# Using existing medications off-label for Long COVID



#### LONG COVID ESSENTIALS: A series by <u>The Sick Times</u> & <u>Long COVID Justice</u>

There are currently no medications approved by the Food and Drug Administration (FDA) to treat Long COVID. However, there are off-label medications that may help provide some relief for common symptoms. "Off-label" means a medication is being used to treat a condition that it wasn't FDA-approved for. Off-label medications don't work for everyone. It can also be harder to get insurance to cover off-label treatments.

If you're interested, ask your medical provider if any might be a good fit for you. If they are unwilling to try them, ask if there's a specialist that might. Otherwise, look into telehealth services specializing in Long COVID like <u>RTHM</u>. Learn more about <u>how to talk to your</u> <u>medical provider</u> and <u>how to use research to access medical care</u>.

Over-the-counter medications that may be useful are listed in this fact sheet.

## \* Medications for fatigue

- Low-Dose Naltrexone (LDN) has anti-inflammatory properties; it can reduce pain, fatigue and cognitive dysfunction in some patients. It's encouraged to start at a lower dose (below 0.5 mg, in liquid form), and gradually increase the dose if needed.
- <u>Pyridostigmine (mestinon)</u> helps people with autonomic dysfunction by enhancing communication between nerves and muscles. This boosts cognitive function and energy levels, and can help alleviate <u>post-exertional malaise (PEM)</u>.
- <u>Abilify</u> is an antipsychotic drug with anti-inflammatory properties. At lower doses, it reduced fatigue and improved sleep in some patients. Some providers may be hesitant to prescribe it.



## \* Medications for cognitive dysfunction ("brain fog")

- <u>Guanfacine</u> is a cognition-enhancing medication that can treat high blood pressure and attention deficit hyperactivity disorder (ADHD). It's helped some patients experiencing <u>cognitive dysfunction</u>, or "brain fog."
- <u>Methylphenidate</u> is another cognitive-enhancing medication used for ADHD. This stimulant boosts frontal pathways and helps improve memory.
- **Other stimulants** may also help with cognitive symptoms and fatigue. These include Amantadine, Duloxetine, Fluoxetine, and Bupropion.

#### \* Medications for MCAS

- <u>Ketotifen</u> is a partial mast cell stabilizer. It blocks histamine receptors, regulating an overactive immune response and chemical release. This drug helps with cognitive dysfunction and mast cell activation syndrome (MCAS).
- Antihistamines can also help with MCAS.

#### **\*** Medications for orthostatic intolerance

- <u>Beta Blockers</u>: These medications, like <u>propranolol</u>, can help some people who have forms of dysautonomia, like POTS.
- <u>Ivabradine</u> is a medication that can help slow down heart rate and stop palpitations.
- <u>Midodrine</u> is used to treat low blood pressure, which can be seen in orthostatic hypotension, POTS, or dizziness from low blood pressure.

### **\*** Other off-label treatments

 <u>Vagus nerve stimulus</u> delivers electrical signals to the vagus nerve, which can relieve symptoms of Long COVID, such as difficulty breathing, chest pain, cough, fatigue, headaches, irregular blood pressure and pain. However, this treatment can be expensive.



- <u>Stellate ganglion block</u> has helped some people with Long COVID regain their smell and/or taste. However, it can be expensive and is not often covered by insurance.
- <u>Hyperbaric oxygen therapy (HBOT)</u> exposes patients to nearly 100% oxygen while inside a hyperbaric chamber that is pressurized to greater than sea-level pressure. It's been shown to reduce pain, and difficulties with sleep and improve mental health. But, it can be expensive and inaccessible.
- <u>Botox</u> and <u>duloxetine</u> has shown benefits for migraines and chronic pain.
- Selective serotonin reuptake inhibitor (SSRI)s can reduce inflammation and help with symptoms.

**Note:** This is not medical guidance. Always talk to a medical provider about trying treatments. And remember to ask your medical provider about the common side effects or if there are any interactions with other medications you're taking.

# **\*** Resources

- Long COVID telehealth clinic RTHM
- Possible treatments for Myalgic Encephalomyelitis (ME) to share with a medical provider – ME/CFS Clinician Coalition
- <u>Treatment data from surveys</u> CURE ID
- Database of clinical trials Long COVID Studies

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#### QUESTIONS? connect@s4hi.org

This series was designed by people living with Long COVID and associated diseases. Each resource sheet has been reviewed by patient and medical experts. This is an informational resource, not medical advice. Publication date: 12/13/2024.