
Recovering from Botulism

EDUCATION, RESOURCES, & TIPS
FOR YOUR HEALING JOURNEY



by Megan McCue

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The plant and flower illustrations in this PDF symbolize the gradual recovery and necessary resilience after botulism. The imagery of roots, stems, and blossoms reflects healing as a patient, an organic process that unfolds over time.

Read This First!

How to use “Recovering from Botulism”

This PDF is a practical guide created specifically for people affected by botulism, offering basic education about the condition, curated resources, and everyday tips to support recovery and adaptation.

It is not a source of medical advice, diagnosis, treatment, or evaluation, and it should never replace guidance from qualified healthcare professionals.

Everyone’s experience with botulism and recovery is unique, and healing does not follow a single timeline or path. This guide is not meant to create fear or anxiety about recovery, but rather to empower readers with knowledge so they can better understand their illness and advocate for themselves with confidence.

You don’t need to read it cover to cover or in one sitting; this PDF is designed to be flexible. Readers are encouraged to jump to the sections that feel most relevant to their current needs, skip parts that don’t apply, and return to different chapters as their recovery progresses. If you only read one chapter, I recommend Chapter 3 - Whole Body Healing.

Please have a trusted and supportive loved one read any sections that are unclear or difficult to understand.

Do not hesitate to reach out to me with any questions:
metoxpretty@gmail.com

Read This Second!

When experiencing adverse effects related to Botox/botulinum toxin injections, or botulism, taking organized and proactive steps can be important.

- Adverse events can be reported to regulatory agencies such as the FDA (through the Medwatch website), EMA, or appropriate national reporting systems to help improve safety monitoring and awareness.
- Preserving complete medical records, including treatment dates, product information, symptom timelines, and test results, can be valuable for continuity of care.
- Seeking second opinions from qualified healthcare professionals may provide additional perspectives and help ensure thorough evaluation

GO TO THE ER / CALL EMERGENCY SERVICES IMMEDIATELY if any of the following occur at any point in your recovery journey:

- Progressive breathing weakness
- Aspiration or choking
- Worsening paralysis
- Serious arrhythmias

Medical Disclaimer and Author Notes

Hi, I'm Megan. I'm not a doctor, an epidemiologist, a microbiologist, or researcher. **I'm not a botulism expert.**

I'm an average, boring suburban soccer mom who happened to develop iatrogenic botulism after receiving botulinum toxin injections for the first time in 2024 (12 units to the crow's feet).

I also happen to be a medical speech-language pathologist and writer, two skillsets that have likely contributed to my insatiable need to learn everything I can about the illness I lived through - and communicate what I've learned with you all!

The information in this PDF was gleaned from the medical literature, my own experience living with botulism, and anecdotal data from group members in my "Botox Side Effects - Iatrogenic Botulism" Facebook support group.

**Most importantly, this information is not medical advice.
Anyone who is suffering from botulism should be under the careful supervision of a trusted healthcare provider at all times.**

Please, never begin or discontinue any supplements or medications without first consulting with a trusted healthcare provider.

Visit www.iatrogenicbotulism.com for more information.

Comments, suggestions, questions, and collaborations are all welcome. Reach me at metoxpretty@gmail.com.

I will do my best to update this PDF regularly to reflect the latest research.

References

Research referenced in this PDF includes:

Gottlieb et al. Long-Term Outcomes of 217 Botulism Cases in the Republic of Georgia, *Clinical Infectious Diseases*, Volume 45, Issue 2, 15 July 2007, Pages 174–180, <https://doi.org/10.1086/518890>

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01. *Understanding Botulism*



IN THIS CHAPTER:

- What is botulism?
- Botulism symptoms
- How does the body heal from botulism?
- Long-term botulism outcomes

What is Botulism?

Botulism is a nervous system disease caused by a toxin, which is produced by the bacterium *Clostridium botulinum*. This toxin, known as *botulinum toxin*, is the most potent neurotoxin on Earth. It attacks the nervous system by blocking neurotransmitter and neuromodulator communication between nerve cells and/or between nerve and muscle cells. Neurotransmitters and neuromodulators are the chemical messages our nervous system “runs on” in order to function properly.

Neurotransmitters that can be disrupted by botulinum toxin include acetylcholine, glutamate (and, as a result, GABA), dopamine, serotonin, and norepinephrine (and likely more in the central nervous system).

Botulism is a form of poisoning rather than a bacterial or viral infection; therefore, treatments such as antibiotics or antivirals are not effective. Botulism can result from ingestion of contaminated food, infection of wounds, or iatrogenic exposure through botulinum toxin injections, in which the toxin unintentionally spreads into the bloodstream and/or brain.

Disruption of the nervous system by botulinum toxin can cause a wide range of symptoms, depending on where the toxin acts in the body. Symptoms occur along a spectrum and can vary greatly in severity, from mild and temporary to severe and life-threatening.

Botulinum toxin can disrupt both the peripheral nervous system (PNS) and the central nervous system (CNS). Botulism poisoning can also trigger secondary medical conditions in the body involving the immune, endocrine, and vascular systems.

On the next page you will find a (mostly) complete list of possible symptoms after botulism poisoning, as documented in Dr. Hristova’s research on iatrogenic botulism victims.

Botulism Symptoms

Central nervous system (CNS):

Brain fog, disorganization, mental fatigue, phonophobia (aversion to loud noises), photophobia (aversion to bright lights), short term memory loss, slow processing speed, word finding difficulties

Psychiatric symptoms:

Anxiety and/or panic attacks, depersonalization, depression, derealization, feeling hopeless, fixation on symptoms, mood swings, suicidal ideation

Peripheral nervous system (PNS) - Somatic Nervous System (which includes sensory neurons):

Burning sensations in the mouth/head/limbs, “buzzing” feeling in the nerves, choking sensations, itching sensations, muscle weakness/paralysis, nerve pain, nerve “zaps”, parasthesias (“pins and needles” feeling)

PNS - Autonomic Nervous System (including the cranial nerves):

Abdominal pain, appetite/weight loss, dizziness and nausea, dry eyes, dry mouth, dysphagia (difficulty swallowing), dyspnea (difficulty breathing), dysarthria (slurred speech), dysphonia (hoarse voice), constipation/gastroparesis, ear disorders (congestion, tinnitus, pain, deafness), heart palpitations/arrhythmias/chest pain and pressure/cardiac arrest, insomnia, night sweats, UTIs/urinary retention, vision impairments

Other:

Alopecia (hair loss) and madarosis (loss of eyebrows and eyelashes), loss of libido, itchy skin, menstruation changes in women, loss of muscle mass, changes in skin texture/moistness, swollen glands

Secondary Medical Conditions that have been reported after poisoning:

MCAS, histamine intolerance, Lyme, POTS (post orthostatic tachycardia syndrome), dysautonomia, orthostatic hypotension, ME (myalgic encephalomyelitis), reemergence of dormant viruses

How Does the Body Heal from Botulism?

The body heals from botulism gradually by repairing the nerve function that was disrupted by the toxin. This process involves the following:

Nerve terminal regeneration

Botulinum toxin does not typically cause permanent damage (although permanent damage has unfortunately been reported in some cases). Rather, it disables the nerve endings that allow neurotransmitter communication between nerves, and nerves and muscles. Recovery occurs when:

- Nerve endings begin to sprout new dendrites, and new connections (synapses) form between two nerves, and/or nerve and muscle fibers.
- This regeneration is slow and can take weeks to months to years, depending on how much toxin has spread, where the toxin spread, and the age/overall health of the victim

Muscle reconditioning

If paralysis or weakness occur, muscles may atrophy from lack of use. As nerve signals return:

- Muscles gradually regain strength.
- Physical and respiratory therapy can help restore function and endurance.

Central nervous system (CNS) recovery

- The brain and nervous system adapt as signals return
- Coordination, speech, swallowing, and vision may improve gradually as neural pathways are relearned and refined
- CNS symptoms seem to persist the longest for many individuals with botulism.

How Does the Body Heal from Botulism?

Recovery from botulism is often **not linear**. Improvement comes in small increments, with plateaus and fluctuations. Many report their symptoms come and go, and some experience full relapses that last for weeks or months. The healing timeline from botulism varies widely depending on toxin dose, if antitoxin was given (and how quickly), overall health and age of the victim, and the severity of nerve involvement. Any secondary medical conditions that occur postpoisoning can also cause a lingering of symptoms.

Many have reported the following can cause symptoms to worsen or flare up:

- vigorous exercise
- overexertion of any kind
- stress
- lack of adequate sleep
- illnesses or other toxins, such as viruses, bacterial infections, bee stings, exposure to mold and/or fungi
- monthly cycles (women)
- high histamine foods (more on MCAS later)
- chemicals/fragrances in common household and beauty products (more on MCAS later)
- certain antibiotics
- vaccines (in the first year after poisoning)

The whole body is under attack in botulism poisoning, and as such, healing is not just a matter of “fixing” one or two symptoms. Because botulinum toxin is the most potent neurotoxin known to man, the recovery process can be a lengthy and complicated one. Botulism is not a skinned knee, the flu, or even a broken bone. It is serious neurological injury, and we must respect the enormous task our bodies are faced with while healing.

How Does the Body Heal from Botulism?

Self-care is a foundational part of healing from botulism, as recovery affects the body, brain, and nervous system as a whole; these are not just isolated symptoms.

- Nourishing the body with organic, whole foods helps reduce exposure to pesticides and additives while providing the nutrients needed for nerve repair, muscle rebuilding, and immune balance.
- Prioritizing high-quality sleep is equally essential, as sleep is when the brain and nervous system repair, inflammation is regulated, and energy is restored.
- Stress reduction and nervous system regulation play critical roles as well, since chronic stress can worsen nervous system dysregulation and delay healing; creating calm environments, recruiting support, simplifying daily demands, and incorporating vagus nerve healing practices can help the body feel safe enough to recover.
- Emotional self-care (seeking mental health support, staying connected with loved ones, allowing space for grief, frustration, and rest) is just as important as physical care.

Long-Term Botulism Outcomes

This section is provided for informational purposes only.

It is not intended to predict how long symptoms will last for any individual botulism patient.

It is also not intended to scare you; if you are not in the right headspace, please skip this section or have a loved one read over it.

Remember: every case of botulism is unique, just as every stroke or other neurological injury is unique. Differences in genetics, physiology, overall health, severity of the poisoning, and environmental factors all influence how a person recovers from botulism, and each individual follows their own healing timeline.

The information below is drawn from a small number of studies examining long-term outcomes in people with foodborne botulism, many of whom received antitoxin treatment. While this data cannot predict individual recovery, it may help provide a general understanding of recovery patterns.

Based on this research, we can infer that prognosis is most likely to be impacted by the following (in order of importance):

- The severity of the botulism symptoms
- Whether or not the patient received antitoxin in the early hours or days after poisoning
- Which nerves the toxin attacked
- Age/overall health of the patient prior to poisoning

Long-Term Botulism Outcomes

In Mann et al.'s study, researchers followed 21 patients for two years after their botulism poisoning. The following list includes the rates of symptoms that persisted in patients in the "moderate botulism" group at 24 months postpoisoning:

- Generalized weakness: 58%
- Shortness of breath: 44%
- Exercise intolerance: 33%
- Blurry vision: 25%
- Constipation: 20%
- Dry eyes: 20%
- Difficulty speaking: 18%
- Dry mouth: 17%
- Limb weakness: 11%
- Double vision: 0%
- Difficulty swallowing: 0%

The following symptoms persisted in the "severe botulism" group:

- Exercise intolerance: 87%
- Generalized weakness: 83%
- Shortness of breath: 83%
- Dry mouth: 83%
- Dry eyes: 66%
- Limb weakness: 43%
- Difficulty swallowing: 42%
- Constipation: 40%
- Difficulty speaking: 33%
- Blurry vision: 16%
- Double vision: 0%

Long-Term Botulism Outcomes

In Gottlieb et al's research, patients were anywhere from 6 months to 6 years out from their botulism poisoning. The following symptoms were more likely to be experienced by botulism survivors than by the control group:

- Fatigue (50% vs 30% in control group)
- Weakness (45% vs 25% in control group)
- Dizziness (25% vs 15% in control group)
- Dry mouth (15% vs 9% in control group)
- Difficulty lifting things (18% vs 10% in control group)

The symptoms that these patients had initially experienced upon poisoning, but that had remediated over time included:

- Blurry vision
- Double vision
- Difficulty swallowing
- Difficulty speaking
- Limb weakness
- Constipation

In Summary

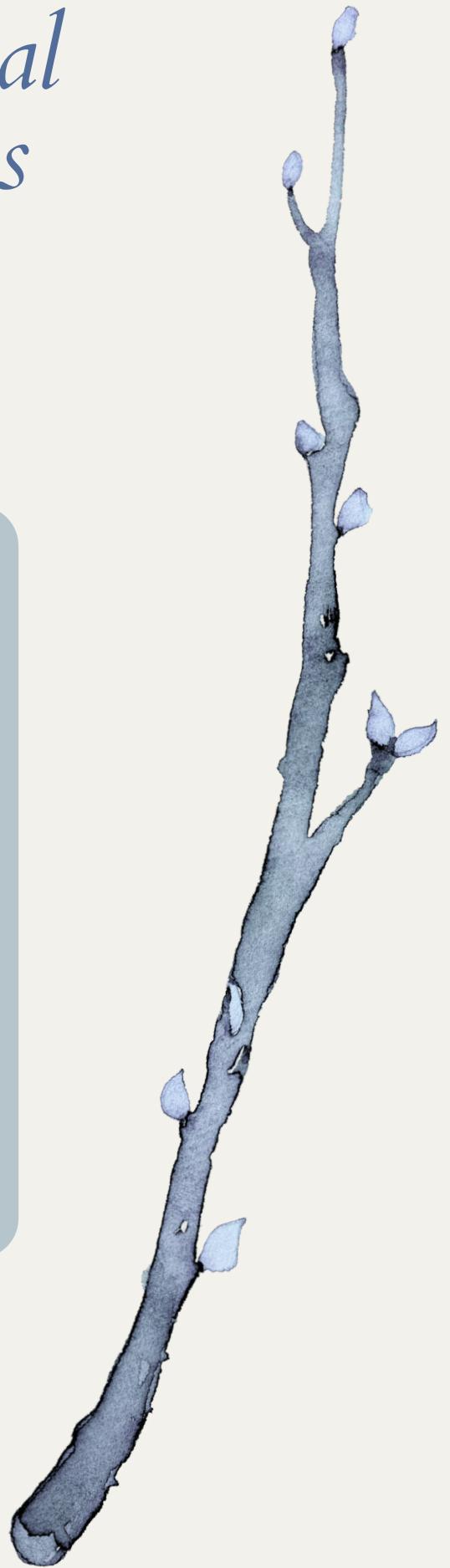
- Botulism is a serious nervous system illness caused by a toxin that interferes with the communication between nerve cells and nerves and muscles
- Botulism symptoms occur on a spectrum from mild and transient, to life-threatening, and can vary widely depending on where the toxin “lands” once in the bloodstream and/or brain
- Both the peripheral nervous system (PNS) and the central nervous system (CNS) can be affected by botulinum toxin, leading to both physical and psychiatric symptoms in many botulism sufferers
- Healing from botulism happens as the body gradually regenerates nerve endings and restores neurotransmitter communication, a process that takes time and differs from person to person.
- Improvement is often slow and non-linear, with periods of progress and plateaus, and recovery can continue for months or in severe cases, years, as strength and function return. Realistic expectations about progress after botulism poisoning are important. Many people find that they turn healing corners around 12-18 months, 2-3 years, and even beyond

The next chapter will help you understand what to expect in the first six months of the illness, which are described by many as the most difficult.

02. The Initial Six Months

IN THIS CHAPTER:

- What to expect in the initial six months
- What to consider avoiding
- Special medical considerations for people with botulism
- A word on alternative health



What to Expect in the Initial Six Months

The initial six months of botulism are considered the “acute” phase of poisoning, and typically bring the most severe symptoms. Many sufferers have described these months as “a living nightmare” or a “rollercoaster through hell that you can’t get off of”, and these phrases don’t come close to expressing what many botulism victims live through. In these early months, it is normal to feel like your entire body is under attack and in “fight or flight”, and that you might die at any moment. The body knows it has been severely poisoned. Botulism symptoms can vary greatly from individual to individual, but some of the more common symptoms in the first six months include:

- Flu-like symptoms, brain fog, fatigue, and lethargy
- Dizziness, nausea, and head pressure
- Anxiety attacks or “fight or flight” episodes that can persist for hours; heart palpitations can coincide with these
- Insomnia
- Coming and going of symptoms - some will experience days where they feel totally normal, only to have symptoms come back even more severe the following day, hence the “rollercoaster”
- About 50-60% of iatrogenic botulism victims begin to experience food, supplement, chemical and medication sensitivities, and/or other symptoms of secondary medical conditions that can be caused by botulism poisoning, including MCAS or POTS (more information on these in Chapter 4: Secondary Medical Conditions)

It’s important to note that the majority of deaths by botulism occur within the first 2-3 weeks after poisoning. Beyond that, death by botulism is extremely rare.

In her research on iatrogenic botulism patients, Dr. Hristova found that new botulism symptoms could continue to pop up within the first year post-poisoning. It is not unheard of for new symptoms to occur at 4, 6, or even 8 months out from poisoning in untreated botulism (botulism where no antitoxin was given).

What to Expect in the Initial Six Months

Medical Gaslighting

Medical gaslighting in botulism cases is extremely common. Historical outbreaks of foodborne botulism victims documented cases of what doctors would call "pseudo botulism", where patients would report concerning symptoms of botulism, only to be told it's "all in their head", because they weren't presenting with objective, measurable symptoms (including flaccid paralysis, aspiration, and/or respiratory failure).

Because botulism is a cluster of a wide variety of subjective symptoms that do not typically show up on objective testing at the hospital, the vast majority of patients who experience the disease will be misdiagnosed and told their symptoms are psychological.

The CDC reported in 2021 that 83% of doctors misdiagnosed botulism.

Know that you will likely face an uphill battle in being believed by doctors. The gaslighting many of us experience can add layers of trauma to an already terrifying illness. Use the resources on my website to educate and inform family members, friends, clinicians, and hospitals in your area about botulism, especially botulism after botulinum toxin injections.

Here are a few resources you can distribute:

- [Botox Adverse Effects PDF](#) - explains what botulism after Botox is to healthcare providers. Includes resources on how to get antitoxin
- Dr. Hristova's research on Iatrogenic Botulism cases is IMPERATIVE to read, or have a loved one read:
<https://austinpublishinggroup.com/bacteriology/fulltext/bacteriology-v3-id1035.php>
- My book *Iatrogenic Botulism 101* was written specifically for medical professionals, explaining botulism after Botox. Paperback and eBook copies are available on Amazon. Email me for a free copy:
metoxpretty@gmail.com

What to Consider Avoiding

The following is a list of foods/drugs/procedures/practices you may want to consider avoiding, particularly in the first 6 months after botulism poisoning. These recommendations were compiled using information from Botox's package insert, Drugs.com interaction checker, Dr. Hristova's research, and the first hand experience of botulism sufferers in the "Botox Side Effects - Iatrogenic Botulism" support group.

*****PLEASE REMEMBER THAT NONE OF THIS IS MEDICAL ADVICE OR A SUBSTITUTE FOR WORKING WITH A TRUSTED HEALTHCARE PROVIDER. WORK CLOSELY WITH YOUR DOCTOR TO DETERMINE THE BEST DRUGS/PROCEDURES FOR YOUR UNIQUE BODY AND HEALTH*****

Foods and Lifestyle Practices to Consider Avoiding:

- Added Sugar
- Processed foods, "fast food" restaurants
- Caffeine
- Alcohol and other recreational drugs
- Vigorous exercise: some group members reported a worsening of symptoms after exercising in the early months after poisoning (3-6 months)
- Saunas: some people swear by saunas, others have had worsening of symptoms, especially if their autonomic nervous system is under attack. Heating up the body can be dangerous if cardiac issues are occurring. Proceed with caution and common sense.
- Less is more. If you don't absolutely need to do it, don't. When your body is under extreme duress, slowing down and nourishing yourself is extremely important. Take care of yourself and consider avoiding stressful situations as much as possible while in the early months of botulism.

I believe an organic well-rounded diet that focuses on high quality protein is optimal for healing from any illness. I personally believe that eating an organic and protein-heavy diet full of nutrients and amino acids played a positive role in my recovery from botulism.

What to Consider Avoiding

Procedures/Therapies to Consider Avoiding:

- **Massage** – never massage the area where you were injected, with a toothbrush or your hands. Some group members reported a worsening of symptoms after intense, full body massages
- **Chiropractor/Osteopathy** – anything that "adjusts" the body and can potentially affect nerves/the nervous system
- **Acupuncture** – some have had a worsening of symptoms after acupuncture, others have done okay with it. Use your best judgment and common sense. Less is more!
- Anything that can **vibrate/disturb** the head or areas where toxin was injected (Dr. Hristova found that vibrating chairs and massage tools [like Gua Sha and microneedling] could cause a worsening of symptoms in her patients). This includes “vagus nerve stimulators”
- **Injections** of any medication in the area where you received botulinum toxin injections; sufferers have reported relapses after these

Supplements/Ingredients to Consider Avoiding:

- **Magnesium** (this is technically a type of muscle relaxer, and muscle relaxants are advised against on Botox's package insert) for the acute period of the illness (first 3-6 months, or if there is muscle weakness/paralysis)
- **Melatonin and DHEA** should be avoided if you have signs of low glutamate (fatigue/low energy)
- **Synthetic vitamins** (B Vitamins, Vitamin D, Zinc, Iron, etc) and IV vitamin infusions can cause a worsening of symptoms for those with MCAS. Please see Chapter 4: Secondary Medical Conditions for a complete list of medications/supplements that can worsen MCAS
- **“Detox”** supplements, including liver cleanses, chlorella supplements, cell openers, etc. have been reported to cause a worsening of symptoms for many, and were not recommended in Dr. Hristova's research.
- **Snap-8 peptides** (in beauty products look for ingredients including "Acetyl Octapeptide-3" and "Acetyl Hexapeptide-8" – these can block neurotransmitter communication)

What to Consider Avoiding

Pharmaceuticals to Consider Avoiding - ALWAYS work with a trusted healthcare provider when beginning or discontinuing ANY medication.

- **Anticholinergic drugs** (Benadryl, Hydroxizine, Tylenol PM, Thorazine, Unisom etc.)
- **Aminoglycoside antibiotics:** gentamicin, streptomycin, amikacin, tobramycin, and neomycin
- **Tetracycline antibiotics:** Support group members had mixed reviews - some did OK on tetracycline, others didn't. **The antibiotics that most people have done well with are the penicillin and macrolide classes**
- **SSRIs** / serotonergic supplements, as well as antipsychotics, including Seroquel: Dr. Hristova found SSRIs/antipsychotics to cause a worsening of symptoms in her patients; PLEASE never stop a medication you're on without working with a qualified mental health practitioner
- **All prescription muscle relaxants**
- **Blood pressure medications** should be used with caution, as botulism can cause hyper and hypotension
- **Tamiflu** has caused a worsening of symptoms in some
- **Vaccines:** Dr. Hristova noted a worsening of symptoms after vaccines in patients, such as Tdap and flu shots, and recommended against vaccination for the first year post-poisoning
- **Steroids** (prednisone, cortisone, etc.) either worsened the condition of or did nothing for Dr. Hristova's patients

More resources:

Tox Safety - an advocacy support group for iatrogenic botulism victims has a lengthy "Caution List" here: www.toxsafety.com/the-caution-list

Drugs.com has a full list of pharmaceutical drugs that may interact with Botox:

<https://www.drugs.com/drug-interactions/onabotulinumtoxina,botox-index.html>

Special Medical Considerations for Botulism Patients

The following are important considerations for botulism patients:

- Botulism can cause new onsets of nutrient deficiencies, especially with the following vitamins/minerals: (Be aware that those experiencing MCAS or secondary inflammatory responses to botulism may not tolerate synthetic vitamins orally or via IV) Vitamin D, B vitamins (including Folate), Iron/Ferritin, Potassium
- Dormant viruses have reportedly reemerged after botulism in some cases, including Epstein-Barre virus and Lyme disease; this could be due to a temporarily weakened immune system
- Many botulism victims have reported NEW onsets of thyroid dysfunction in the months post-poisoning
- Botulinum neurotoxin can spread into the central nervous system (CNS) via the bloodstream and/or retrograde axonal transport. This is why botulism victims can experience brain fog, slow processing speed, memory loss, psychiatric symptoms, and depersonalization/derealization.
- Botulism patients may benefit from additional referrals, including those to physical therapists (for muscle weakness), speech therapists (for speaking, swallowing, and/or cognitive difficulties), ophthalmologists (for vision disturbances), neurologists (for testing to rule out other conditions), and psychologists/psychiatrists for mental health needs
- Botulism can cause new onsets of cardiac issues, including heart arrhythmias and POTS. Please monitor yourself for symptoms of these conditions.
- The respiratory distress experienced by botulism patients typically does **not** result in lowered oxygen saturations. This is why we typically have normal O2 readings at the hospital, even though it feels like we are struggling to get a deep breath.

A Word on Alternative Medicine

In the initial months after botulism poisoning, the nervous system is often under extreme stress and vulnerability, and during this phase some alternative or aggressive healing practices can do more harm than good. While many complementary approaches can be supportive later in recovery, early on the body may not tolerate intensive detox protocols, stimulating herbs, or invasive practices that place additional demands on an already dysregulated nervous system.

It is especially important to be cautious of anyone who claims they can “heal” botulism through specific herbs, supplements, or proprietary practices, especially when these products come with high costs or promises of rapid recovery. Unfortunately, some botulism victims have spent thousands of dollars on alternative healing products/practices, only to have them worsen symptoms or do nothing at all.

Botulism causes serious neurological injury, and healing requires the slow regrowth and reconnection of nerve synapses; this process cannot be forced or rushed. Time, adequate rest, proper nutrition, and a stable internal environment set the stage for the nervous system to feel safe enough to repair.

Supporting the whole body patiently and cautiously, rather than chasing quick fixes, helps protect recovery and honors the reality of the complexity of botulism damage.

A Word on Alternative Medicine

This is not to say that all alternative or integrative medicine approaches are unhelpful after botulism. In fact, many sufferers have reported benefits from certain therapies later in their recovery, once they've passed the initial year or so after poisoning. By this point, for most people, the nervous system has stabilized and the body is no longer in an acute state of distress.

Practices such as

- Hyperbaric oxygen treatment
- IV ozone therapy
- AAT (Advanced Allergy Therapeutics)
- Traditional Chinese Medicine (TCM)
- Bioresonance therapy and more

have been helpful for many individuals in their healing journeys when introduced at the appropriate time.

The key distinction is timing and individual tolerance. After the initial year, when foundational healing has taken place and nerve regeneration is further along, some alternative modalities may complement recovery.

It is best to work with a reputable, experienced medical practitioner who is familiar with your medical history and any secondary medical conditions you may have developed after botulism, such as MCAS or POTS.

In Summary

- The initial six months after botulism poisoning are often the hardest (and scariest!), and healing is occurring slowly but surely, even if it's not yet noticeable.
- During this time, healing must be approached with extreme gentleness, as the nervous system is highly sensitive and vulnerable.
- Although it is tempting to rush to try a variety of medications or supplements, botulism is very different from other illnesses, and often times certain pharmaceuticals, supplements, and practices do more harm than good.
- Prioritizing self-care, including adequate rest, proper nutrition, gentle movement as tolerated, and stress management, can support the body as it slowly rebuilds strength and function.

The next chapter will address what I call “whole body healing”: which involves paying attention to and nurturing our physical, psychological, emotional, and spiritual needs.

03. Whole Body Healing



IN THIS CHAPTER:

- The foundations of whole body healing
- Resources

The Foundations of Healing

Recovering from any toxic, viral, bacterial, or fungal exposure requires many of the same foundational supports:

- Nourishing food and hydration
- Adequate sleep
- Stress reduction and vagus nerve healing
- Limiting toxins
- Caring for our mental and emotional wellbeing

In botulism specifically, autonomic nervous system dysregulation can result in frightening and traumatic symptoms. Many survivors are left with PTSD-like responses after living through this illness, making whole-body healing an essential part of the recovery process.

We will explore each of these areas in more detail individually. It is very important to note that **I am not a doctor and am not providing medical advice**. The information I am sharing comes from my personal experience, the practices I believe supported my own healing journey, insights gained from reading dozens of research articles on botulism and general illness recovery, and the collective wisdom shared by other victims in my support group who have healed from botulism.

Nourishing Food and Hydration

Nourishing the body with high-quality, organic food is a vital part of the healing process.

Organic foods help reduce the body's exposure to pesticides, additives, and other chemicals that can place additional strain on already stressed detoxification and immune systems. Adequate protein intake is especially important during recovery, as protein provides the amino acids necessary for repairing tissues, rebuilding muscle, and restoring strength after periods of weakness or immobility. Without sufficient protein, muscle recovery and overall physical resilience can be significantly delayed. Healthy fats are also essential, as they support brain and nervous system function, help regulate inflammation, and contribute to hormonal balance.

WARNING: FASTING IS NOT RECOMMENDED! Even though you may find that your hunger cues are gone (very common in botulism), please do what you can to nourish your body adequately.

Healing foods I focused on during healing included the following (please note: not all of these foods are appropriate for those experiencing MCAS; please see Chapter 4. Secondary Medical Conditions for more info on MCAS and meal ideas):

- Organic meats, including beef, lamb, & chicken (I personally don't eat pork or cured meats)
- Wild caught fish and shellfish (cod liver oil)
- Beef organ supplements
- Broth
- Organic eggs and whole fat dairy
- Organic nuts and rice
- Organic vegetables and fruits

I avoided most added sugar, caffeine, alcohol and other recreational drugs for at least the first 12-15 months after poisoning. I was slowly able to incorporate low caffeine teas and 1-2 occasional servings of alcohol after about 15 months post-poisoning.

Nourishing Food and Hydration

Keeping the body hydrated with clean, filtered water and electrolytes is essential after botulism poisoning. I personally use the Clearly Filtered Water Pitcher, but there are many other great brands for water filtration.

You can buy electrolyte liquid/powder mixes or make your own. Coconut water is a great natural electrolyte if you add Celtic sea salt to it. I like the brands LMNT and Nectar for prepackaged electrolytes (note: these are **not** MCAS friendly).

Here are two simple homemade electrolyte recipes:

Electrolyte Recipe

Ingredients:

- 1 liter (about 4 cups) filtered water
- $\frac{1}{4}$ – $\frac{1}{2}$ teaspoon high-quality Celtic salt or Himalayan pink salt
- 2–4 tablespoons fresh lemon or lime juice
- 1–2 teaspoons raw honey or pure organic maple syrup (optional, for glucose and taste)

Low Histamine Electrolyte Recipe

Ingredients:

- 1 liter (about 4 cups) filtered water
- $\frac{1}{4}$ teaspoon high-quality Celtic or Himalayan salt
- $\frac{1}{8}$ – $\frac{1}{4}$ teaspoon potassium chloride powder (often sold as “NoSalt”)
- 1–2 teaspoons pure organic maple syrup (preferred over honey for low-histamine tolerance)

Botulism can affect the autonomic nervous system, leading to conditions like POTS and orthostatic hypotension; electrolytes are especially important if you are displaying symptoms of these conditions.

In Summary

Botulism, and particularly the development of secondary conditions like MCAS, can make the body more prone to nutrient deficiencies, which in turn can worsen symptoms such as fatigue, muscle weakness, cognitive difficulties, hair loss, hormonal and immune dysregulation.

Chronic inflammation, digestive disturbances, and heightened mast cell activity can interfere with the absorption and utilization of essential vitamins and minerals, making careful monitoring your metabolic functioning **critical**.

Patients recovering from botulism should work closely with a trusted healthcare provider to track nutrient levels, thyroid function, and overall metabolic health over the months (and, in some cases, years) following poisoning.

Seeking out integrative or functional medicine doctors can be especially helpful, as they often have access to more comprehensive testing that goes beyond standard labs, allowing for a deeper understanding of imbalances and deficiencies.

Addressing these nutritional and metabolic needs proactively supports nerve repair, immune balance, and overall recovery.

Adequate Sleep

The power of sleep should never be underestimated, especially during recovery from botulism poisoning, when the body and nervous system are working tirelessly to repair and rebalance.

Adequate, restorative sleep also supports muscle repair, immune regulation, and hormonal balance, all of which are negatively affected by botulism.

Getting good quality sleep can be extremely difficult during recovery due to the insomnia caused by nervous system dysregulation. **This insomnia can be particularly intense in the first 3-6 months after poisoning.**

Creating gentle sleep supports can help the nervous system relax before bedtime. The following were helpful for me:

- **Listening to guided meditation sleep podcasts**
- **Herbal supplements** (like “Luna Sleep” or Pure Encapsulations “Best Rest”), that include chamomile, lemon balm, passionflower, valerian root, and L-theanine. **I recommend avoiding anticholinergics and melatonin**
- Prioritizing **consistent bedtimes**, minimizing overstimulation (ie: screen time, bright/blue lights, and EMR exposure) for at least 2 hours before bed
- I did have to take small amounts (.25-.5 mg) of Ativan (Lorazepam) for a few weeks while my body was in a state of extreme insomnia. I was able to wean myself off of this drug without any lingering effects. I include this information not because I am recommending this drug at all. I want others to know the reality of how difficult it can be to treat botulism symptoms, especially in the first few months.

Do EVERYTHING in your power to prioritize sleep while recovering from botulism (and for the rest of your life!)

Stress Reduction & Vagus Nerve Healing

Reducing stress (from overwhelming situations, chaotic environments, or stressful relationships) and healing the vagus nerve are critical components of recovering from botulism poisoning. After botulism, the nervous system is often fragile and dysregulated, and ongoing stress can keep the body in a constant fight or flight state, worsening symptoms such as fatigue, weakness, dizziness, gastrointestinal issues, and anxiety.

The vagus nerve is a major nerve that connects the brain to many organs, including the heart, lungs, and digestive system, and it helps control automatic functions like heart rate, breathing, swallowing, and digestion. It works by sending signals that tell muscles and glands when to activate.

In botulism poisoning, the botulinum toxin blocks the release of acetylcholine, a chemical messenger needed for nerve cells that make up the vagus nerve to function properly.

Stress is a significant trigger for vagus nerve dysfunction and mast cell activation syndrome (MCAS), a secondary condition that can develop after severe illness or toxic exposure, leading to increased inflammation, histamine release, and symptom flares throughout the body. (See the next chapter on Secondary Medical Conditions for more on MCAS).

Gentle nervous system-supportive practices such as **slow, deep breathing, short periods of meditation, dry brushing, grounding barefoot in nature, restorative movement, journaling, one on one time with calming loved ones, prioritizing rest** can help signal feelings of safety to the body.

See Chapter 5: A-Z Symptom Relief for more Vagus Nerve Healing practices

Limiting Toxins

Limiting toxin exposure in your environment is especially important while healing from botulism, as the body's detoxification pathways and nervous system are already under increased strain.

Hormone-disrupting chemicals and artificial fragrances can interfere with endocrine signaling, immune balance, and neurological function, potentially worsening symptoms or slowing recovery. These substances are commonly found in everyday household and personal care products:

- scented laundry detergents, fabric softeners, air fresheners and candles
- cleaning sprays
- perfumes and colognes
- lotions, shampoos, & soaps
- cosmetics & skincare products; hair dye & nail polish
- plastics and food packaging

Choosing **fragrance-free, non-toxic, and minimally processed products** can significantly reduce the chemical burden on the body.

<http://www.ewg.org/skindeep> is a great resource for looking up low toxin alternatives to common beauty products.

I personally use the following nontoxic, fragrance-free products (all available on Amazon). (I'm not affiliated with any of these brands):

- Vanicream shampoo / facial lotion; Cleure shampoo
- Pure tallow or olive oil soap without fragrances
- Humble deodorant
- Redmond toothpaste
- Makeup from the brand Alima Pure or Toups & Co.
- I make my own cleaning products with water/vinegar/lemon oil. There are tons of "recipes" available online for homemade cleaning products
- I personally stay far away from bleach, synthetic fragrances, hair dye, nail polish, and unnecessary ingredients in products.

REMEMBER: LESS is MORE!!! If you don't absolutely need a product, don't use it, especially in the early months after poisoning.

Limiting Toxins

Reducing exposure to **blue light from screens and electromagnetic radiation (EMR/EMF)** may be supportive for an already sensitive nervous system, as some individuals experience heightened symptoms such as headaches, sleep disturbances, or nervous system overstimulation with excessive exposure.

Simple steps like limiting screen time, turning off Wi-Fi at night, avoiding putting your phone directly on your body, and avoiding high EMF devices like Bluetooth and Airpods can help promote a calmer environment. Visit <https://emfsafeliving.com/creating-low-emf-smart-homes> for more ideas.

Limiting exposure to pesticides, herbicides, and other chemical residues can be important while healing. Choosing organic foods whenever possible and drinking filtered water (I use the pitcher by the brand “Clearly Filtered”) can reduce this chemical burden, giving the body more energy to focus on neurological recovery.

Consider protecting yourself from **“toxic” social and informational environments**. Negative or stressful interactions, exposure to alarming news, or unwanted advice from sources that don’t align with you can trigger nervous system dysregulation and increase stress, which may worsen symptoms.

By consciously minimizing toxins you are laying down the foundation for a more holistic and healthy recovery process.

Mental and Emotional Well Being

Mental and emotional wellbeing are critical components of healing from botulism, as long-term outcome research has shown that psychosocial health can decline significantly in the years following poisoning. Survivors may experience anxiety, depression, post-traumatic stress, and/or a sense of isolation due to neurotransmitter disruption from the toxin, or prolonged recovery and lingering symptoms.

Actively supporting mental health can help stabilize mood, improve coping skills, and support overall recovery.

Resources such as the National Alliance on Mental Illness (NAMI), Psychology Today's therapist directory, PTSD Alliance, and meditation or mindfulness apps like Headspace or Calm can provide guidance and support.

Support group members have found the following helpful for their mental and emotional well-being:

- Overall whole foods organic diet with an emphasis on limiting toxins and incorporating gut-healing foods
- Dry brushing and lymphatic drainage exercises
- Vagus nerve and breathing exercises (many on YouTube)
- Primal Trust program (www.primaltrust.org)
- Dynamic Neural Retraining System (retrainingthebrain.com)
- Apps like BrainTap and NuCalm
- Stoic, Buddhist, and other spiritual teachings for increasing resilience and reframing trauma
- Calming frequency sound devices (such as ORA Sound machine)
- Joining a support group for botulism poisoning

Work closely with a qualified mental health professional if you need to explore pharmacological interventions to assist with mental health.

Mental and Emotional Well Being

Recovery from botulism can be physically exhausting and emotionally overwhelming. Symptoms that come and go, persistent and scary psychiatric symptoms, and uncertainty about the future can take a serious toll on our mental health. Many botulism victims report suffering from PTSD, even years after healing.

If at any point during recovery you feel hopeless, overwhelmed, or afraid you might hurt yourself, please do not hesitate to seek out help.

In the United States, confidential, free help is available 24 hours a day through the 988 Suicide & Crisis Lifeline. You can call or text 988, or use online chat at <https://988lifeline.org> to connect with trained counselors who listen without judgment and can help you through a difficult moment. If you are in immediate danger, calling 911 or going to the nearest emergency room is the fastest way to get help.

For readers outside the United States, international support is available through Befrienders Worldwide at <https://www.befrienders.org>, which lists crisis helplines by country, and Find a Helpline at <https://findahelpline.com>, which connects people globally to local mental health and crisis resources.

If reaching out by phone feels hard, many of these services offer chat or email options. Talking to a trusted loved one is imperative. Recovery from botulism is not only about healing the physical body; caring for mental and emotional well-being is an essential part of the journey.

More Resources

Clean Eating Kitchen - Animal-Based diet -
<https://www.cleaneatingkitchen.com/animal-based-diet/>

Clean Eating Kitchen - How to Eat Clean -
<https://www.cleaneatingkitchen.com/how-to-eat-clean/>

Dr. Axe - Naturopathic Doctor who speaks and writes on many holistic health related topics - <https://draxe.com/>

Earthley - organic, USA-made herbal tinctures and remedies -
www.earthley.com

EMF Academy - everything you ever wanted to know about EMF/EMR reduction strategies - <https://emfacademy.com/>

EWG's database for nontoxic cleaning products -
<https://www.ewg.org/cleaners/>

EWG's database for nontoxic products -
<http://www.ewg.org/skindeep>

Healing the Vagus Nerve - <https://boulderholistic.com/vagus-nerve-dysfunction-signs-causes-and-how-to-heal-it-naturally/>
(note: bioelectrical devices have caused a worsening of symptoms for some botulism sufferers)

Institute for Functional Medicine directory -
<https://www.ifm.org/find-a-practitioner>

Psychology Today's therapist directory -
<https://www.psychologytoday.com/us/therapists/>

Stoicism 101 - a book I found extremely helpful for increasing my mental and emotional resilience while ill - <https://a.co/d/15I8bf1>

04. Secondary Medical Conditions

IN THIS CHAPTER:

- MCAS
- POTS
- Dyautonomia
- Lyme Disease
- ME
- Other



What are Secondary Medical Conditions?

In Dr. Hristova's research, it was reported that around 60% of botulism patients developed one or more secondary medical conditions as part of a prolonged or atypical recovery process.

Similar to what is often described as "long COVID," some victims experience what can be thought of as "long botulism," where instead of returning to baseline, the body remains in a heightened inflammatory or dysregulated state.

Ongoing nervous system, hormonal and immune disruption can contribute to the emergence of conditions such as mast cell activation syndrome (MCAS), postural orthostatic tachycardia syndrome (POTS), dysautonomia, Lyme disease, myalgic encephalomyelitis (ME), and more.

These conditions may arise as the body struggles to recalibrate after the neurological and systemic stress caused by botulinum toxin. Recognizing that these secondary conditions can occur is important, as it can explain the lingering symptoms that many sufferers report, and highlights the need for individualized, supportive care rather than the expectation of a quick or linear recovery.

This chapter will explore some of the more common conditions that can occur after poisoning.

MCAS

Mast Cell Activation Syndrome (MCAS) is a condition in which mast cells (immune cells involved in inflammation, allergy response, and tissue repair) become overly reactive and release inflammatory chemicals (such as histamine) inappropriately or excessively.

This can lead to a wide range of symptoms affecting multiple systems in the body, including flushing, gastrointestinal distress, heart rate and blood pressure changes, fatigue, brain fog, anxiety, and sensitivities to foods, medications, chemicals, or environmental triggers.

Botulism can act as a trigger for MCAS because it places extreme stress on both the nervous and immune systems. The neurological injury, autonomic nervous system dysregulation, prolonged physical stress, and inflammatory response associated with botulism can disrupt normal immune signaling and mast cell regulation.

In some individuals, this disruption may persist beyond the acute illness, leading mast cells to remain in a hyper-responsive state. Understanding MCAS in the context of botulism recovery can help explain ongoing, multisystem symptoms and underscores the importance of gentle, nervous system-supportive healing approaches that reduce inflammation and avoid unnecessary triggers.

MCAS

According to [MastCell360.com](https://www.mastcell360.com), the most common signs of both Mast Cell Activation Syndrome (MCAS) and histamine intolerance include:

- Anxiety
- Depression
- Asthma or other issues with shortness of breath
- Fatigue
- Diarrhea or constipation
- Headaches
- Inflammation/swelling
- Insomnia
- Sinus issues like congestion or runny nose
- Skin issues like hives, rashes, or flushing

The website further indicates:

"Unique symptoms that may indicate you are dealing with Mast Cell Activation Syndrome:

- Anaphylaxis
- Autoimmune disorders
- Brain fog
- Chemical sensitivities
- Chronic infections
- Difficulty healing
- History of toxic mold exposures
- History of Lyme
- Sensitivities to light or sound "

[MastCell360.com](https://www.mastcell360.com) writes that reaction time is an important clue to whether or not you have MCAS. Typically with MCAS, reactions happen within 30 minutes of exposure to a trigger, including certain foods, supplements, medications, and personal care products/cleaning products.

MCAS

Histamine Intolerance

Histamine intolerance is not quite as complex as MCAS; it occurs when the body is producing too many histamines, and begins reacting to high histamine foods.

According to DrBeckyCampbell.com, symptoms of histamine intolerance can include the following:

- Headache
- Itching
- Flushing
- Hives
- Nasal congestion
- Gastrointestinal issues, including diarrhea, nausea, or vomiting
- Low blood pressure
- Difficulty breathing

And causes can include:

- histamine-rich foods
- Certain medications, like NSAIDs
- DAO-inhibitors
- leaky gut and inflammatory bowel disease
- hormonal changes
- bee stings
- seasonal allergens

To get evaluated for MCAS, you can ask your doctor about being referred to an allergist/immunologist. It's important to note that many have been unsuccessful in receiving official diagnoses of MCAS, but have still benefitted from histamine-reduction interventions.

MCAS

Next steps if you think you have MCAS:

Figure out your triggers and avoid those, at least initially

- If you think you're suffering from MCAS or histamine intolerances post-Botox, pay close attention to foods (possibly high histamine) and products that trigger symptoms. Write these down in a log and try to avoid them as much as possible, at least for the first 6-12 months of your illness. People I know who suffered from MCAS have reported being able to slowly incorporate more foods/products after the first 12-18 months of their illness.
- Here is a great list of low histamine foods:
<https://mastcell360.com/low-histamine-foods-list/>.
- Here is a great app you can use to look up MCAS friendly foods:
<https://apps.apple.com/us/app/food-intolerances/id419098758>
- **Meal ideas:**
 - a. **Breakfast:**
 - i. Smoothie with whole and/or coconut milk, low histamine fruits, egg yolks, coconut oil, almond butter, chia & flax seeds
 - ii. Gluten free bread with ghee or almond butter
 - iii. Scrambled eggs (if tolerated)
 - b. **Lunch:**
 - i. Soup with chicken/beef/lamb and veggies; gluten free bread or gluten-free ramen noodles
 - ii. Salad with fresh/frozen fish filet/grilled chicken/steak strips and veggies
 - iii. Sandwiches with gluten free bread
 - iv. Creamy soups made with coconut milk (like carrot ginger or sweet potato)
 - c. **Dinner:**
 - i. Steak or roasted chicken with rice and low histamine vegetables
 - ii. Fresh/frozen fish with steamed veggies and potatoes
 - iii. Lettuce wraps with meat of choice
 - iv. Stews/soups made with broth (not bone broth), meat, veggies

MCAS

Read this helpful and thorough list of medications to AVOID if you suspect you have MCAS:

<https://www.histaminet.com/post/medications-to-avoid-with-mcas>

Natural and OTC supplements to help with MCAS symptoms (these were obtained from my own primary care doctor, as well as support group members who suffered from MCAS) - **Never start any new drug or supplement without the guidance of a trusted healthcare provider**

- a. Quercetin
- b. Low histamine probiotic
- c. Chamomile and Peppermint Tea
- d. Vitamin C
- e. DAO enzyme if you have high histamine - Beef Kidney is a great natural source and can be found in pills on Amazon from the brand Zen Principle
- f. Milk Thistle
- g. L-Theanine/GABA
- h. Alka-Seltzer
- i. Pepcid (famotidine, OTC)
- j. Claritin, Allegra, & Zyrtec (OTC) can help with histamine symptoms (anticholinergics like Benadryl or Hydroxyzine would not be recommended if you are in the early phases of the illness as these can exacerbate the effects of botulinum toxin)
- k. Ketotifen (Rx)
- l. Cromolyn spray (OTC)

NOTE: You may want to try 1 supplement at a time, for a week or so, before introducing new supplements. This way, you will be able to figure out which supplements/products (if any) trigger your symptoms. You can also try starting with a small dose of a medication, such as .25 or .5 of the regular dose, if your healthcare provider OKs this.

Be aware that many with MCAS have suffered reactions after synthetic vitamins (including B & D vitamins, and iron) and naturopathic “remedies” and supplements. Try to get your nutrients from food or food-based supplements as much as possible.

MCAS

Alcohol, caffeine, recreational drugs, and inflammatory foods, like sugar, processed and “fast” foods, and seed oils (including sunflower seed oil, safflower seed oil, canola oil, etc.) can exacerbate MCAS symptoms, and should be avoided as much as possible

Consider alternative medicine therapies and the importance of regulating the nervous system

Some group members have had success reducing MCAS symptoms with alternative medicine therapies, including AAT and bioresonance therapy. It's VERY important to understand the relationship between the nervous system and MCAS symptoms. Dr. Gabrielle Lyon has a great article explaining this here:
<https://drgabriellelyon.com/its-not-all-in-your-head-mcas-histamine-and-the-nervous-systems-role-in-chronic-symptoms/>

Work with a trusted healthcare provider to ensure your vitamin/mineral levels remain within normal limits, especially if you find yourself on a limited diet. Naturopathic doctors and functional medicine doctors can be great sources of information for healing from MCAS.

I personally focused on eating an animal-based, organic diet (grass fed beef, wild caught fish, organic chicken, organic eggs, broth, etc.) while sick. I also took beef organ supplements (please note: beef kidney would be a wise choice for those suffering from MCAS, as it is a natural DAO enzyme; beef liver should be avoided because it is high in histamine.)

The website includes a sample MCAS healing protocol generated by ChatGPT by one of our group members:
<https://www.iatrogenicbotulism.com/post/botulism-and-mcas>

POTS and Dysautonomia

POTS (Post orthostatic tachycardia syndrome) is a condition in which the autonomic nervous system (which regulates involuntary functions like heart rate and blood pressure) does not properly manage circulation when standing. People with POTS can experience rapid heart rate, dizziness, lightheadedness, fatigue, brain fog, and sometimes fainting upon standing or during mild exertion.

A primary care doctor may be able to diagnose POTS, or refer you to a cardiologist for a thorough examination.

Dysautonomia is an umbrella term for the disruption of the autonomic nervous system. After botulism poisoning, dysautonomia can occur because the botulinum toxin disrupts nerve signaling, and even as the toxin's effects wear off, the nerves that control these automatic processes may take much longer to recover. This can lead to symptoms such as dizziness, fatigue, heart rate changes, digestive issues, temperature sensitivity, or blood pressure fluctuations during recovery.

These conditions typically improve with time, as the nervous system continues to heal.

Managing POTS and dysautonomia often involves lifestyle adjustments:

- increasing hydration and salt intake
- wearing compression garments
- pacing activity
- using gentle movement or recumbent exercise to improve circulation
- mindfulness, stress reduction, and good sleep can help regulate the nervous system
- Staying under the care of a trusted healthcare provider who can monitor your condition closely and recommend any necessary medications

For more information, visit:

- Dysautonomia International
- Standing up to POTS
- Support groups on Facebook for individuals with POTS and dysautonomia

Lyme Disease after Botulism

Some individuals recovering from botulism poisoning have reported experiencing symptoms similar to those seen in Lyme disease. Symptoms can include fatigue, joint and muscle pain, cognitive difficulties or “brain fog,” headaches, and neurological disturbances—many of which overlap with post-botulism or autonomic dysfunction symptoms.

Because these symptoms are nonspecific and can be caused by multiple factors, anyone who suspects they may have Lyme disease in addition to botulism should seek evaluation from a knowledgeable healthcare provider who can order appropriate testing and interpret results carefully.

Resources for learning more about Lyme disease, its symptoms, and how to get a diagnosis include:

- [International Lyme and Associated Diseases Society \(ILADS\)](#)
- [the Facebook support group titled “Lyme After Botox”](#), which was started by fellow botulism victims who developed Lyme disease post-Botox injections. The group admin are extremely friendly and helpful.

Early and accurate assessment is key for determining the underlying cause of ongoing symptoms and creating an appropriate care plan.

Myalgic Encephalomyelitis (ME)

ME is a complex, chronic illness characterized by profound fatigue, post-exertional malaise, cognitive dysfunction (“brain fog”), sleep disturbances, pain, and autonomic nervous system irregularities.

Post-exertional malaise (PEM) is a hallmark symptom of ME in which physical, cognitive, or emotional exertion leads to a significant worsening of symptoms. This crash is often delayed by hours or days and can include extreme fatigue, pain, brain fog, and flu-like feelings. Unlike normal tiredness, PEM is disproportionate to the activity and can take days, weeks, or months to improve with rest.

Some individuals have reported developing ME after botulism poisoning, likely due to the prolonged neurological and systemic stress the body experiences during recovery.

Diagnosis is typically made by a healthcare provider through careful evaluation of symptoms and exclusion of other conditions.

Symptom management often involves pacing activity to avoid post-exertional crashes, prioritizing restorative sleep, carefully balancing nutrition and hydration, and addressing “sister illnesses”, including POTS or MCAS.

Because ME shares many symptoms with “long COVID,” treatments and strategies that are emerging for long COVID may also be useful approaches for those navigating ME after botulism.

More information here:

- [American ME & CFS Society \(AMMES\)](#) – Offers support group listings, online and phone groups, and resources for patients and caregivers
- [#MEAction](#) – A global patient-led network with multiple support groups, including peer groups for people with ME/CFS, long COVID, and caregiver

Other

In addition to the conditions detailed above, some individuals have reported the development of other neurological issues following botulism poisoning.

These can include small fiber neuropathy, autonomic nervous system dysregulation, cognitive difficulties, and muscle weakness that extend beyond the initial recovery period.

While not everyone will experience these complications, the risk highlights the importance of careful monitoring and early intervention.

If you suspect that you may have developed a secondary neurological condition after botulism, it is essential to seek the guidance of a neurologist or an integrative medicine doctor who is experienced in complex, post-toxic or post-infectious conditions.

These professionals can help evaluate symptoms, perform appropriate testing, and develop an individualized plan for managing ongoing neurological and systemic challenges that linger.

05. A-Z *Symptom Relief*



IN THIS CHAPTER:

- Practices, supplements, medications, & ideas for botulism symptom relief

A-Z Symptom Relief

This chapter includes practices, supplements, medications, therapies, etc. that helped support group members with specific symptoms of botulism and/or MCAS.

Medical Disclaimer: Please note that none of this is medical advice. ALWAYS work closely with a trusted healthcare provider before beginning or discontinuing ANY supplements or medications.

What helps one person, can cause a worsening of symptoms for others, so please use your common sense, do your own research, consult with a trusted medical professional, and remember that every drug/supplement comes with its own list of benefits and risks.

The following key was developed to label each symptom relief recommendations:



Supported by research



Based on patient experience



May worsen symptoms in some



Prescription medication to discuss with your doctor

What helped with symptoms overall for most people:

- Time
- Healthy, organic foods - consider a high protein, low sugar diet rich in healthy fats
- Sleep
- Electrolytes and celery juice
- Family/friend support and time off from work
- Reducing Stress
- Healing the Vagus Nerve

A-Z Symptom Relief

Anemia

- ⚠️ • Iron supplement with Vit C if tolerated - note that many (especially those with MCAS) will not tolerate synthetic vitamins
- Beef spleen
- ⚠️ • Oysters and chicken liver (note: these are NOT MCAS friendly)
- Beef

Anxiety

- 👥 • Ashwagandha (OTC) - note that short term use of Ashwagandha is generally considered safe
- 👥 • Vagus nerve healing (see “Vagus Nerve Healing” below)
- 👥 • Mental distraction (walks, calling a friend, watching a funny movie, etc.)
- 👥 • Avoiding caffeine, excess sugar, and processed foods
- RX • Progesterone cream (Rx)
- RX • LDN (Rx)
- RX • Benzodiazepines (Rx) are sometimes used as a last resort; if you choose to take them, it is **imperative** that you work closely with a trusted healthcare provider

Back pain

- 👥 • Icy hot packs

Brain fog and fatigue

- 👥 • Huperzine A (OTC) - note: can worsen muscle spasms
- 💻 • Omega 3's (cod liver oil)
- 💻 • Creatine
- 👥 ⚠️ • Ginseng - may cause more anxiety in initial 6 months
- 👥 ⚠️ • Nicotine patches (2-4 mg) have helped some; for others it made them more anxious. **Nicotine products may not be safe or appropriate for everyone and can have side effects or interactions with medical conditions or medications.**
- 👥 ⚠️ • Magnesium malate - necessary for producing ATP, body's primary energy source (magnesium relaxes muscles and is not recommended if you are experiencing acute muscle weakness from botulism)

A-Z Symptom Relief

Constipation

- Increase water and fiber intake
- Glycerin suppositories
- Artichoke extract/milk thistle
- ⚠️ • Senna/"Smooth move" tea (note: may cause stomach pain)

Difficulty breathing

- Time and distraction
- Note that sometimes this symptom can be caused by histamine triggers

Dry eyes

- Warm towel compresses
- RX • Carbomethylcellulose preservative free .05%
- Eye drops
- Cod liver oil or eating more oily fish like salmon, sardines, & mackerel

Dry mouth

- Biotene products (spray, lozenges, mouthwash)
- Chewing gum
- Peppermint drops
- Xylimelts

Dry nose

- Saline spray
- Petroleum jelly
- Steam/saline mist

Ear congestion

- Chewing gum

Eyelid ptosis (drooping)

Ptosis will typically improve with time (3-6 months). Your injector can prescribe eye drops to help with ptosis, including:

- RX • Upneeq
- RX • Apraclonidine

A-Z Symptom Relief

Gut healing

- Avoid processed foods, seed oils & added sugar whenever possible
- Stick to a simple, organic whole foods diet. It's important to eat organic grains (wheat, corn, soy, etc) whenever possible, as herbicides and pesticides can disrupt the gut lining
-  • Bone broth (**not** MCAS friendly) and broth (MCAS friendly)
-  • Low histamine probiotic if you have MCAS
-  • Sauerkraut and whole fat kefir (**not** MCAS friendly)
-  • Marine collagen
-  • Digestive enzymes
- The GAPS diet website is a great resource: www.gapsdiet.com

Hair loss

- Gently washing hair with fragrance-free shampoo (like Vanicream or Cleure) every 3-4 days
- Don't comb your hair when wet
- Collagen supplements like Heart & Soil Hair Skin & Nails pills
-  • Commercial hair regrowth vitamins like Nutrifol seem to do nothing for botulism-induced hair loss. Large amounts of synthetic vitamins can do more harm than good
- Time is the best healer, and many report that it takes 2-3 years for their hair to thicken back up after botulism-induced hair loss

Heart Palpitations/Chest Pain

- Reduce stressful situations/over-exertion; heart palpitations can come from histamine triggers/MCAS
- Deep breathing
- **Do not hesitate to seek emergency medical care if these symptoms are worrisome**

A-Z Symptom Relief

Insomnia

- 🛌 • L-theanine and Valerian root
- 🛌 • GABA supplements - look for pure GABA with no added vitamins
- ⚠️ • Magnesium glycinate - note that magnesium is a muscle relaxer, so if you are experiencing muscle weakness it would not be recommended
- RX • Benzodiazepines (some have had to use these as a last resort short term under the guidance of a doctor)
- Rx ⚠️ • Low-dose naltrexone (LDN)
- Meditation podcasts

Memory loss

- ⚠️ • Nicotine patches (2-4mg) have helped some; for others it made them more anxious
- Sleep
- ⚠️ • Ginseng/Ginkgo - may cause more anxiety in first 6 months
 - Write everything important down, on post its or in your phone
 - Use your phone to set reminders and alarms
 - Repetition of new information is key to making new memories.

Migraines/head pressure

- Acetaminophen (OTC)
- Rx ⚠️ • Gabapentin is the only thing that helped some

Muscle spasms

- ⚠️ • Magnesium glycinate (orally) - note that magnesium is a muscle relaxer, so if you are experiencing muscle weakness it would not be recommended

Muscle pain and joint paint

- Physical therapy
- Rx • TENS unit
- ⚠️ • Red light therapy (after initial 6 months)
- ⚠️ • Magnesium (oral or transdermal, such as lotions or bath soaks) - note that magnesium is a muscle relaxer, so if you are experiencing muscle weakness it would not be recommended
- 🛌 • Biofreeze or Arnica lotion

A-Z Symptom Relief

Muscle weakness

- ⚠️  • Pyridostigmine has been prescribed for muscle weakness in various iatrogenic botulism case studies. Keep in mind that it comes with its own list of risks and has caused a worsening of symptoms for some sufferers, so ask your doctor if it's something that might help you
- ⚠️ • Citicholine (pure) - may not be appropriate for those who are sensitive to supplements

Nausea

-  • Zofran
-  • Phenergan

Neck weakness/pain

- Neck pillow
- 👤 • Icy hot packs and cream

Nerve pain

-  • TENS unit
- ⚠️ • Magnesium glycinate (oral and transdermal) - note that magnesium is a muscle relaxer, so if you are experiencing muscle weakness it would not be recommended
- 👤 • Lion's mane mushrooms
- 👤 • St. John's Wort
- 👤 • PEA supplements
- ⚠️ • Red light therapy (after first 6 months)
- ⚠️  • Cannabinoids (CBD helped most; THC should be used with extreme caution, as it can cause a worsening of symptoms)
-  • Some found that prescription medications, like Amitriptyline, Gabapentin, and Oxycodone were the only things that helped

Relapses

- 👤 • Activated charcoal
- 👤 • Reducing stress
- 👤 • Quercetin + Vit C
- 👤 • Electrolytes and rest

A-Z Symptom Relief

Speaking difficulties

- Slow down when speaking and articulate words as best as you can
- Use speech only when necessary; you can use text to speech apps if you're too tired to talk

Swallowing difficulties

- Pureeing food, smoothies, soups, & shakes
- Using sauce/gravy with solid foods to help moisten them
- Crushing medications in applesauce if OK'd by MD/pharmacist
- A Modified Barium Swallow Study (MBSS) can confirm whether or not aspiration is occurring

Thyroid dysfunction

-  • Careful monitoring by doctor, as thyroid medications may be necessary
- Whole, organic diet; avoiding soy products
-  • Ashwagandha; I used the tincture [Thyroid Support by Earthley](#)

UTIs and interstitial cystitis

-  • Focus on gut health (see above)
-  • Water and electrolytes
- D-mannose + Vit C
- Difference between UTIs and interstitial cystitis:
<https://biologyinsights.com/how-to-tell-the-difference-between-a-uti-and-interstitial-cystitis/>

Vagus nerve healing

-  • Vagus nerve exercises
-  • Dry brushing and lymphatic drainage practices
-  • Primal Trust program
-  • Dynamic Neural Retraining System
-  • Apps “BrainTap” and “NuCalm”
-  • Calming frequency sound devices
- Limiting EMR exposure
- Improving gut health

A-Z Symptom Relief

Vision impairments

- Thorough evaluation performed by neurophthalmologist
-  • Eye exercises on Youtube
-  • Sunglasses if light sensitivity is present
- Addressing MCAS symptoms if present; vision disturbances can be caused by histamine triggers

Potential therapies mentioned (but never formally studied)

by Dr. Hristova in her 2016 paper:

- Activated charcoal
- 400 MG of Echinacea daily
- Coffee enemas
- Toosendanin
- Reserpine
- Celery juice consumption
- Potassium-rich foods

Conclusion

Botulism is a complex and often misunderstood nervous system illness that can affect multiple systems in the body, resulting in a wide and unpredictable range of symptoms.

No two recoveries look the same. Healing unfolds on an individual timeline, and progress may be gradual, uneven, and influenced by many factors unique to each person.

What brings relief to one individual may be ineffective (or even aggravating) for another, reflecting the differences in body chemistry, metabolic function, and any secondary medical conditions that may develop after botulism poisoning.

Because of this complexity, it is essential to work with healthcare providers who listen carefully, believe patients' lived experiences, and are willing to partner closely with them over time. Ongoing monitoring of symptoms, metabolic changes, and appropriate lab work can help guide care and adjustments as the body heals.

Some individuals may benefit from seeking out functional or integrative medicine practitioners who take a whole-body approach, considering nutrition, sleep quality, nervous system regulation, vagus nerve healing, and other foundational aspects of recovery.

I hope this guide has served as a helpful companion along your recovery journey and that I met my goal of providing clear and easy-to-understand education, practical resources, and reassurance during an overwhelming time. My intention in creating this guide was to empower readers with knowledge, validation, and tools to better understand their illness and advocate for themselves. If even one section has helped you feel more informed, supported, or confident in navigating recovery, then I've done my job.

Thank you for reading and SHARING this information.

Wishing you a healthy and complete recovery,
Megan

Resources

IatrogenicBotulism.com - my website includes many resources for botulism patients and medical professionals supporting patients with botulism. Specific resources include:

- Handouts for doctors explaining the symptoms of iatrogenic botulism and how to get patients antitoxin
- Resource Hub - growing list of research articles related to botulinum toxin and iatrogenic botulism
- Doctors/hospitals in the US and UK familiar with iatrogenic botulism
- Links to podcast interviews and recommended books

The Botox Injury Stories Podcast - a podcast featuring interviews with people who have been injured by Botox and other BoNT products. Available on Spotify and iTunes.

Botox Side Effects - Iatrogenic Botulism support group for iatrogenic botulism sufferers

BotoxInjuries.com - blog about all things botulinum toxin authored by fellow botulism victim Jennifer Ballard

FDA Medwatch - FDA website for reporting adverse effects following botulinum toxin injections. This helps the FDA have accurate numbers on how often these side effects are occurring.



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“You can heal. You will heal. You ARE healing.”
- My daily mantra while recovering from botulism