

## IT'S ALRIGHT BY DEACON ZELCH

|                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                 |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| It's alright<br>To be sad,<br>To be angry,<br>To be mad.<br>To be lonely<br>In a crowd,<br>When inside you're screaming<br>loud<br>To be empty,<br>Full of doubt.                                                      | It pulls at you.<br><br>And now,<br>It feels as if<br>It is taking your very<br>breath away.<br>Leaving you weaker...<br>And weaker.<br><br>And now,<br>In this silence that is you,<br>Everything is so loud<br>Nobody hears you,<br>Hears you crying...<br>Crying...<br>Help. |
| It's okay<br>To be scared,<br>To feel your fear,<br>To feel ashamed.<br>You're not the only one with<br>pain<br>Who's beaten by relentless<br>waves<br>Who lies awake and loses sleep<br>As thoughts of suicide speak. | You are not alone.                                                                                                                                                                                                                                                              |

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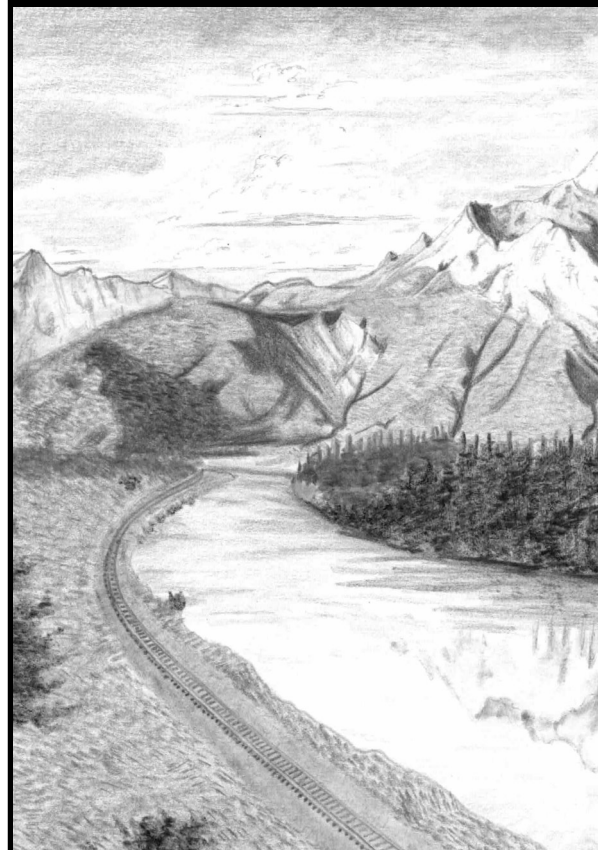
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# PRISON HEALTH NEWS



Artwork by George Dominguez

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survived it. We're here  
to take your health  
questions seriously and  
make complicated  
health information  
understandable. We  
want to help you learn  
how to get better health  
care within your  
facility and how to  
get answers to your  
health questions. Be  
persistent—don't give  
up. Join us in our  
fight for the right to  
health care and  
health information.  
Read on...

From  
The PHN Team

## IN THIS ISSUE

|                                        |       |
|----------------------------------------|-------|
| March of the Legionella.....           | 2-3   |
| Feeling Off? You're Not Alone.....     | 3-6   |
| Recognizing Long Covid.....            | 7-9   |
| Ask PHN: Hemorrhoids.....              | 10-11 |
| Incarcerated by Cancer.....            | 12-13 |
| Information and Support Resources..... | 14-15 |
| It's Alright.....                      | 16    |
| Subscribe!.....                        | 16    |

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Would you like to see your art, writing or poetry in *Prison Health News*?

If you want to write an article on something you think is important for prison health, send it and we will consider publishing it in *Prison Health News*. Tell us your story of struggling to receive quality health care, either for yourself or others. Do you have tips and tricks for staying healthy and taking care of yourself behind the walls that could be useful to others in the same position? You can also write us first to discuss ideas for articles. Please let us know if it's OK for us to put your writing or artwork on our website or social media. Let us know if you'd like us to use your full name, first name only, or "Anonymous." Having your name on the internet means anyone can find it. Please keep in mind that we may make small changes to your article for length or clarity. For any major changes to your work, we will try to get in touch with you first. You can submit your work to this address:

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19143

## “MARCH” OF THE *LEGIONELLA*

BY THOMAS MICHAEL SIMMONS

Many baby boomers recall 1976, when people attending an American Legion convention fell gravely ill to a form of pneumonia later named “legionnaires disease.” Legionnaires disease is caused by the bacteria *Legionella pneumophila*, which is among the most common causes of pneumonia. *Legionella* can be attributed to biofilms found in plumbing and water storage systems, construction, and water temperature fluctuations. They thrive and grow quickly in 98.6-degree Fahrenheit environments. *Legionella* grows best in large, complex, and poorly maintained water distribution systems, such as air conditioning and cooling systems.

Usually *Legionella* live in natural freshwater locations, rarely causing illness. Human-made settings foster its growth, and the bacteria can make it into showers, fountains, and cooling towers. The infected vapor-water droplets can be inhaled into the lungs. Even if exposed, most healthy people don't develop the disease. It's not spread through person-to-person contact.

Cases of legionnaires disease can range from mild to severe. Symptoms include a “dry” cough, chest pains, shortness of breath, muscle aches, and fever. *Legionella* attacks the lungs and respiratory tract. More severe cases present with higher fever, abrupt chills, or changes in mental state. Depending on the severity, people who contract legionnaires disease might need hospitalization and antibiotic therapy. Legionnaires can be more dangerous for people who have a compromised immune

**Jailhouse Lawyers' Handbook**  
National Lawyers Guild - Prison Law Project  
PO Box 1266  
New York, NY 10009-8941  
Write them to ask for a free copy.

**Coalition for Prisoners' Rights Newsletter**  
P.O. Box 1911, Santa Fe NM, 87504  
Monthly newsletter about current events important to people in prison. Write to them to ask about the cost.

**Prison Legal News**  
P.O. Box 1151 Lake Worth, FL 33460  
Monthly 72-page magazine on the rights of people in prison and recent court rulings. Sample issue: \$5. Subscription: \$36/year.

**Protecting Your Health & Safety: A Litigation Guide for Inmates**  
PLN, P.O. Box 1151 Lake Worth, FL 33460  
325-page manual explains legal rights to health and safety in prison, and how to advocate for those rights when they are violated. A publication of the Southern Poverty Law Center. Make a \$16 check or money order out to Prison Legal News.

**ameelio.org**  
If you have loved ones on the outside, they can use this nonprofit phone app to send you letters and photos for free.

### **Prison Health News Guidebooks**

Write to Prison Health News at the address on the next page to request our guidebooks on the following topics:

- Diabetes
- COVID-19
- Commonly Prescribed Medications

**Write to us** if you know about a great organization that is not yet listed.

**National Resource Center on Children and Families of the Incarcerated**  
856-225-2718  
<https://nrccfi.camden.rutgers.edu/resources/> This is a resource for those with family members on the outside. They do not respond to mail, but your loved ones can find their resources on their website. They have fact sheets and a directory of programs that offer services for children and families of the incarcerated.

**Transgender Law Center**  
PO Box 70976  
Oakland, CA 94612  
Collect line for people in prison: 510.380.8229  
Connects transgender and gender-nonconforming people with advocacy information. They cannot take on legal cases or direct advocacy, but provide access to resources.

**Fair Shake Re-Entry Center**  
P.O. Box 63, Westby, WI 54667  
Send them a donation of \$5 or more for a reentry packet to help you plan for your release. They can also send free offline software that allows you to find resources without using the internet.

# Information and Support Resources

## Center for Health Justice

900 Avila Street #301

Los Angeles, CA 90012

Prison Hotline: 213-229-0985

Free health (including HIV and mental health) hotline Monday to Friday, 8 a.m. to 3 p.m.

Those being released to Los Angeles County can get help with health care and insurance.

## Prison Yoga Project

P.O. Box 415

Bolinas, CA 94924

Write to ask for a free copy of one of the following books: *Yoga: A Path for Healing and Recovery*, *Yoga: un Camino para La Sanacion y la Recuperacion*, or the prison yoga book for women, *Freedom from the Inside*.

## POZ Magazine

Attn: Circulation Department

157 Columbus Ave, Suite 525

New York, NY 10023

Magazine for people living with HIV/AIDS.

Give your full name and address, and state that you are HIV positive and cannot afford a subscription.

## Black and Pink National

Inside Member Mail

6223 Maple St #4600

Omaha, NE 68104

Black & Pink distributes a free national newsletter to incarcerated LGBTQIA2S+ members and incarcerated members living with HIV/AIDS around the country. Each issue includes pieces submitted by incarcerated members, relevant news, history, opinions from our non-incarcerated community, and a calendar.

## California Coalition for Women Prisoners

4400 Market St., Oakland, CA 94608

Organizes with members inside and outside prison to challenge the institutional violence imposed on women, trans and GNC people, and communities of color by the prison industrial complex (PIC). They send The Fire Inside newsletter.

## National Prisoner Resource Directory

Prison Activist Resource Center

PO Box 70447

Oakland, CA 94612

Free 26-page national resource guide for people in prison. It contains contact information for other organizations that can provide free books and information on finding legal help, publications, resources for women and LGBT people, and more.

## SERO Project

P.O. Box 1233

Milford, PA 18337

A network of people living with HIV working to end HIV criminalization, mass incarceration, racism and social injustice and to improve policy outcomes, advance human rights and promote healing justice.

## Just Detention International

3325 Wilshire Blvd, #340

Los Angeles, CA 90010

If you have experienced sexual harm in custody, write to ask for their Survivor Packet, which includes a self-help guide for survivors and info on prisoners' rights and how to get help via mail and phone. Survivors can write via confidential, legal mail to Cynthia Totten, Attorney at Law, CA Attorney Reg. #199266 at the above address. Please note that they do not provide legal representation or counseling services.

## Hepatitis Education Project

1621 South Jackson Street, Suite 201

Seattle, WA 98144

Write to request info about viral hepatitis, harm reduction, and how you can advocate for yourself to get the treatment you need.

system. Treatment involves a 10-14 day (21 if immunocompromised) course of antibiotic therapy.

Diagnosing legionnaires disease involves chest x-rays followed by tests on phlegm expelled from the lungs. Being 50 years or older, a current or former smoker, having chronic lung diseases, or having a weakened immune system from diseases or medications are risk factors for more severe illness.

At least two California prisons have had *Legionella*, with some cases of legionnaires disease diagnosed. Administrators and health care staff initiated protocols that limited exposure to fresh water supplies. These involved closing access to showers, fountains, hot water, and ice dispensers. Portable showers were brought in, and one gallon of bottled water was issued to every inmate daily for consumption, face-washing, and oral hygiene. Inmates with symptoms were brought into medical treatment clinics for evaluation and, if needed, treatment.

A methodical, unit-by-unit, site-by-site hyperchlorination of all areas was employed. Toilets, sinks, water fountains, and related plumbing were drained, flushed with chlorine for several hours, then flushed again. This was followed by testing of the water systems, a process that can take several weeks for results and determinations to be made.

During such situations, accurate information is paramount to prevent unnecessary worries or panic among inmates, their families, and local communities. Administrators and custody and health care staff working with Inmate Peer Educators and Men's/Women's Advisory Council members can be a vital link to the population at large to ensure correct information, and not speculation or rumors, is provided.

## CONVICT CHRONICLES: FEELING OFF? YOU'RE NOT ALONE.

BY LEO CARDEZ

I read an article in *Men's Health* that really struck me. It wasn't specifically written for the inmate community, but it should have been. In the piece, Dr. (psychiatrist) Gregory Scott Brown is discussing something called adjustment disorder (AD).

In layman terms, AD is a disproportionate reaction to something stressful in one's life. AD may make one feel worried, hopeless, or a general sense of unease. Sound familiar? Post-COVID inmate issues are pretty similar across the U.S.: anger over job/program/assignment loss, despair about the difficulty in staying in touch with loved ones, sensitivity over race relations, and general malaise over extended lockdowns brought about by anything from quarantine protocols to staff shortages. In time, all these tiny attacks to your routine and well-being add up.



Artwork by Joshua Smith

I often wondered after that day, was his stoic demeanor due to the strength of his resolve? Was he so content with what fate had dealt him that tears served him no benefit? Was he divinely inspired and saved from the torment of his sickness? Those are all good and noble ideas about a man standing tall and strong against hardship and turmoil. One of those heroic stories you read about, somewhere in some book. But I fear the truth is much darker and tragic.

Some men feel that their incarceration, their guilt, precludes them from the niceties of empathy. They feel that they are condemned and do not deserve human things like sympathy and emotional support. I know this because I hear them say it. I know this because I have felt it myself at times. One of the running themes about incarceration is that inmates do not deserve... (fill in the blank). And it does not happen right away, but after a while, you start to buy into the theme.

So when an inmate is stricken with an illness whose very nature is to rob you of your life force and independence, he retreats into himself because that's what he "deserves." That's "what he gets!"

He does not look for comfort and support because no one ever told him that he could. And he does not reach out for hands and hugs because no one ever told him that he could. All that he's ever been told is that he does not deserve...

Another sad reality of being incarcerated by cancer is that prison is perceived as a place of predators and prey. Whether actual or not, inmates are indoctrinated with this idea before they even commit a crime, and so it goes; you cannot show weakness in prison!

So when an inmate is stricken with an illness whose very nature is to inflict immense pain upon its host, he hides his shameful tears, his fragile wince, and his terrified scowl. He has to show strength 24/7 and not shed so much as a single tear in public because if he does shed a tear, it would be taken as a sign of weakness. No, it is not reality, but it is his truth.

So he pretends to be the strong man who can bear it all alone, but inside he is crumbling. Inside he is uncertain, terrified, and confused. Inside he is screaming HELP! But no one hears him. All that they see is a courteous smile or two when they look in his direction.

I wanted to start this cancer support group so that these men would come to know that they deserve to be supported so that they could have a place to go where they could feel every emotion and express every bit of anger, fear, and hope, without judgment. And hopefully, as a result, live longer and not have to suffer alone.

## INCARCERATED BY CANCER

BY SHAWN HARRIS

“There is a list of 132 inmates diagnosed with cancer,” announced the psychologist assigned to my block. She was sitting in front of her computer as the Psychology Department head and I discussed the commencement of the first-ever Cancer Support Group at my prison. I had for the past year been stressing the importance of having a cancer support group at my facility. We were having a meeting to finalize the date and time when the group would start. We weren’t certain if there were even enough inmates diagnosed in the prison to warrant a support group. In fact, the Psychology Department head specifically asked me how many inmates I knew were currently battling the illness. He even struggled to recall one or two he remembered working with in recent days. So, when the psychologist said the number, we were all stunned.

“So, what’s the age range?” he asked. “All ages,” was the response. “And what are the types of cancer?” he asked. “All types,” was the response.

A cold and sobering reality came over the room. Those present didn’t verbally announce it, but I could see it in their faces that they were as in shock as I was. I figured there were maybe 10 inmates in this prison suffering from cancer. But I vastly underestimated just how aggressive this illness was, and how places like these are incubators for disease and sickness of both the mind and body.

The revelation only strengthened the weight of my claim that incarcerated people silently suffer in an apathetic vacuum. I think of the old adage, “If a tree falls in the forest, and there’s no one there to see it...?”

I once witnessed a man slowly die of cancer. He could no longer control his bowels and had to wear diapers. The diapers did little to prevent his sheets and blanket from becoming soiled. So every morning the block workers had to retrieve his linen, wash them, and return them to him by day’s end. At least thrice a week, his prison browns had to be washed. And nearly every other week, he needed a fresh pair of underwear. He would walk out of his cell, sit by himself at the table, and offer a smile or two if someone looked his way. And he never once expressed sorrow—or any emotion, for that matter. Just a courteous smile or two. And just like that, one day he was gone. No one talked about him except to say, “You know, the guy in 23 cell died.”

## FEELING OFF? (CONTINUED)

In prison, aggressions are a part of life. These mini hostile attacks can come from anywhere—from the guards, nurses, counselors, teachers, and fellow inmates—based on everything from general dislike to race (mostly race). For the most part, you learn how to let them slide off your back, but combine these microaggressions with COVID-19 related stressors and now we can be looking at mental, emotional, and physical distress. Research shows that those who feel they are being treated differently because of their race often feel stressed (duh) and that can lead to problems in the future, both seen and unseen, like feeling isolated and angry.

In prison, we’re told to be tough and that if we are disrespected, the correct response is anger and, if necessary, violence. The rules of the facility, though, tell us that such a response can get us in serious trouble, even more time. So we push down our feelings and let the indignities build up inside of us. What’s worse is we are not getting or seeking help. A 2018 study estimated that 56% to 74% of Black men in America who have experienced trauma (like prison life) “may have an unmet need for mental health services” (Motley and Banks, 2018). I would argue that those percentages are much higher today and for the inmate community. (I mean, it’s just common sense.)

Take Mayor (not his real name, but something we call him because he has a politician’s charm and knows everyone in the camp), a respected ex-gang chief with long braids and the body of someone who has recently lost a lot of weight. He is well-liked on both sides of the fence. He knows all the right people and can make things happen. We’d worked together for five years in the prison law library, where we’d become something as close to friends as you can have in prison. He once helped me get a new celly when he saw I was having issues, but over the past couple of years something changed in him.

He became short with people—and a cell slug in the rare moments we were allowed some social connectivity. I tried to talk to him about it. “I can’t sleep through the night. I’m scared shitless over this bug because of my asthma. And something is off in my brain. I had to read a page in a book three times before I finally understood it. That’s not like me, and I’m nervous,” Mayor explained. He told me he felt like he was finally losing it and, worse, taking it out on innocent bystanders. He told me a story about how he blew up at his celly for finding a hair in the sink—turned out to be his own. Per Dr. Brown’s article, it seemed he had all the symptoms of AD, but he didn’t have the tools necessary to work through them.

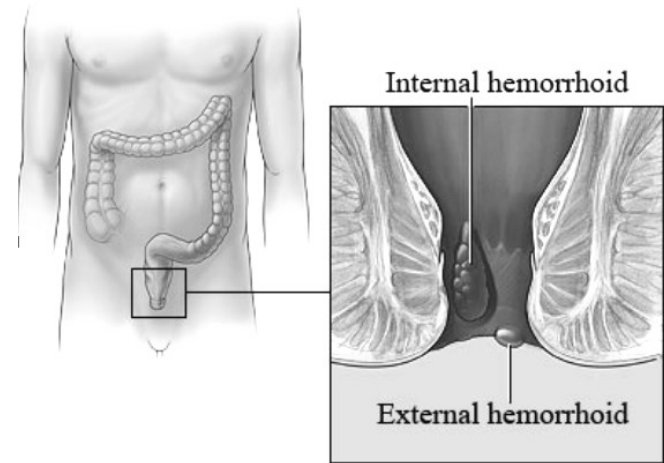
## CONVICT CHRONICLES (CONTINUED)

According to the article, AD can come on strong and fast, but it doesn't typically last that long, and we can usually pinpoint how it started, like divorce, death, and job loss. (Other mental health issues can keep you "keyed up for months" with no idea why.) It was clear COVID-19 related social side effects had messed with the Mayor's ability to be at his best.

Now that we know that AD is possible, maybe even common, when our life is temporarily upended (like going to prison or being stuck in prison during a pandemic), we can start to recognize the effects in our lives. Listen, in prison or not, life will throw us some curveballs or even hit us with a couple of pitches (to complete the cliché); therefore, it would benefit all of us to know how to deal with them. Based on Dr. Brown's suggestions in the article, I would recommend:

1. Reconnect with the world, in any way possible. Call friends and family (video visit, in-person visit, letters, text messages, whatever), get a workout buddy or a chess nemesis—the point is to spend time with others in a space where you are focused on something other than your problems. Find something to get excited about, and then share it with others in your life.
2. Re-engage in life by creating new goals and hopes to aspire to, then create a plan to achieve them—even in this strained and constrained new environment. Sure, everything you had planned may have been blown to bits by COVID-19. Focus on what you can do now. Get creative! We inmates are nothing if not inventive. (Mayor recently started to paint and take a correspondence paralegal course.) The goal is to do something that can help fight against the feelings of helplessness, loneliness, and stagnation.
3. Get help. Talk to a counselor, nurse—someone. They may recommend yoga or meditation, or maybe you may even temporarily need medication (to help you sleep, for example). The point is, do something before you fall into a death spiral you can't pull yourself out of.

The reality is we are constantly being asked to make hard life adjustments while serving any lengthy prison sentence and, whether we know it or not, we are in a constant state of flux, dealing with a litany of unknowns that are out of our control. That's just prison. The Mayor knows that now, and he has started to make some small changes to work on his feelings. I don't know if we'll ever get back to the law library, I don't know if one or both of us will be transferred soon, but I do know that whatever happens, we'll know how to recognize AD and take steps toward addressing it. And that's a pretty good start.



washcloth; and using ice packs can help relieve pain associated with hemorrhoids. Additionally, over-the-counter medications like Tylenol or ibuprofen can also help with severe pain. Usually, hemorrhoids go away on their own within a week.

### ***How can I prevent hemorrhoids in the future?***

Luckily, there are several lifestyle changes you can make that can help prevent future recurrences. Adding fiber to your diet to soften your stools, drinking lots of fluids, exercising, spending less time sitting on the toilet, avoiding straining with bowel movements, and trying to have a bowel movement when you have the urge to rather than holding it can all be beneficial.

### ***What foods have a high fiber content?***

Fruits: Raspberries, apples (with skin), bananas, oranges, strawberries

Vegetables: Boiled broccoli, baked potatoes (with skin), raw carrots

Grains: Whole wheat spaghetti, oatmeal, brown rice, whole wheat bread

Legumes/Nuts/Seeds: Lentils (boiled), black beans (boiled), baked beans (canned), almonds, sunflower kernels

### ***Should I be concerned if I see blood with a bowel movement? What are some red flags to look out for?***

While some benign conditions like hemorrhoids cause bleeding, there are other causes of rectal bleeding that are concerning. Bleeding can also be a sign of more serious conditions like colon or rectal cancer, which require a colonoscopy for diagnosis. If there is a change in your bowel habits or changes in stool color or consistency along with bleeding, it is recommended you see a medical professional.

## ASK PHN: HEMORRHOIDS

BY M. ALI

**Dear Prison Health News,**

I was wondering if you could do an article on the topic of hemorrhoids. Some points of interest might be: What causes hemorrhoids? Is bleeding a common occurrence? What are the treatments for them?

Sincerely,  
Pete B.

**Dear Pete B.,**

### ***What are hemorrhoids?***

Hemorrhoids are swollen veins that can develop inside the rectum and around the anus. There are two types of hemorrhoids: external hemorrhoids, which occur beneath the skin around the anus, and internal hemorrhoids, which occur inside the rectum. The symptoms depend on the type of hemorrhoid.

### ***How common are hemorrhoids?***

Hemorrhoids are very common. They should not be a cause for concern. However, it is important to see a medical professional if the hemorrhoids don't improve after a week of care.

### ***What causes hemorrhoids?***

Some causes include sitting on the toilet for long periods of time, straining during bowel movements, eating a low-fiber diet, chronic constipation or diarrhea, and anal intercourse. Hemorrhoids can more commonly occur in people who are overweight or pregnant.

### ***What are the signs and symptoms of internal hemorrhoids?***

Since these are located inside of the rectum, they cannot be felt or seen. However, a doctor can visualize them using a proctoscope or anoscope. Internal hemorrhoids can cause painless bleeding during bowel movements that is seen on toilet paper or in the toilet.

### ***What are the signs and symptoms of external hemorrhoids?***

These can cause pain, discomfort, itching, or swelling around the anus, as well as bleeding seen on toilet paper or in the toilet.

### ***What are treatment options for hemorrhoids?***

10

Topical hemorrhoid creams; soaking the area with a clean, warm

## RECOGNIZING LONG COVID

BY KIRBY SOKOLOW

Three years have passed since the World Health Organization first declared COVID-19 a pandemic. However, people worldwide continue to suffer from this novel coronavirus' devastating effects. Among them are an estimated 65 million people with symptoms of Long COVID.

Long COVID—also called post-COVID syndrome or post-acute sequelae of SARS-CoV-2 infection—is when someone keeps having COVID-19 symptoms or gets new symptoms that last weeks, months, or years after they get COVID. Anyone infected with COVID-19 can develop Long COVID, even vaccinated folks and people whose initial symptoms were mild. However, vaccination does lower your risk of both getting COVID and developing long COVID.

Long COVID presents differently in every person, with over 200 symptoms reported in total. Despite new research suggesting that Long COVID might be a neurological condition, much remains unknown about the illness; experts continue to research and debate the mechanism or perhaps mechanisms by which COVID-19 infection can disable millions. The lack of definitive answers about Long COVID has been one barrier to diagnosis and treatment for many patients. Another has been lack of access to COVID-19 testing. While a positive test is not required for a Long COVID diagnosis, hard data like test results carry weight for many doctors and may streamline care.

The history of stigma in the medical field against post-viral illnesses like myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), which Long Covid cases often resemble, also poses problems for patients. Even as leading researchers affirm that Long COVID (like ME/CFS) is a physical condition, patients still encounter providers who reduce the cause of their symptoms to stress or anxiety.

Long COVID patients (often called “Long Haulers”) have been fighting together and alongside ME/CFS activists for recognition and care through sharing knowledge. They are empowering one another to recognize and understand their symptoms, to demand relevant tests and treatments, and to advocate for Long COVID research. As an extension of this network, below is some information about 4 common yet complex Long Covid symptoms.

### **Post-Exertional Malaise (PEM)**

PEM is the hallmark symptom of ME/CFS and common in Long Covid as well. PEM is an experience of reduced functioning and/or worsening of someone's symptoms following physical or mental activity. The symptoms appear hours or days after the initial activity, which can

7

be minor: often something a person could do easily before getting sick, like taking a shower. Patients sometimes describe PEM as a “crash” or “shutdown” of their body. Others compare it to a bad hangover or the beginning of the flu (aches, weakness, a sore throat, congestion). For many, it involves overwhelming fatigue.

For years, medical providers incorrectly told people with ME/CFS to exercise their way to recovery. Today, experts recognize that for patients experiencing PEM, exercise can cause their bodies harm. Instead, they emphasize managing activity through **pacing**: being active when you are able, but starting slow and stopping and resting *before* you get tired, when you still feel okay. The advocacy group MEaction’s “Stop.Rest.Pace.” campaign provides an easy way to remember the steps that offer people with PEM the best chance at recovery.

### Fatigue

Many Long Haulers experience fatigue, an extreme exhaustion that persists regardless of how much sleep they get or their activity level. Fatigue can make your body feel weak or intensely heavy (a dull, dead weight). Some people also report sleep that is not restful or refreshing, no matter how long they sleep. As with PEM, activists and experts emphasize the importance of stopping, resting, and pacing, rather than pushing through fatigue.

Activists suggest that being descriptive about how fatigue feels (e.g., how it impacts your day or how your energy levels changed after catching COVID) may help medical providers recognize the severity of fatigue. If you do want to be more active, expressing this may also help medical providers distinguish Long COVID fatigue from depression.

### Postural Orthostatic Tachycardia Syndrome (POTS)

Many folks with Long COVID develop POTS, a problem with the autonomic nervous system that causes a high heart rate (tachycardia) when a person is in an upright (orthostatic) position. The autonomic nervous system is the “autopilot” of the nervous system: It regulates unconscious body processes like heart rate, blood pressure, temperature, and digestion. In POTS, this system is not regulated properly.

POTS symptoms like lightheadedness, fainting or almost fainting, a pounding heartbeat, shakiness, chest pain or tightness, and nausea often happen when a person is upright. Lying down can usually provide relief. The diagnostic criteria for POTS is a 30-beat-per-minute rise in heart rate when someone stands up, which is sustained over time. Because POTS specialists are rare, however, many Long

Haulers with symptoms have had to self-advocate for testing to diagnose POTS: either a **Tilt Table Test** or a more informal **10-minute stand test**, which record a patient’s heart rate and blood pressure while they are first lying down and then upright. In a formal Tilt Table Test, the patient is strapped to a flat table designed to tilt upright, and an electrocardiogram (EKG) also tests for irregular heart beats (arrhythmias).

Treatment for POTS includes medications that regulate heart rate (e.g., beta-blockers or calcium-channel blockers) and blood pressure. However, such medications often require trial and error since each patient is different. Finding the right medication, however, can make a huge difference in a POTS patient’s life. Medical providers also often recommend increasing one’s water and salt intake. However, adding salt to your diet may worsen other medical conditions and should only be done under the care of a medical professional. While medical providers sometimes recommend physical therapy for POTS, if you are also experiencing PEM, exercise is not recommended and can be harmful.

### “Brain Fog”

Experienced by nearly half of all Long Haulers, “brain fog” describes a variety of brain symptoms including increased forgetfulness, memory loss, difficulty concentrating, and a feeling of mental sluggishness. Some researchers have found similarities between the effects of Long COVID and those of concussions.

Learning to pace yourself mentally can help you cope with brain fog. This may involve recognizing which mental activities make your brain fog worse (e.g., having conversations, reading, writing, looking at a computer) and, when doing them, stopping to rest before you get tired in order to build up your endurance. This can be an emotional process, since these activities can be tied to our identities and communities. Coping with brain fog may also mean finding new ways to do things, like writing things down, keeping a calendar, and keeping to one task at a time. Some providers also prescribe medications to help with concentration.

### Camaraderie and Support

Long COVID can be a lonely and isolating experience, but building relationships with other people living with it can be extremely affirming for Long Haulers—especially in a world trying to forget the pandemic. Talking with others who understand the loss and fear that may come with Long COVID, who support rest and embrace pacing, and who affirm that each one of us knows our own body best can provide strength. Even though it may feel otherwise, people with Long COVID are not alone: Millions of us have the same symptoms and continue to fight for recognition, research, and treatment.