up extra energy. You should have a number above 2,000 calories per day. Mine was 2,800 with the extra 15% added in, because I needed to gain back the weight I'd lost while being sick. If you are not meeting your basic caloric needs, then you are operating at a deficit, which will make you feel exhausted, anxious, run down, depressed & will keep your nervous system dysregulated because your body is not getting enough energy to do what it needs to do to function. Got your number? This alone, adding in more calories, fixed most of my fatigue.

There are multiple studies showing that patients with Long Covid require higher calorie intakes during recovery & more protein in their diets. Here is a fantastic one: "The protein requirement should be higher in patients with post-COVID-19 syndrome to improve sarcopenia and avoid further wasting of muscle mass [72]. Patients should be recommended to include high-quality proteins, both from plant and animal sources, and to consume 15-30 g protein/meal, depending on body weight, to ensure their intake of all the essential amino acids, which might exert an anti-inflammatory effect" ~ NIH, "Dietary Recommendations for Post-COVID-19 Syndrome"

^ I highly recommend reading that whole study if you have the time & energy! Meeting your Macros can help with PEM - also having a protein shake after exercising or exertion, too.

3. DIET: Clean, Whole Food Plant Based & Low Histamine

Try eating only whole foods with simple ingredients (like a literal baked potato instead of french fries) with no added dyes, sweeteners, chemicals or preservatives. Clean eating = eating only organic, fresh foods. Plant based = choosing plants for protein. And if you are histamine intolerant, then Low Histamine = no processed foods, no junk food, no gluten, no dairy and no high histamines (aged, smoked, processed, fermented or heavily preserved foods). Check out the Swiss International Group of Histamine Intolerance for a complete list of foods & histamine levels. Also look into getting a DAO supplement to help you digest histamines & lower your overall histamine bucket. Note: if you're not histamine intolerant, don't worry about staying on a LH diet. Histamine intolerance is anaphylaxis or serious allergic reactions to histamines in foods. Still, go ahead & try out Low Histamine for a week or two & see if it helps your symptoms! Sometimes it helps POTS, fatigue, pain, sleep or other symptoms.

"So what the heck do I eat?" You may be asking. Eat LOTS of fresh veggies, plant proteins if tolerated (lentils, chickpeas, tofu, etc) plant milks, spices, plant oils (coconut, olive oil, flax) & herbs (whatever you tolerate, if low histamine). If you need to keep eating meat, stick to white meat & salmon as they are less inflammatory than other meats. Make sure to include Chia seeds, hemp seeds, flaxseeds for omega 3s. Eat big salads. Green smoothies. Soups. Read the book "Miracle Metabolism" by Thomas Tadlock for a great healing diet protocol. He explains how fixing your metabolism heals your body. Try eating just fruits & veggies for a few days. Notice how this makes you feel (probably better) then start bringing in more foods one at a time to see how you feel or if your body reacts at all. This alone, changing my diet, cured almost all my POTS symptoms. I'm plant based these days & feeling great! Better energy & better digestion.

NOTE: If you are NOT tolerating veggies & plant based proteins, just focus on Macros for now. Meeting your basic caloric needs is the most important thing to start healing.

If you ARE tolerating veggies & plant based proteins, then the "Miracle Metabolism" protocol boils down to this: eat Whole Foods Plant Based, focusing on eating a MINIMUM of 1 lb of raw cruciferous veggies* per day (kale, broccoli, cauliflower, cabbage, turnip greens, brussel sprouts, etc) plus a gallon of water & 1/2 cup of chia or flax seeds for a mega dose of Omega-3s. This is in addition to your choice of carbs (rice, quinoa, potatoes, etc) & protein (tofu, tempeh, beans, lentils, etc) to gain muscle. You can eat as many veggies & fruits of any kind as you want, all day long. You can eat veggies in smoothies, salads, soups or however you choose. My daily smoothie is: Kale packed in a blender + a green apple + grapes + frozen mango + mint + 1/2 cup chia seeds + water = a delicious, filling green smoothie!

*Source: Researchers at Johns Hopkins Children's Center report evidence from lab experiments that a chemical derived from a compound found abundantly in broccoli and other cruciferous plants may offer a potentially new and potent weapon against the viruses that cause COVID-19 and the common cold.

Please make sure, if you go plant based, that you are getting all of your nutrients. For example, you'll need to take a <u>B12 supplement</u> if you go vegan / vegetarian. You also need Omega 3s (flax oil / chia oil) & to take a daily Vitamin D. For low Iron, get an <u>iron fish</u> for infusing or

lactoferrin to help you better absorb the iron in your veggies. That's why <u>Cronometer</u> is such a great way to track your meals, because it will show you if you are low in any nutrients.

Note: Most "seed oils" are inflammatory - but Flax oil & Chia oil are anti-inflammatory (chia seeds omega 3 to 6 ratio is 1:3 & Flax seeds have an omega-3 to omega-6 ratio of 1:4.) Source: "Ingesting flaxseed can provide ALA to the circulation & tissues of the body. ALA levels are increased as early as two weeks after the initiation of flaxseed supplementation (19). The bioavailability of ALA is dependent on type of flax ingested (ALA has greater bioavailability in oil than milled seed & greater bioavailability in milled seed than whole seed)" https://pmc.ncbi.nlm.nih.gov/articles/PMC2989356/

This particular plant based diet ^ has already healed thousands of people from autoimmune & chronic inflammation diseases like Lupus, Sjogrens, Rheumatoid Arthritis, Long Covid and more. Check out Dr Goldern's website GoodbyeLupus.com for recipes, testimonials, the science behind the diet & more info. I am currently doing the "HyperNourishing" version of her protocol to keep up calories & eat more protein. There are several studies supporting a plant based diet to treat COVID & Long Covid, including this one "following a plant-based diet could be effective in preventing COVID-19 severity. The findings of this study support our hypothesis that the higher the PDI, the lower the chance of hospitalization in patients with COVID-19".~ BMJ NPH

What if you are not tolerating enough plants to go plant based? If you have MCAS, then please focus on calories & macros first. You have to eat enough food to function, no matter what you are currently eating. Eat what you can tolerate and try to shoot for 80% plants, 20% other food sources, if this is possible. If not, then again, please eat whatever you can to get calories.

The 80% plant focus will still provide the benefits of phytonutrients & vitamins found in your veggies, but ensure you are still getting enough protein. For example, while introducing plants, I ate chicken & ground turkey every meal to hit my target of 50g of protein. Just note that red meats & processed meats (sausage, bologna, etc) are highly inflammatory (<-- Source) The last time I ate beef in a pot roast, it made me relapse & I was stuck in bed for days. No fun. Source: "Higher meat consumption, particularly of processed meat, positively associated with inflammatory markers" ~ NIH, "Higher Meat Intake Associated w Higher Inflammatory Markers"

There are lots of diets: Keto & Pescatarian, Candida & Carnivore, Intermittent Fasting & more often discussed in the Long Covid community. It's important to explore what feels best to your body. When I was highly reactive with MCAS, my diet got very limited on carnivore & keto for a while. This curbed my reactions but also made my fatigue worse & wrecked my colon, so I added quinoa & rice back into my diet, as well as plants & other carbs. If something makes you feel worse after about a week or so, it may not be what your body needs at this time. It's also been found that people with severe fatigue feel worse with Intermittent Fasting because it affects your cortisol levels & can lead to "adrenaline dumps" so please be aware of that & DO NOT do any fasting if you are trying to gain weight / build back muscle mass or address deficiencies.

GUT HEALTH TESTING: I highly recommend the <u>BiomeSight gut health test</u> to figure out what imbalances you have in your gut microbiome. They offer a discount to Long Covid patients. It gives you personalized results of what probiotics to take, which foods to eat, what to cut out of your diet & more. I took this test about a year ago, and it showed me that I needed to lower my consumption of animal products, introduce more veggies (specifically artichokes, lentils & chickpeas), get more sunlight, and start focusing on getting more quercetin & resveratrol.

If you have MCAS - You will probably need to take antihistamines (allegra, pepcid, claritin, etc) for awhile as well as some Mast Cell stabilizers (low dose naltrexone, ketotifen, quercetin, stinging nettle, etc) to get more foods back in your diet. These are meant to be temporary, though. You are teaching your body that foods are "safe" again as you expand your diet.

4. SPINE: Getting Aligned - You are only as healthy as your spine. When I was laying in bed for months, I remember wishing that I had someone to pop my back because it felt like I was constantly in pain and inflamed in my upper back, between my shoulders, all the way down. I should have listened to that instinct and gone straight to the chiropractor.

Unfortunately, it wasn't until almost two years later after reading "The Perrin Technique" by Dr Perrin that I realized the connection between my back problems & all my other health issues. His treatment is based on correcting posture, creating healthy spinal alignment & getting the

The most common structural disturbance that I have seen in ME/CFS and patients was a flattening of the curvature in the mid-thoracic spine, usually exaggerated convex curvature in the lower back). An example of this defect is shown in Figure 19a which can be compared with the healthy posture shown in Figure 19b. In spostural defect is often caused by a prior condition, spinal osteochondrosis, also known as Scheurmann's disease, which affects spinal development in adolescence, and which may have occurred years before the onset of the characteristic symptoms of ME/CFS and FMS.



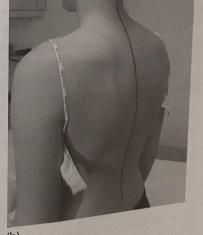


Fig. 19 Comparative photographs showing a flattened mid-thoracic spine. Photo (a) shows the familiar flattening of the mid thoracic spine seen in many ME/CFS and FMS patients. This differs from a normal spinal posture in the healthy subject, photo (b).

lymphatic system back online again (more on that in the "MOVEMENT" section later)

Dr Perrin, based in the UK, has studied ME/CFS for over 30 years & discovered that there are five physical / biomechanical signs of CFS/ Long Covid. The most prominent being a flattened thoracic spine. (see photo) <

As soon as I read that, I checked my spine. And yes, my spine has flattened. Even doing toe touches, it stays flat. That's when I began seeing the chiropractor weekly, for 12 weeks straight. Since there is no

Perrin practitioner in my area, I found a local chiro. This treatment has greatly increased my energy, flexibility, mobility and overall lowered inflammation in my body. WARNING: the first few visits may cause a crash afterward, so be ready to rest for the next few days & get plenty of hydration.

Make sure you discuss your health condition with the chiropractor first & ask them for only a very short, GENTLE adjustment the first few times. Let them know your nervous system is pretty inflamed and so you do not want any neck adjustments until you are more stable & tolerating treatments better. You may also want to ask for X-rays to check for CCI (cranio cervical instability) which can be a root cause for POTS before adjustments.

If you'd like to learn more about the glymphatic system and the role it plays in chronic fatigue and chronic illness, check out this online research article "The Glymphatic System"

5. DETOX: Binders & Detoxing

You have to detox. Especially if you have mold toxicity. I know, cue the "if you have a liver your body is detoxing" crowd but our body can only detoxify so much, so fast. So, if you kill off a virus or bad bacteria TOO FAST with herbs, supplements or exercise... you'll relapse & feel god awful with fever, chills, panic, elevated heart rate, excessive thirst, sweating & stomach cramps. This is known as a "Herxheimer" die-off (Source) - a reaction where your body dumps toxins from bacteria / viral infections into your system faster than your liver can clean out. It really sucks.

So, to assist your body as it detoxes, you need to keep some <u>charcoal pills</u> & <u>bentonite clay</u> around. <u>Aloe vera</u> is good, too. Or <u>chlorella</u>. This way, if your symptoms suddenly flare up, these binders will be available to bind to the toxins & flush them out quickly & safely. They also help lower histamine buildups. Works for food poisoning, too! Seriously, binders are absolute game changers and have saved me from going to the emergency room several times! (Source)

NOTE: charcoal pills are very harsh & will "dry you out" so please take them sparingly and with lots of water. Bentonite clay is also "drying" so take it diluted with a big glass of water. For daily cleansing, instead try to use chlorella or Aloe vera as they are less drying & easy on the gut.

These binders help remove viral debris or "viral persistence" that is still in the body, which has been found to be living in long covid patients long after they test negative for the virus. "Patients with persistent symptoms have traces of the virus in their stool many months after being infected, while tissue samples from the gut have also shown evidence of viral persistence. In other reports, biopsies taken from different parts of the body have led to similar conclusions, that parts of the virus can be recovered from some patients many months later." Source: https://www.npr.org/sections/health-shots/2023/05/02/1172806898/why-viral-reservoirs-are-a-prime-suspect-for-long-covid-sleuths

Further Reading: NIH - Damage to endothelial barriers and its contribution to long COVID https://pmc.ncbi.nlm.nih.gov/articles/PMC10134732/

6. PACING: Heart Rate & HRV Tracking

Part of the reason I kept getting sicker for the first six months of Long Covid is because I had PEM and kept "overexerting" myself & then having "Crashes". Basically, I would do too much & have a symptom flare up & be stuck in bed for days. Learning "Pacing" fixed this problem for me. Pacing is the art of moving slowly, taking breaks & listening to your body during activities. Start tracking which activities are using the most energy. Here's a video on Pacing by Long Covid Physio: https://www.youtube.com/watch?v=USLg5FT86TQ

Also, if you still have an acute infection of COVID or EBV, you need to rest a lot. That should be your main focus - quality rest & then "pacing" your activities by giving yourself lots of breaks. When pacing, it's important to make things as easy for yourself as possible - small adjustments like purchasing pre-cut veggies, doing meal prepping, using stools to rest on (shower stool linked below in the Health Hacks section), and asking for help with daily tasks can be a gamechanger in your daily energy levels. See the "Health Hacks" section for more.

Personally, I prefer to use an app called "Visible" (this link will give you \$20 off) that actively tracks my heart rate & heart rate variability, 24/7. It gives real-time information on how stressed my body is, when I need to rest, and how much energy or "pace points" each of my daily activities takes up. It sends alerts in real time telling me to rest, slow down, or take a break to keep from getting a "crash" or post exertional malaise. It also tracks symptoms, medications & overall health. It gives a daily number score on how "stable" my body is for the day, based on resting heart rate & heart rate variability. They have a free version of the app. But if you can't afford the paid version / don't want to use it, I still recommend pacing yourself. Take lots of breaks. Take breaks after every activity. Rest. Make sure your heart rate drops below 70 bpm to properly "rest & digest."

Heart Rate Variability has been shown to be a strong indicator of the amount of fatigue or energy that a person with chronic illness will have for the day. Source: "Heart rate variability (HRV) is an objective, non-invasive tool to assess autonomic dysfunction in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). People with CFS/ME tend to have lower HRV" ~ Translational Medicine

The Visible app uses a morning check in for tracking HRV, but if you'd like all day HRV readings then check out the HeartWatch app https://heartwatch.tantsissa.com/ <-- costs only \$5 for lifetime access, and it tracks your HRV & heart rate all day long, including while you sleep.

Note: When I first got Covid in Sept 2022, my HRV average was 31 ms on AppleWatch. Last November, my HRV was averaging at around 42 ms. This November, it's averaging at 50 ms. So I'm definitely seeing a steady incline in health overall on my HRV tracking since initial infection.

7. HYDRATION: Salt Water & Electrolytes

If you are just drinking tap water, then you are probably not staying hydrated. In fact, you are probably stripping your body of minerals & electrolytes if your water is not properly alkaline or a natural spring water source. That's why it's important to take electrolytes (especially if you have POTS, like me). Electrolytes are minerals that are essential to your body's daily functions, such as: muscle & nerve function, fluid balance between cells, pH balance, heat & blood pressure, and nutrient and waste transport. I use LMNT raw electrolytes daily. They are unflavored & easy to add to a glass of water. Make sure you're using a variety of salts - iodized (you NEED iodized salt for a functioning thyroid!), sea salt, himalayan & celtic. Don't use too much of only one. Here is a PDF with some tips for salty foods intake, types of salts, etc for Dysautonomia.

Dysautonomia International recommends 8-10 additional grams of salt per day, but please make sure to check in with your Dr or Dietitian before making significant changes to your salt intake. For more info about salty food & snacks, check out https://www.dysautonomiainternational.org/

Electrolytes & hydration are also recommended before doing any physical activity for someone who has POTS (more in the POTS treatment section). I drink a glass of 8 oz water with ¼ tsp of pink himalayan salt every morning. I also generously salt my food at all of my meals. Then, in the afternoon I drink a glass of LMNT before going for my daily walk or engaging in exercise or doing a yoga video. This helps my body normalize blood pressure while I am physically active. Source: "Electrolytes like sodium, chloride, potassium, calcium, and magnesium help maintain fluid balance in the body. Sodium in particular helps the body retain water, which increases blood volume" ~ EDS Nutrition

8. DON'T PANIC: Reset the Nervous System (ANS)

I know this is easier said than done when your nervous system is inflamed & trapped in Sympathetic Response, also known as fight / flight / freeze. What you are experiencing is temporary and you CAN navigate your way to a place of healing. This was the single most important part of my healing journey: CALMING DOWN. It's the only way your body will be able to enter a state of homeostasis (Rest & Digest, aka "Parasympathetic" ANS) to get the chance to rest and heal itself. You need to send yourself messages of safety 24/7. Try setting a timer to pause every 20 minutes and tell yourself "I am okay. I am safe. My body is healing". Slow down. Walk slower. Talk slower. Choose your reactions carefully. Do everything slowly, gently, carefully, calmly and in a "safe" way. Be gentle with yourself.

This means cutting out anything and anyone that stresses you out or raises your cortisol. For me, it meant moving in with family, taking time off work and putting my email into vacation mode. During this time there was no social media, and most importantly no more News channels or apps. No watching reality TV, no new movies or any entertainment that I hadn't seen before.

This will be temporary, but it is SO important. You need to feel SAFE 24/7. Read good books. Take naps. Meditate. Rest. Listen to chill music. Do gentle yoga stretches. Build a cozy, healing

nest for yourself and get some good quality rest. Get plenty of sleep. You have to teach your nervous system that you are SAFE & allowed to take the time & space you need to rest & heal.

Source: "The parasympathetic nervous system, also known as "rest and digest," can be thought of as functioning in opposition to the sympathetic nervous system. Its functions include: A decrease in heart rate & contractility of cardiac muscle, Constriction of the ciliary muscle and the pupil for near vision, Increased secretion by lacrimal glands and salivary glands, Increased gut motility, bronchoconstriction of the lungs, Contraction of the detrusor muscle with the relaxation of urethral sphincters, Glycogen synthesis by the liver, Activation of the immune system" ~ NIH, Physiology, Autonomic Nervous System

"Resting" is achieved when your heart rate drops below 70 bpm, your pelvic floor relaxes, your saliva flows, your eyes tear up from yawning, your jaw unclenches, and your stomach starts gurgling because it is finally relaxed enough to properly digest your food. Laying in bed, <u>listening to a guided meditation</u>, and appreciating the fact that this state of relaxation is how your body will heal itself is something you need to prioritize on a daily basis in order to heal yourself. For more info, check out the book <u>"The Healing Power of the Vagus Nerve" - Stanley Rosenberg</u>

Here are the things that helped me calm down my nervous system the most:

- **1. EFT (Emotional Freedom Technique)** tap into your nervous system directly on specific pressure points on the body. Similar to acupuncture, but non-invasive, gentle & self-guided. Here's a YouTube video for this technique: https://www.youtube.com/watch?v=AKCmdHN9JX8
- **2. Vagus Nerve Reset Exercises** These exercises calm your nervous system by stimulating the Vagus Nerve. You'll know you're doing it right if you start to feel more relaxed, your eyes tear up, you start to yawn, or if your heart rate starts to slow. Start gently, go slowly, here's a video to walk you through the exercises https://www.youtube.com/watch?v=zUx5kLFyx-M&t=8s
- **3. Yoga Nidra Meditations** Changed my life. I use these daily. These are guided body scanning meditations that connect you back to your breath, your body, and the present moment. They are also known as NSDR or "Non Sleep Deep Rest" meditations that reprogram your nervous system into deep states of relaxation for rest & repair. Here's a favorite of mine: https://www.youtube.com/watch?v=8mM5Oks8yZc&t=130s
- **4. Breathing Techniques -** alternate nostril breathing is a great way to regulate your nervous system. This involves covering one nostril as you breathe in, then swapping to the other as you breathe out. It can take a few minutes to feel the benefits. Here's a great video to follow along: https://www.youtube.com/watch?v=OhBU2CcOkSM

9. MIND BODY: Healing Both Together

Many long haulers are astounded at the progress in their healing journey once they start addressing the "Mind Body" Connection. Our bodies physically store trauma & pain inside of us (for more info, read the book "The Body Keeps The Score") and this trauma trapped in our

bodies can manifest as physical illnesses, sickness & disease if it goes unprocessed for too long. This trauma also lowers our immune system, making us sick & quite literally sucking up all of our energy into managing pain, stress & negative thoughts instead of using our energy positively to build a happy, healthy life. If you have struggled with people-pleasing, PTSD, codependency, trauma, CPTSD, grief, anxiety or depression, etc. it's important to get help!

The good news is - you also have the power to release trauma & coax your mind & body back into a state of joy, healing & forgiveness. To relax into & enjoy your daily life, instead of being plagued by stress, worries, pain, anxiety, fear or negative thoughts. Now, you can learn how to let go, & reach a state of inner harmony, tranquility and peace. It's work. But it's worth it.

TMS is known as "The MindBody Syndrome" and learning how to mindfully "break out" of your body's conditioned responses to pain, inflammation & chronic illness can be life changing & reduce your symptoms. This is discussed in the book "The Mind Body Prescription" by Dr Sarno & also "The Way Out" by Alan Gordon. This can also be described as "Perceived Danger Pain" & Dan Buglio discusses this on his YouTube channel "Pain Free You". Take this free online test to see if you are dealing with TMS issues, which means your healing will need to focus on TMS.

Therapy - I highly recommend seeing a therapist 1:1 if you can afford it. EMDR therapy has personally helped me a lot. Find someone with whom you can build a relationship in a safe space where you can comfortably explore your emotions and experiences. BetterHelp offers financial aid to those who need it, and I was able to qualify for a large discount to see my therapist for a few months after letting them know that I had Long Covid. Their membership also includes unlimited access to daily group coaching calls, seminars & workshops which are offered at all times of day on numerous topics. Contact customer support & ask about their financial aid options, they are very helpful & accommodating.

Journal Speak - A great example of MindBody Healing is JournalSpeak by Nichole Sachs. This is a practice where you journal your raw, unfiltered feelings for twenty minutes straight (letting your inner 9 year old rage) then do a 10 minute self compassion meditation, and then delete or destroy everything you've written. This helps you release pent-up negative emotions & process past traumas in a safe and private way. Here's more about it - https://audioboom.com/posts/7061582-meet-journalspeak-your-new-best-friend

Affirmations - The incredible Louise Hay pioneered positive affirmations in her day, and claims to have healed herself from cancer by changing her thoughts, beliefs, and attitude through the sheer power of positive affirmations. Starting your day with affirmations before you get out of bed can "program" your thoughts for the day, and ending your day with more affirmations can also reinforce these beliefs as you sleep. Check it out in her audiobook "You Can Heal Your Life" which you can listen to for free on YouTube:)

10. MOVEMENT: Lymphatic Support

If you, like me, had exercise intolerance (PEM) due to illness, then this is for you. You have to know this: our body requires movement in order to function properly. It's how your lymph system

functions, which is a super important part of your immune system. Staying in bed all day doing nothing will actually make you more sick & will cause your muscles to atrophy until you experience "de-conditioning" where you cannot physically go upstairs or walk around anymore. Here's a great article about recovering from Lyme & PEM discussing slowly re-conditioning: https://www.globallymealliance.org/blog/exercise-and-lyme-disease-how-to-stay-active-without-overdoing-it

The good news is there are lots of options to add movement into your daily routine. Even staying in bed! Movement includes: self-massages, deep breathing, dry brushing, lymphatic drainage massages, gentle stretching, restorative yoga, qi gong, forest bathing, nature walks, rebounding, vibration plates, and anything else that gets you moving. If you cannot tolerate "exercise" then you need to start very small. Start with what feels easy. I started with a "bed yoga" video on youtube that was only five minutes. I did it for as long as I felt good, then turned it off. After a few days, I was able to get out of bed and start doing yoga on my mat. After a few more days, I started being able to do 10 minutes of yoga instead of five. Now, I'm up to 30 minute daily walks.

UPDATE 3/3/2025: I have noticed significant improvements in my overall exercise tolerance & overall health & energy levels since starting the Perrin Technique by Dr Perrin (click for video playlist about the technique & exercises). Dr Perrin has spent the last 30 years treating ME/CFS via lymphatic drainage, spinal alignment & osteopathic rehabilitations of the body. This is a treatment all about getting your lymph system (which gets backed up, in CFS) flowing correctly again so that you have a functioning & healthy immune system, as well as detoxing your body from years (sometimes decades) of trapped toxins due to illness or injuries. Here is a link to his book if you want to read it, his website to check out, and a PDF I made of the protocol. He has also just released a new book specifically about long covid, which he predicted during the original COVID outbreak based on his research & history of dealing with CFS patients who had gotten diagnosed after EBV & contracting other post viral illnesses. As he is based in the UK, here is not a certified Perrin practitioner in my area in the USA, so instead I am seeing a local chiropractor & massage therapist weekly, as well as doing the daily self-help exercises.

I highly, highly recommend reading his book. No matter what symptoms or diagnoses you have. It is by far the most comprehensive, well researched & informative guide to healing from post viral illness that I have ever encountered. If reading is difficult for you, here is a link to the Long Covid Podcast on YouTube where he discusses the science behind his technique & how it works: https://www.youtube.com/watch?v=P1jAGvC RVE (end update)

NOTE: You need a lot of resting to heal from EBV & COVID, it took months to get healthy & stable enough again to start building exercise tolerance. Pacing is a mindset shift, even as I've started exercising I still take breaks, monitor my heart rate & never "push through" symptoms. If they flare up, I stop immediately & rest. This Guide is a long term approach to healing, not something that will happen overnight & should also be done with a physical therapist, ideally.

Just remember: don't push yourself. Go slow. Do the absolute minimum that feels comfortable, safe and tolerable for your body. Then do it over & over again for a few days until you feel ready

to try a little more. If you start getting chills, shakes, a fever, sore throat, or other symptoms of illness then STOP what you are doing and rest. There is no gold medal for pushing yourself too hard, only relapsing into your old symptoms. So take it easy, champ.

POTS YOGA PLAYLIST - Here's a YouTube playlist of POTS & CFS friendly yoga & exercises I use daily. You can try it out (remember, start slowly, only do one video at a time)

There's incredible <u>new research pioneered by Dr Perrin</u> showing that a lot of CFS symptoms are caused by toxin buildup in the brain, due to lack of proper lymphatic drainage & circulation after head trauma, injuries or viral infections. Check out the <u>Perrin technique</u> for easy self-massages you can do daily for relief to flush out your lymphatic in the correct way to get brain relief.

11. MEDS: Supplements & Herbs

I saved these for later, because really... they should come later in your treatment plan. A lot of long haulers (like me) make the mistake of trying a ton of different supplements (and having bad side effects, oops). Because if you do not have the previous treatment plans in place (^diet, movement, mindset, pacing, hydration, etc^) then no amount of supplements is going to make a significant difference. You have to make important dietary, physical, mental and overall lifestyle changes to heal your whole body at a cellular level.

These are the meds & supplements I'm currently taking: **Low Dose Naltrexone** (lowers overall inflammation in the body) **5,000 Vitamin D3** (to fix the deficiency) **NaturDAO** (to fix histamine intolerance, I take it before every meal) **Iron Gummies** (to fix deficiency) and **Allegra** in the evenings (to lower my histamine bucket). That's it. Those are the only ones I'm taking. I get Omega 3s from flax & chia seeds.

Why? Because my favorite practitioner, "The Long Covid Dietitian" Lily Spechler, told me to always try to limit my supplements to about 5 at a time. That way, I can always tell which ones are working and if they start to interfere with each other or if I need to wean off of one. The problem with taking too many supplements is you start to lose track of why you're taking them and for how long you were supposed to, then before you know it you're taking a ton of supplements every day & stressing out your nervous system with all these foreign substances.

It's miles & away far, far better to adjust your diet. Add more fruits & veggies. Add herbs. Need more Vitamin C? Eat some citrus, bell peppers, apples or potatoes. Need more iron? Eat Tofu, beans, lentils,peas, etc. Potassium? Eat sweet potatoes or drink some coconut water. Seriously, most of your nutrients should come from your diet and not from a pill. Our bodies don't absorb isolated nutrients as well as they do when the same nutrient is in natural food sources.

For suggestions of herbs, doses & medicinal support from plants, check out the book "<u>The Cellular Wellness Solution" by Dr Rawls</u>, he has a lot of great recommendations. Herbal teas are great, too. I'm planning to try marshmallow root tea & slippery elm (for mucosal support in healing stomach lining) and stinging nettle tea (for antihistamine support for MCAS) soon.

Other great herbs & supplements for Long Covid to check out: (only try one at a time!! If you have MCAS, try rubbing on your wrist first to make sure you don't react. Then try a tiny bit on the tip of your tongue. Wait 15 minutes to make sure you don't react. Then swallow a tiny bit.)

SSRI's - you need a prescription from your Dr, but boosting serotonin can be helpful for depression & anxiety. Check the GeneSight test to see which meds your body metabolizes best.

Milk Thistle (for liver support) - you can have this as a tea or a pill. Start small.

CBD - for sleep, or other hemp / CBD products like moisturizers. Calms your nervous system.

Artichoke Extract - helps with digestion, bile secretion & immune support.

L-Glutamine - a vital energy source for the immune system. Contributes to protein synthesis, which helps build muscle and lean body mass.

Creatine - helps maintain a continuous energy supply to muscles during exercise. In addition to providing more energy & helping increase muscle growth, creatine helps muscle recovery.

Magnesium Butter - Find a local herbalist, apothecary or make your own! Since it's topical, there are very low chances of side effects. Magnesium butter can improve your sleep. <u>Here's a link to read more about it from one of my favorite apothecaries</u>.

12. PURIFY: Remove Triggers

Triggers are anything that send your body into a stress response, by triggering the release of cortisol & adrenaline, which leads to further sickness & inflammation. These can be anything - environmental, emotional, social or physical triggers. It's important to start tracking your triggers & figuring out how to either get rid of them or manage them more mindfully. This is a crucial step in the healing process, because having toxins in your walls, food or water will keep you sick.

Environmental Triggers:

MOLD - make sure you do not have mold in your living space. Get an air purifier, clean out any old air filters or air conditioners, scrub down stains, and make sure there is no way for mold or mildew to thrive in your space. Mold toxicity causes MCAS & a whole host of other medical issues, it also inhibits your immune system & stops you from healing. It's practically impossible to heal your body while still living in a mold-infested building. Clean it out.

WATER - get your water tested. If you have well water, or another source that isn't regularly tested by the city, you need to make sure it is not contaminated. Get a water filter you can keep in your fridge, or one that you can attach to your sink faucet. You must have pure water to heal. **FOOD** - go organic. Seriously, buy organic if you can afford it. Or buy it at a farmer's market or grow your own or join a farm co-op. You don't want to be regularly ingesting chemicals, pesticides, antibiotics, steroids or any of the other crazy toxins in food products these days. **CLEANERS** - swap out your cleaning products for plant based, organic & natural cleaners. Toxic chemicals will get in your skin & your lungs & can make you sick or keep you sick. Use https://www.ewg.org/ to research & see how healthy your products are or to find new ones. This includes your: detergent, shampoo, deodorant, toothpaste, dish soap, etc. Literally everything.

13. POTS: Treatment Plan

Anyone with POTS usually already knows the go-to treatments: compression garments (like socks, tights & shorts) mobility aids (like shower stools, ta-da canes) salt & electrolytes (as discussed earlier) and also other lifestyle changes, like raising the head of your bed (I got a pillow wedge) or resting with your legs up the wall to encourage blood flow to the head. Avoiding temperature extremes (hot tubs, saunas) is also important as it affects blood vessel dilation.

"The foundation of treating POTS is to **drink fluids frequently throughout the day**. For most POTS patients, the goal is at least 64-80 ounces (about 2-2.5 liters) a day. You also need to increase your intake of salty foods & add more salt to your diet with a salt shaker or salt tablets" ~ Johns Hopkins Medicine

Did you know there are Olympic athletes who have POTS? Yep. Just because you have POTS does not mean that you'll be stuck in bed forever. You can build up strength & stamina. All exercise should be recumbent to start off with, but if you're doing well with the "movements" discussed earlier, like stretching, then talk to your Dr about checking out the CHOPS protocol, the POTS exercise program. It's also called the Levine Protocol. I've linked the PDF for you to print out. It's recommended to have a physical therapist or medical supervision when starting the protocol. It's controversial in the medical community, because you need to have a stable baseline & proper nutrition & exercise tolerance before starting it. Here's a great podcast episode with the Long Covid Physical Therapist, Dr Meg Anderson, discussing this topic. Please note that CHOPS was developed for children so you need to focus on your own heart rate zones as you begin activities.

NOTE: If you are still having bad PEM, you may want to try the Adapt Utah Protocol instead! Here is a link to check it out, but it's a much gentler approach to graded exercise: https://medicine.utah.edu/neurology/documents/utah-adapt-protocol-provider-manual-10924

Make sure you start laying down on your back & monitor your heart rate as you begin exercises. Try not to let your heart rate "overexert" for longer than a minute at a time (see below). Stop if you start experiencing any symptoms at all (like breathlessness, chest pain,etc). Take it easy.

NOTE: DO NOT start this protocol ^ if you still have an acute COVID or EBV infection. You need to rest & let your body heal & stabilize. Just stick with gentle stretches in bed for now.

For heart rate zones while doing CHOPS, I recommend using the Visible app. <u>Visible calculates</u> <u>your heart rate zones based on your resting heart rate baseline</u>. They give you three zones: resting, activity & overexerting. You can sign up with them, or use a fitbit / apple watch / activity tracker to track your heart rate. Try to stay in the "activity" zone, without "overexerting"!

- Rest up to 5% above Resting Heart Rate (70 bpm for me)
- Exertion up to 60% of Max Heart Rate (110 bpm for me)
- Over Exertion over 60% of Max Heart Rate (over 110 for me)

Lily Spechler (Long Covid Dietitian) had POTS so severe that she was bed bound for months after her acute infection, but after doing the CHOPS protocol she was back to biking the countryside, snow skiing, running and living her best life again. Read her story here. Goals.

14. MCAS: Treatment Plan

Mast Cell Stabilizers are the most important thing to focus on, if you have MCAS. Get your copper levels checked if you can. Please make sure to find a Dr or specialist to help you figure out which supplements & med are best for you. Here's a <u>great blog post discussing treatment options</u> by Dr <u>Jennifer L. Gaudiani, MD, CEDS-S, FAED</u>. Take it slow, one supplement per week. Here are a few of the most popular ones that seem to help a lot of people:

- 1. Quercetin make sure it's pure & ONLY quercetin. This is a great stabilizer.
- 2. DAO enzyme that breaks down histamine in foods, take before eating. I use NaturDAO.
- 3. Zinc deficiencies of zinc lead to allergies. Helps modulate the immune system & reduce allergic symptoms. Only to be taken under Dr guidance!! As it affects copper levels.
- 4. Vitamin B12 Methylated means it is broken down so your body doesn't have to. I use a sublingual spray by Mary Ruth for maximum absorption.
- 5. Vitamin C if sensitive to citric or ascorbic acid, try exotic berries or camu camu. This is another great stabilizer, try to add foods with this in (apples, berries, citrus) too.
- 6. Vitamin D3 try taking it at a minimum of 2,000 HDU first. You can also get it w/K2.
- 7. Montelukast Singulair. Effective for treating allergies & mast cell issues.
- Stinging Nettle a natural antihistamine, can be taken in pill form or as a tea.
- 9. Ketotifen you have to get this prescribed & compounded. It's a MC stabilizer & antihistamine. I did not tolerate it well personally, but many other people love it.
- 10. Low Dose Naltrexone I cannot say enough good things about this one. Life saver. Lowers overall inflammation in the body & stabilized my mast cells in 1 2 weeks.
- 11. AntiHistamines & Histamine Blockers these are H1 (zyrtec) & H2 (pepcid) that are useful for lowering your overall histamine symptoms. Talk to your Dr about these. I'm currently taking allegra.

MCAS has been, by far, the most debilitating part of this whole illness for me. Not being able to eat my favorite foods or go outside for walks in the sunshine without reacting was heartbreaking.

But the important thing to keep in mind is that you CAN stabilize & also that mast cells need lots of coddling. Try not to always blame your foods if you're feeling bad because your triggers can

be lots of things - hormones, pollen, pollutants, chemicals, mold, temperature, dust, lack of sleep, stress, lack of sufficient calories, etc - and histamines in food only account for less than 10% of the histamine in your body. Focus on "emptying your histamine bucket" by eating low histamine, taking antihistamines, DAO, mast cell stabilizers & regulating your nervous system.

Here's a list of natural antihistamine foods you can try out. Start slow. Do one at a time, one day at a time. Rub it on your skin first, then try a tiny bit on your tongue. If you're fine, try chewing it up & holding it in your mouth for 15 minutes. Then try a small swallow. I know, trying new foods can be scary, so make sure you do Vagus nerve calming exercises before & after. You can do it!!

If you start to have anxiety or need more support please check out this PDF <u>"Healing from MCAS"</u> by the Long Covid Dietitian, Lily Spechler, for more specific exercises, directions & self talk examples to calm you down. I have made some edits & reworked it into a PDF to share.

Last year I was eating less than 20 "safe foods". Now I'm at over 60 & adding more daily. Every day I take DAO before eating, drink stinging nettle tea if I'm feeling a "flare up" (itchy, on edge), take an allegra if I'm eating higher histamine foods, and have a ton of Vitamin C in my diet (from the green apple & mangos & kale in my daily green smoothie). You can get there, too!!

15. MINDSET: Overcoming Illness

The most important thing to keep in mind as you're healing is that each day is a new day, a fresh start, and a new opportunity to heal. If you're still sick, that doesn't mean you CAN'T heal it just means you haven't gotten there quite yet, or haven't found the right solution for your body yet.

I've seen people claim they're giving up because they "tried everything" and nothing worked. "Really?" I want to ask them, "did you get a fecal transplant? Did you achieve zen mastery & enlightenment? Did you meet with an herbalist? Try moving to another country? Read every scientific study available on your condition? Sign up for any research groups?" Because frankly, that's literally impossible... to try everything. This is good news though, because it means there are always more things to learn & new methods to try in order to heal.

Your Mindset is how you will overcome & fully recover. The whole time I've been sick, I've been taking meticulous notes because once I fully recover, I am going to publish a book about my experiences & everything I've learned to help others to heal from Long Covid. It's motivating.

The 1% Rule - try to do something small, every day, to get you 1% closer to where you want to be. Maybe that's checking out a new book, going for a short walk, adding in a new food, finding inspiration in someone else's recovery story, or getting a new doctor. Just move 1% at a time.

Then, as time passes, you will notice that those percentages start compounding into more. Suddenly, you'll be feeling 10%, 30% or 50% better than you did. Just take it 1% at a time.

Focus on WHY you want to recover - the things you're looking forward to. Stay focused on the things you love, the people you love, and build pockets of joy into your day. That's how you heal.

RESOURCES:

BEST Apps for Healing:

- 1. Visible (for pacing) FREE https://www.makevisible.com/
- 2. Rise (sleep & energy tracking) \$6/mo https://www.risescience.com/
- 3. Curable (pain management) FREE https://www.curablehealth.com/
- **4. Insight Timer** (meditation) *FREE* https://insighttimer.com/
- 5. AutoSleep (Apple Watch) \$5 lifetime purchase https://autosleepapp.tantsissa.com/
- **6. HeartWatch** (Apple Watch) \$5 lifetime purchase https://heartwatch.tantsissa.com/
- **7. Stress Monitor** (Apple Watch) \$70/year https://apps.apple.com/ug/app/stress-monitor-for-watch/id1510429086

HEALTH HACKS: Favorites on Amazon

NOTE: these are affiliate links, but I've also tried all these myself!

Squatty Potty / Toilet Stool

Pillow Wedge for POTS & Acid Reflux

LMNT Raw Electrolytes

(More Added Daily... Click Here for a full list of recommendations)

BOOKS: Further Reading

<u>"The Perrin Technique: (How to diagnose and treat CFS/ME and fibromyalgia via the lymphatic drainage of the brain)" - Dr Raymond Perrin</u>

"Miracle Metabolism" by Thomas Tadlock

"Goodbye AutoImmune Disease" by Dr Brooke Goldner

"The Cellular Wellness Solution" by Dr Rawls

"The Body Keeps The Score" by Bessel Van Der Kolk, M.D.

"The Healing Power of the Vagus Nerve" - Stanley Rosenberg

"The Way Out" Alan Gordon

"You Can Heal Your Life" by Lousie Hay - \$5 on Thriftbooks

YOUTUBE: Favorite Channels

The Long Covid Podcast - Jackie Baxter

The Cure for Chronic Pain - Nicole Sachs

Santosha Spirit (POTS & CFS Yoga) - Rachel Marie

Me/CFS & Long Covid Recovery Stories - Raelan Agle

Pain Free You - Dan Buglio

Goodbye Lupus - Brooke Goldner, MD

DRs & Practitioners For Healing

NOTE: I am not getting paid or asked to endorse any of them, they have just been very helpful to me on my healing journey. Most are free to follow online for tips & social media posts.

The Perrin Technique (How to diagnose and treat CFS/ME and fibromyalgia via the lymphatic drainage of the brain) - Dr Perrin

The Long Covid Dietitian - Lily Spechler

Long COVID Physiotherapist & Coach - Meg Anderson

Functional Medicine Doctor - Dr Brian Lum (chiropractor)

<u>Hypermobile Specialist - Dr Melissa Koehl</u>

Emory Atlanta Hospital POTS Cardiologist - Dr Alexis Cutchins

Goodbye, Lupus & AutoImmune Disease - Dr Brooke Goldner

Release CFS - Daniel & Valentina