

Dec 2022

The Patient Experiences Protocol

How patients recovered from vaccine injury and Long COVID



Long
Haul
Wiki

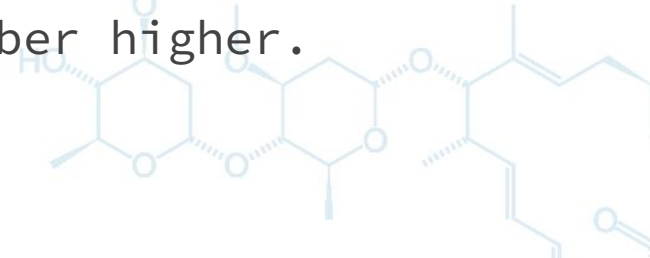
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LongHaulWiki.com

What this protocol is about



We know enough to start getting some people healed. Only about **23%** of vax-injured patients have tried **ivermectin**, one of the top treatments rated highly by people who have recovered. Only **16.8%** have tried **nigella sativa (black seed oil)**, an even safer treatment.

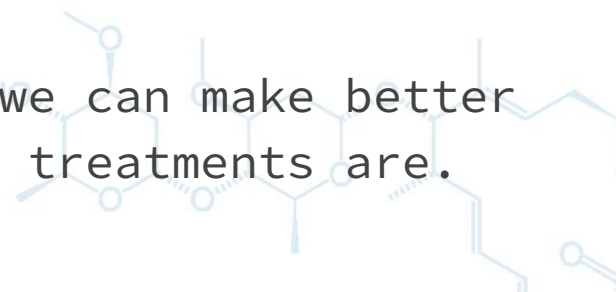
I'd like to see greater awareness of treatments that have worked for patients. Only around **7%** of surveyed patients have recovered and I want to see that number higher.



Key concepts



1. **Most treatments are a double-edged sword.** Some people will respond badly to treatment. Right now, we can't predict who those people will be.
2. **You should try to play defense against long-lasting or permanent worsening.** Start with low doses before going higher. Abandon treatment that goes the wrong way. Both strategies will likely lower your risk of permanent worsening.
3. **Data.** By pooling patient experiences, we can make better decisions about what the most promising treatments are.



Reliable versus unreliable data



I try to avoid data from people who make stuff up, manipulate data, or fabricate data. For example, a [NIH paper by Safavi, Avindra Nath, and others](#) claims that vaccine injury is easy to treat and that every patient recovered. Patients from that study (e.g. [Danice Hertz](#)) are saying otherwise.

I try to be cautious about what patients, doctors, and researchers are saying. Right now, we haven't identified any magical treatments that work for most people. Usually treatments don't work. But, I think there needs to be greater awareness about the key concepts from the last slide.

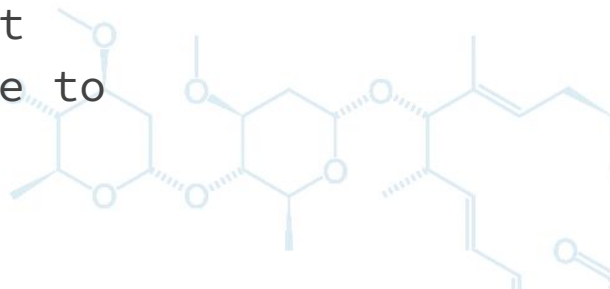
DISCLAIMER



Practically all of the treatments discussed in this presentation have risk. This presentation is no substitute for **competent medical oversight**.

While access to healthcare may be difficult, please do not take any unnecessary risks (e.g. wrong dosing, [drug interactions](#), etc.).

Also keep in mind that the current data is not that reliable. In the future, we will be able to see what people got wrong.



Data and evidence



See my [November 2022 video](#) for an overview of the data on treating Long COVID and vaccine injury.

This presentation includes *unreleased* analysis of patient survey data. This protocol gives more weight towards treatments that worked among those who are recovered.

Risk categories: Based on negative experiences reported in survey data, treatments are classified into categories: very low, low, medium, and high risk. These are just estimates.

For links, please see this video's description for the slide deck.












First Line Treatments

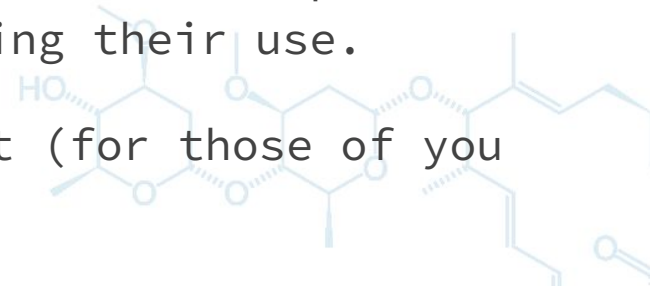
First line treatments



- **Fasting for more than 2 days** 
- **Ivermectin** 
- **Black seed oil** (from the *nigella sativa* plant) 
- **HBOT (>1.5 ATA)** 
- **Hydroxychloroquine (Plaquenil)**
- **Pacing strategies** 

The treatments above offer the best combination of acceptable risk, efficacy, and better evidence supporting their use.

 = Natural,  = Made by bacteria or yeast (for those of you interested in natural treatments)



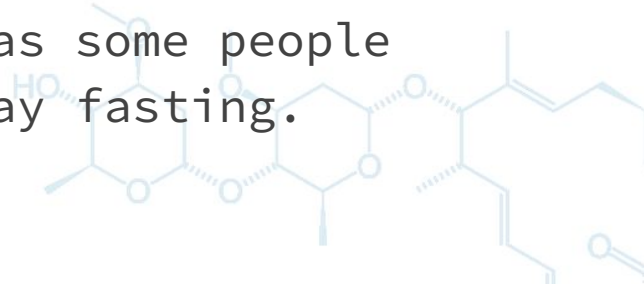
Multi-day fasting (without any juices or cleanses)



While you should start with less extreme forms of fasting, the people who mostly recovered did so with more extreme forms of fasting (more than 1 day).

The more extreme forms of fasting were rated better than less extreme forms such as OMAD (one-meal-a-day) and intermittent fasting.

Safety (medium risk?): Please be careful as some people report significant worsening from multi-day fasting.



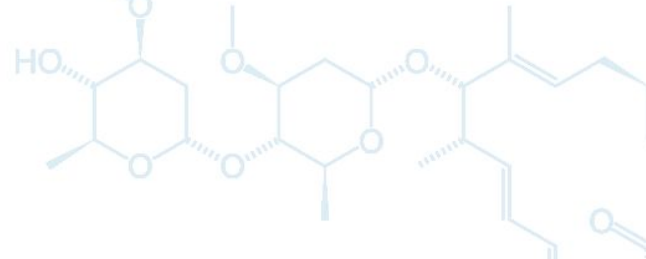
Pacing strategies

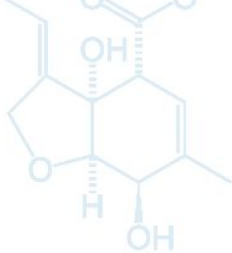


Pacing strategies (e.g. spoon theory) all involve limiting exertion so that you do not trigger post-exertional malaise (PEM). PEM can be triggered by physical exertion, mental exertion, and/or emotional exertion.

While pacing strategies were the highest-rated treatment on [the survey](#), they unfortunately do not seem to help people recover. It may offer quick, easy relief of some symptoms.

Safety: Very low risk.





Resources on pacing strategies

[ME-pedia article on spoon theory](#)

[Me-pedia article on pacing](#)

The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

If you only had 12 spoons per day, how would you use them? Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.

get out of bed	bathe	make & eat a meal	go to work/school
get dressed	style hair	make plans & socialize	go shopping
take pills	surf the internet	light housework	go to the doctor
watch TV	read/study	drive somewhere	exercise

The Spoon Theory was written by Christine Miserando, which you can check out on her website www.butyoudontlookick.com.

Black seed oil (from the *nigella sativa* plant)



Contains anti-microbial compounds such as **thymoquinone** and **carvacrol**. It likely works by shifting your microbiome around (hopefully into a healthier place).

Dosing: Work up to 1-4 teaspoons/day. You can take a small amount every day until the taste improves. Higher doses seem to be more effective than eating the seed or taking BSO via capsules.

Available from some ethnic supermarkets (Iranian, Indian, Pakistani, etc.) and supplement retailers such as iHerb.com. Buy the oil instead of raw seeds. Supermarket-sized bottles may be cheaper.

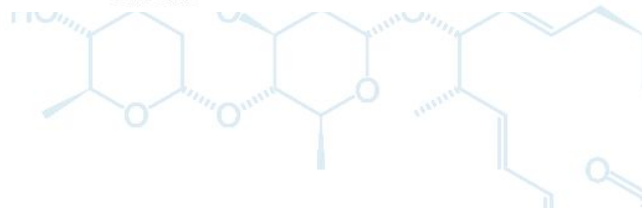
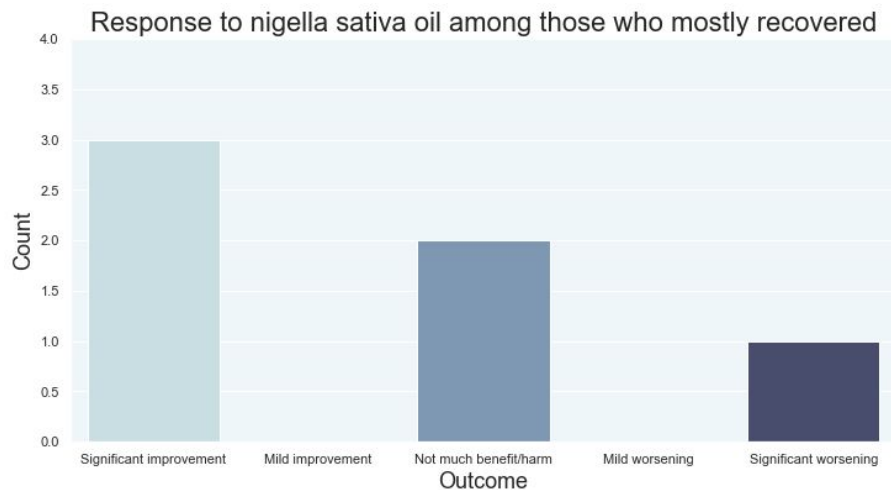


Black seed oil is not completely risk-free



Among those who mostly recovered, one person reported significant worsening from black seed oil. A bad reaction is possible among those with chronic illness, *despite* black seed oil being sold in supermarkets as food.

Safety (low risk): it is among the treatments with the least risk and is very well tolerated in normal healthy people.



Ivermectin

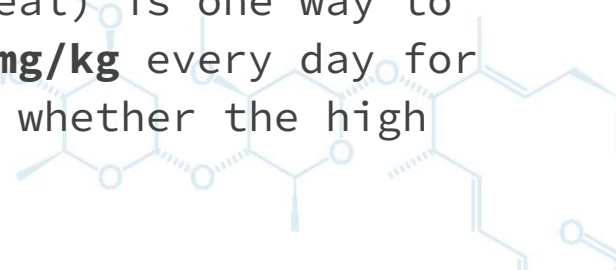


Ivermectin is another antimicrobial that works against parasites, SARS-CoV-2, and other viruses.

Access: See [the wiki page on ivermectin](#) for information on how to get it without or without a prescription (e.g. over the counter).

Safety (low risk): A few people report negative effects from ivermectin. While *all* of the antimicrobials seem to have a risk of a bad outcome, ivermectin is among the least risky.

Dosing: While **0.2mg/kg** every day (taken with a meal) is one way to dose this, it may be worthwhile to also test **0.6mg/kg** every day for 5-7 days. However, there is not much data as to whether the high doses are more effective.



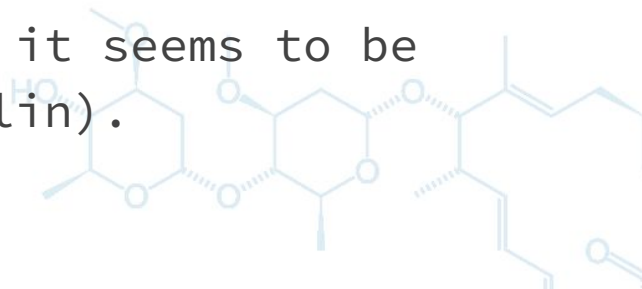
Hydroxychloroquine (Plaquenil)



Hydroxychloroquine (HCQ) is another anti-parasite drug. It is often used against malaria.

Access: Because it has been a controversial drug, getting HCQ may be difficult. It is often prescribed for some autoimmune diseases. Otherwise... [this thread](#) may help.

Safety (medium risk): It has more side effects than ivermectin. In chronic illness patients, it seems to be much safer than antibiotics (e.g. penicillin).



HBOT (Hyperbaric Oxygen Therapy)



How it works: One theory is that it helps the body heal- see [Paul Harch's lecture](#). Another possibility is that it kills bacteria like the Borrelia bacteria that cause Lyme- see [Ken Stoller's talk](#). It treats [a multiple sclerosis-like disease in mice](#).

Cost: Very expensive unless you are in the UK. Patients rate HBOT higher than other expensive therapies such as EB00, intravenous vitamins, IV ozone, apheresis, etc. Save your money for HBOT first.

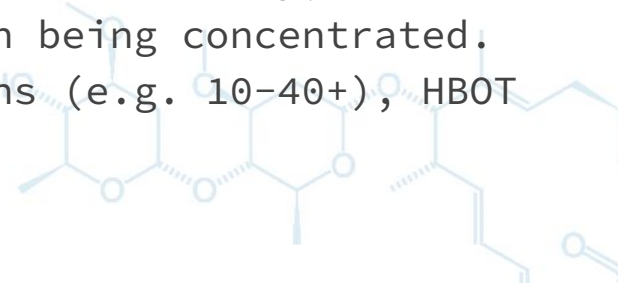
Safety (medium risk): While HBOT does not require a prescription, it is not that safe in chronic illness patients. Some experience long-lasting worsening from HBOT. See next slide.



HBOT safety issues (continued)



1. **Immediate worsening**, e.g. during sessions 1-3. Your doctor may not know that this is far more common among chronic illness patients. You should likely stop if you experience worsening.
2. **Herx (Herxheimer) reactions**. If you have Lyme or spirochete bacteria dying off, you may experience serious side effects. However, *if* you can confirm that a Herx reaction is happening (e.g. previous similar reaction with antibiotics), it may be worthwhile to use HBOT to slowly kill off bacteria *under competent medical supervision*. Horowitz is a Lyme doctor [who explains Herx reactions](#).
3. **Fire and in-home use**. While owning a chamber can save money, there are fire safety issues to consider due to oxygen being concentrated.
4. **Oxygen toxicity**. After a high number of sessions (e.g. 10-40+), HBOT can become counter-productive and harmful.





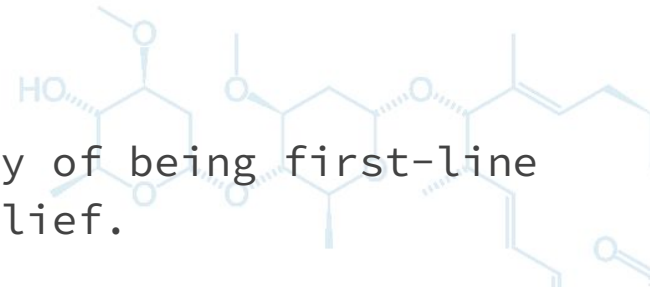
Second Line Treatments

Second line treatments



- **Natural anti-microbials** 🌱 - oil of oregano, monolaurin, lavender supplements, cat's claw, lion's mane
- **Certain anti-microbials** - methylene blue, antifungals such as fluconazole, Alinia/nitazoxanide, antivirals such as acyclovir and Valtrex.
- **Statins** 🌱
- **Diet** - gluten-free, low histamine 🌱
- **Anti-histamines**
- **DAO enzymes** 🦠
- **LDN (low-dose naltrexone)**
- **Magnesium**

Some of these treatments like diet may be worthy of being first-line treatments due to excellent safety and quick relief.



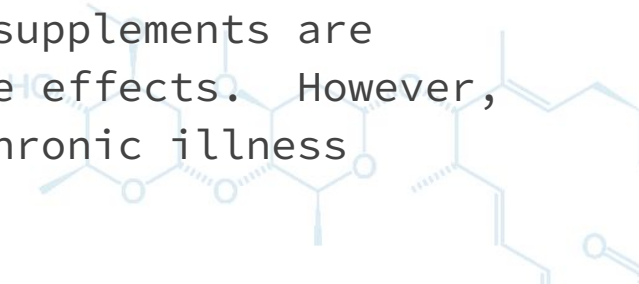
Certain natural anti-microbials



Oil of oregano, monolaurin, cat's claw, and lion's mane have been used for chronic Lyme. Lavender supplements (which contain lavender essential oil) have been marketed as sleep aids. All of them have anti-bacterial effects.

Current data suggests that all or most anti-microbials act as double-edged swords in chronic illness patients. The idea is to work through them one by one to find the ones that help you without hurting you.

Safety (low and medium risk???): Many of these supplements are popular among healthy people, with very few side effects. However, there isn't much data on these supplements in chronic illness patients.



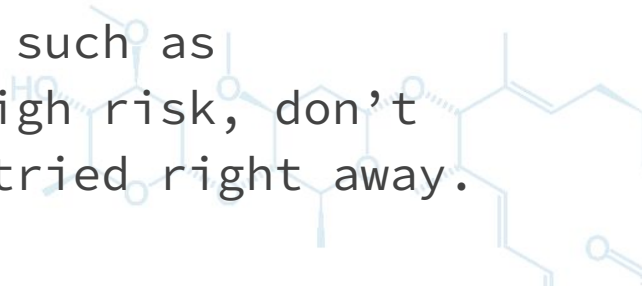
Certain prescription anti-microbials



Methylene blue, antifungals such as **fluconazole**, and **Alinia/nitazoxanide** seem to be good treatments but *there is only very limited data right now*. Antivirals such as **acyclovir** and **Valtrex** may be mildly helpful.

Safety: Antifungals are medium risk. There is little data on the other anti-microbials.

Not on this list: Traditional antibiotics such as penicillin, doxycycline, etc. They are high risk, don't have good risk/reward, and should not be tried right away.



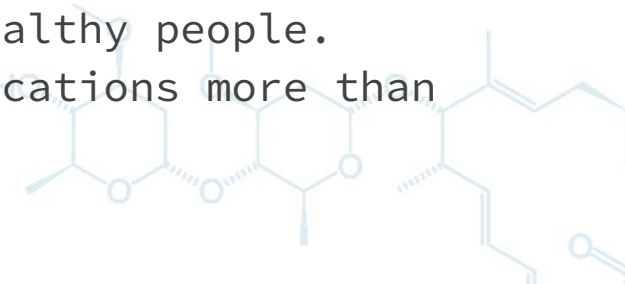
Statins



How it works: One theory is that it helps the body clear spike protein. However, very few people who use statins recover.

Access: Many doctors do not have a problem with prescribing statins. They are also legally sold as a **red yeast rice** supplement. Nature's aid UK claims that [their supplement](#) has 10mg lovastatin per pill. Ebay resellers and [Eco Natural Products](#) ship that internationally. However, the lovastatin molecule is the *same* as the prescription drug so please treat the supplement as such.

Safety (medium risk): Various side effects in healthy people. Chronic illness patients generally react to medications more than health people.



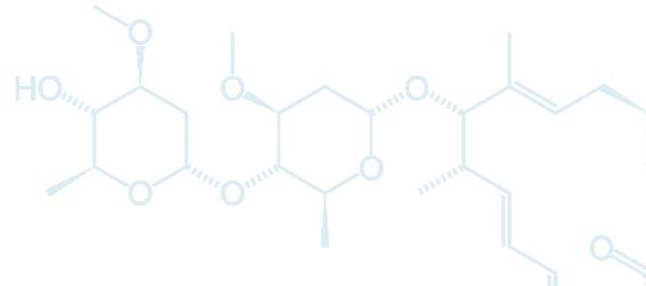
Gluten-free diet



On average, diets work better in those with severe and profound suffering from food intolerances.

How it works: There are various theories. One theory is that gluten causes ‘leaky gut’ (intestinal permeability) which contributes to autoimmune disease and foreign substances entering the body.

Safety: Very safe.



Low histamine diet

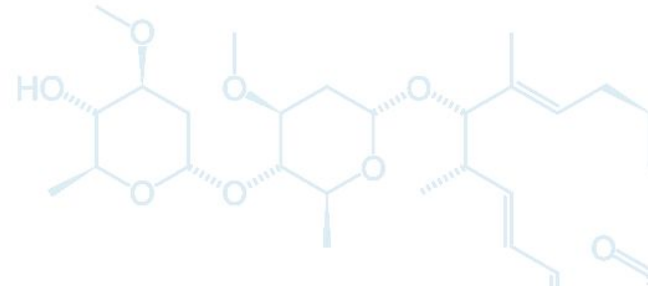
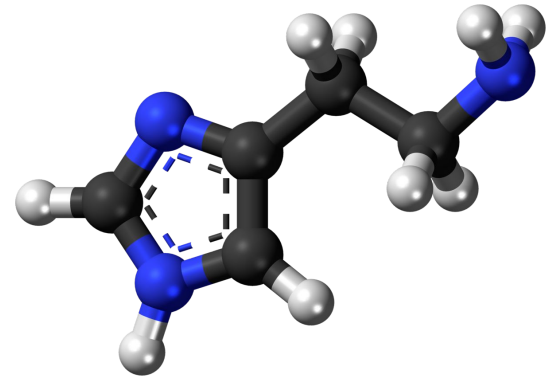


How it works: An imbalance between histamine production and breakdown may cause a toxic response in the body. For more details on the conflicting science, see [the wiki](#).

How to implement: Because food lists are different, pick one list and stick with it. Experiment to see what does and doesn't trigger your symptoms. See [the wiki](#) for links to food lists and diet guides.

Safety: Very safe.

If this diet fails, you may still respond to other diets such as gluten-free and [meat-only](#)/carnivore.



Certain anti-histamines



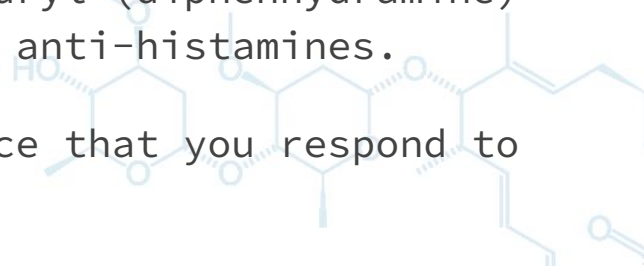
Anti-histamines are commonly used to treat MCAS (Mast Cell Activation Syndrome), which is common in chronic illness patients. The 4 most popular ones are:

- Zyrtec (cetirizine)
- Pepcid (famotidine)
- Claritin (loratadine)
- Acrivastine (Benadryl Allergy Relief in the UK)

Access: Some anti-histamines may not be available in your country.

Safety: Low risk. Allegra (fexofenadine) and Benadryl (diphenhydramine) may be somewhat higher risk than the other popular anti-histamines.

If one anti-histamine fails, there is a small chance that you respond to a different anti-histamine.

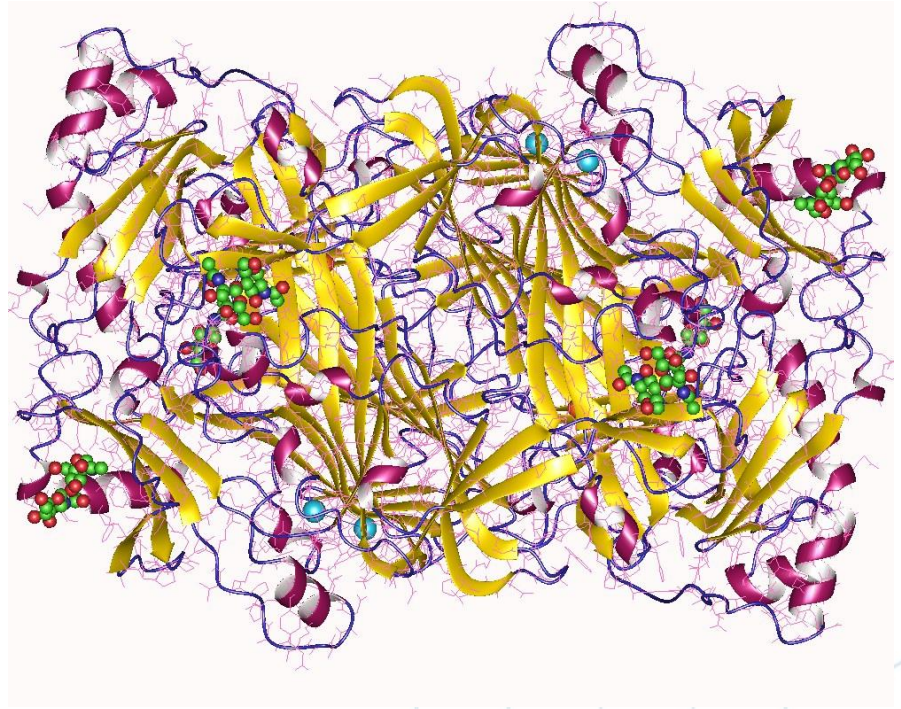


DAO Enzymes



DAO (Diamine Oxidase) is an enzyme that helps break down histamines. Its use has been popularized by MCAS specialists. While they do not seem very effective, they are very safe so the downside is low.

Safety: Very safe.



Low dose naltrexone (LDN)

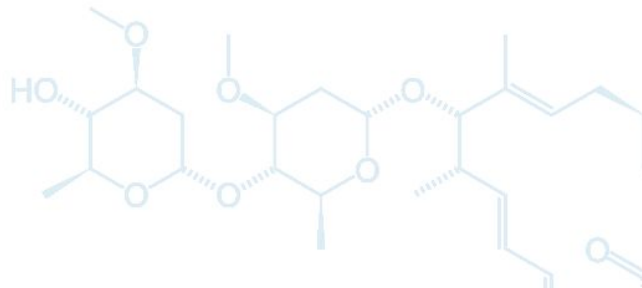
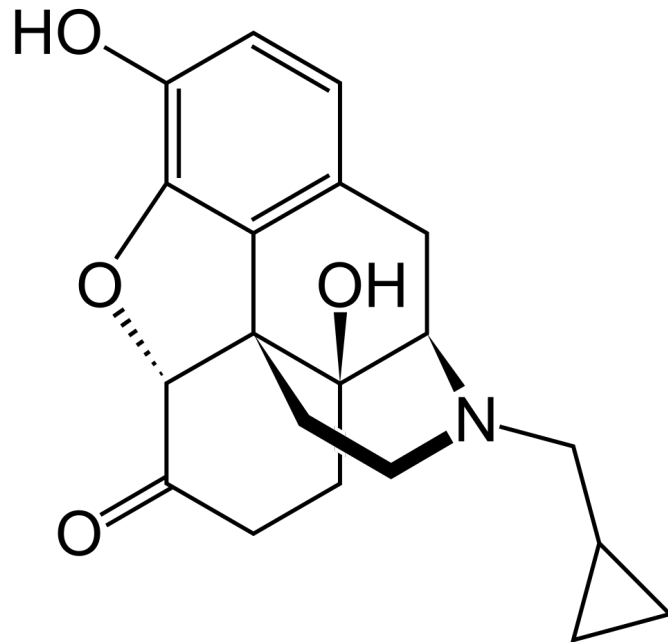


LDN is rated higher in patients with severe food intolerances.

Resources: Dr. Saleeby MD has [an excellent primer on LDN](#).

Access: This is a prescription drug.

Safety: Medium risk.



Magnesium

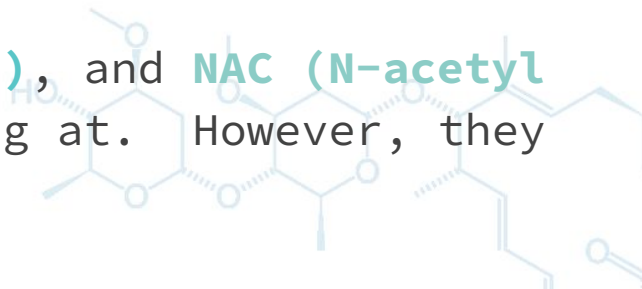


Magnesium is the highest-rated supplement according to patient survey data. It probably does not help you recover but the downside is quite low.

The [FLCCC I RECOVER protocol](#) has some tips on which supplement to buy/use.

Safety: Very low risk.

Melatonin, **quercetin**, **ALA (alpha lipoic acid)**, and **NAC (N-acetylcysteine)** are other supplements worth looking at. However, they are higher risk.



The background of the slide is a repeating pattern of white interlocking puzzle pieces. A solid teal horizontal band is positioned in the center of the image, containing the word 'Recap' in white text.

Recap

Why aren't people recovering?



I'm not too worried about which theory is correct. Right now, all of the popular theories don't translate very well into recovered patients.

What we do know is that each patient is different and requires individualized treatment. The best that we can do right now is to discover effective treatment through **trial and error**.





Slow and steady wins the race



It will take **time** to figure out which treatments are headed the wrong way and which treatments are headed the right way.

Many treatments will not do much. If a treatment doesn't succeed, patients can move onto the next treatment. To quote Arianna Grande:

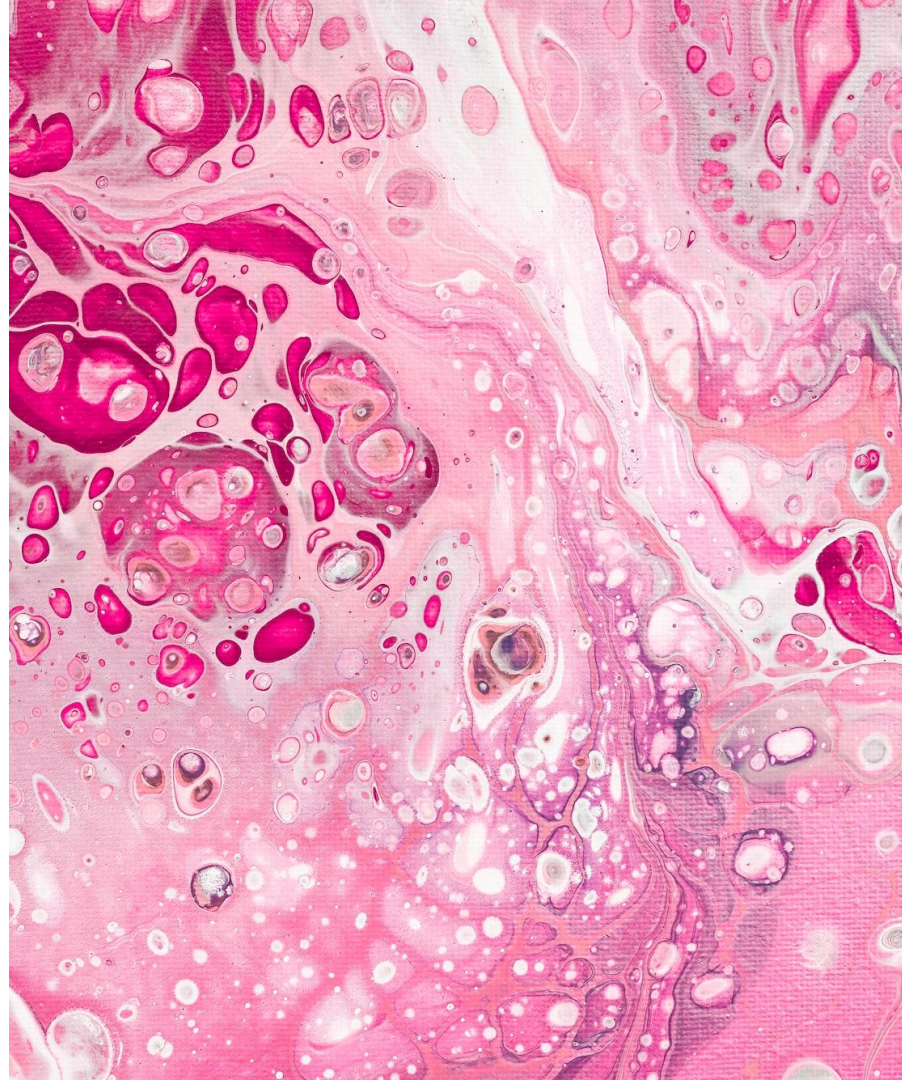
thank u, next

Science is constantly evolving



While I'm clearly biased towards anti-microbials, hopefully I've given room to other treatments that have worked (e.g. multi-day fasting, statins, etc.).

As we learn more, our ideas about how to treat long haul syndromes will change. We will likely see big changes in how patients are treated and how patients recover.



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My work

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[Persistent Symptoms](#)

[Risk Factors](#)

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