

LONG COVID STORY SHORT



PEACE WATERS
& DIMITREA TOKUNBO



Content Warning:

p. **3**, Tidal wave illustration: depiction of natural disaster as a metaphor

p. **4** & **5**, listing of long COVID & chronic illness symptoms

p. **6**, brief description of medical ableism

p. **7**, Death of Black people of marginalized genders and racial disparities in COVID & long COVID

p. **9** & **10**, AIDS impact on Black women

p. **11**, HIV/AIDS & COVID-19 parallels & racial disparities

p. **18**, list of struggles include medical violence while birthing, DV, and trafficking without descriptions. Depiction of woman restrained under water.

p. **20**, same as above

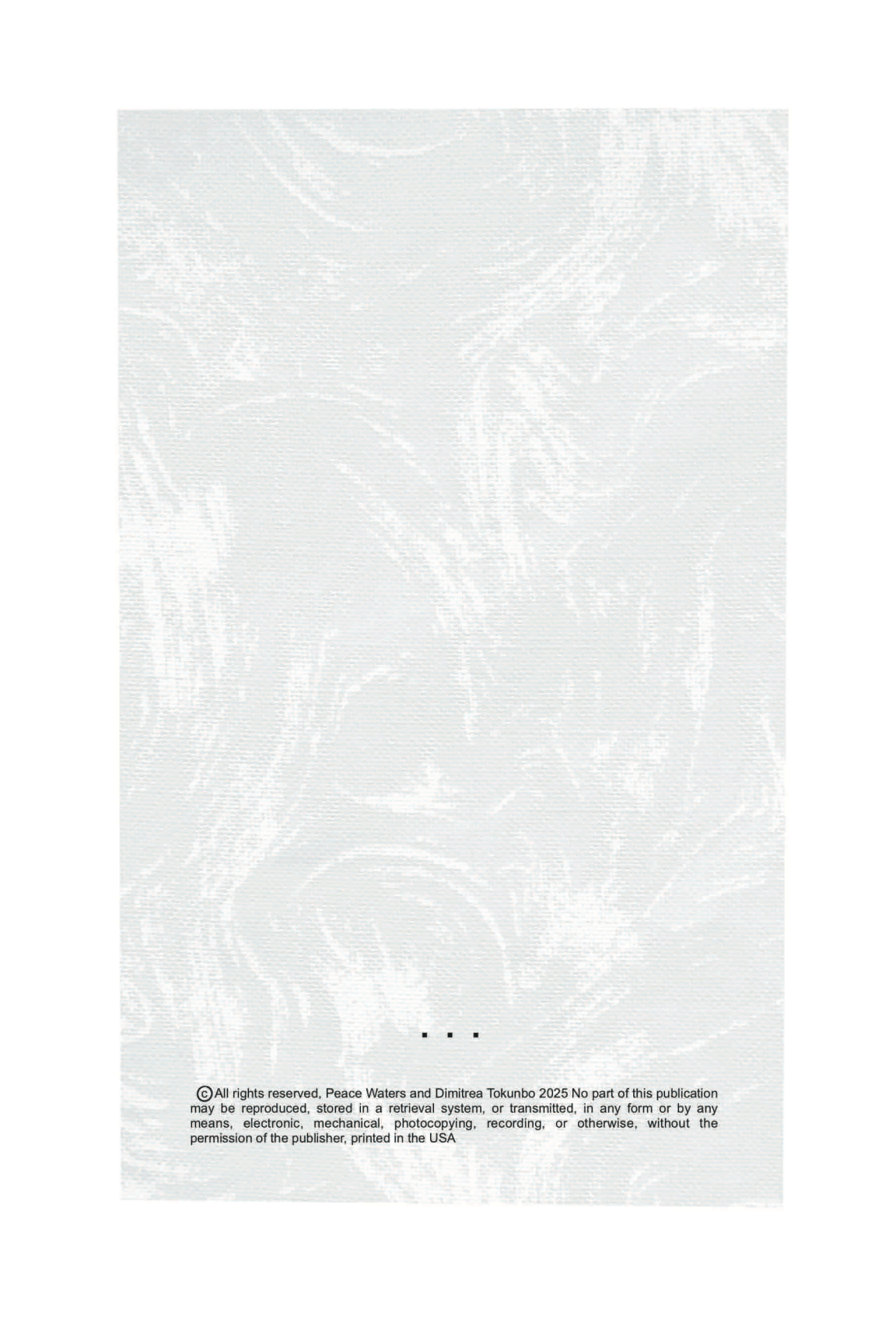
p. **21**, example of communal neglect

p. **22**, cost of living & living wage calculations

p. **26** & **27**, brief mention of illness in children & elderly, COVID Denialism

p. **32**, brief mention of infant death and illness in children and the elderly. Ableism & the disadvantages of federal disability programs





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PEACE WATERS
& DIMITREA TOKUNBO

LONG COVID STORY SHORT

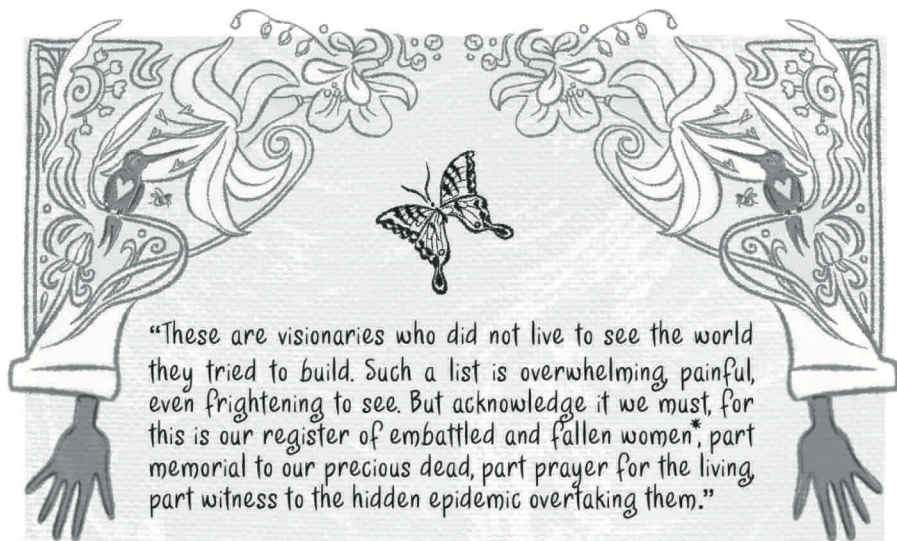




For my
seven-year-old self
and Black disabled
children
- P.W.



"...moving slowly you see
the wonders of the deep,
just waiting there for me..."
A Turtle's Dream by - Abbey Lincoln



"These are visionaries who did not live to see the world they tried to build. Such a list is overwhelming, painful, even frightening to see. But acknowledge it we must, for this is our register of embattled and fallen women*, part memorial to our precious dead, part prayer for the living, part witness to the hidden epidemic overtaking them."

Dr. Myisha Priest, "Salvation is the Issue," 2008.

* 'women' is the wording of the original essay, however this zine and our work is in dedication to Black folks across and beyond the gender spectrum.

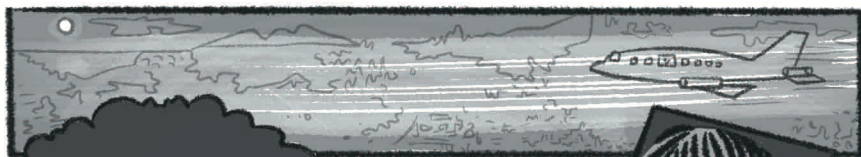
Dedicated to

Lorraine Hansberry, **34 33**, Leilah Danielle Jones
Audre Lorde, **58 65**, June Jordan
Octavia Butler, **58 73**, Lucille Clifton
Sylvia Boone, **54 67**, Virginia Hamilton
Toni Cade Bambara, **56 31**, Minnie Riperton
Ntozake Shange, **70 70**, Nina Simone
Barbara Christian, **56 37**, Marlon Riggs
Tinu Abayomi-Paul, **52 71**, Shirley Horn
Hydeia Broadbent, **39 49**, Lloyd Porter
Shafiqah Hudson, **46 49**, Susan Wantanabe
Tonya Ingram, **31 31**, Phillis Wheatley
Aziza Barnes, **32 46**, James Sadler
Guelila Iyob, **25 45**, Sara Tavares
Nikki Giovanni, **81 58**, Patty Berne





New beginnings were on the horizon.



Mama

Finally blending my love for research with my passion for performance, I was accepted into a PhD program in Theater and Performance Studies as part of a cohort of three.



Titi

My sister moved to the Midwest to finish her degree.



And Mimi joined me in California, to help us with the transition.



Mimi



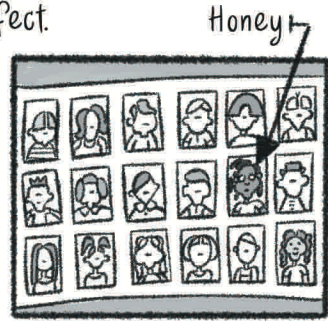
Honey

I couldn't wait to be a full-time, financially stable scholar and artist.

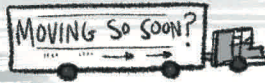
When we moved onto the campus,



COVID safety protocols were in full effect.



And even though I got Honey into a prestigious nursery school three days a week—just a five minute walk from our dorm, the daycare's safety measures meant she wasn't allowed to go with a runny nose. Back then, Honey's nose seemed to be runny most days.



Honey

I found a forest school that boasted of a decolonized curriculum designed for marginalized and disabled children, outside classes and masks (mostly) required. We moved to Oakland and transferred Honey.



A month later, Honey came home from school with a fever.

SEPTEMBER 2021

Mama starts
her PhD
program

AUGUST 2022

Mimi returns
but Mama
still has a
fever

JULY 2022

Mimi goes
away for MFA
comic intensive,
Honey & Mama
catch COVID 19

JUNE 2022

Honey
starts at
forest
school

MAY 2022

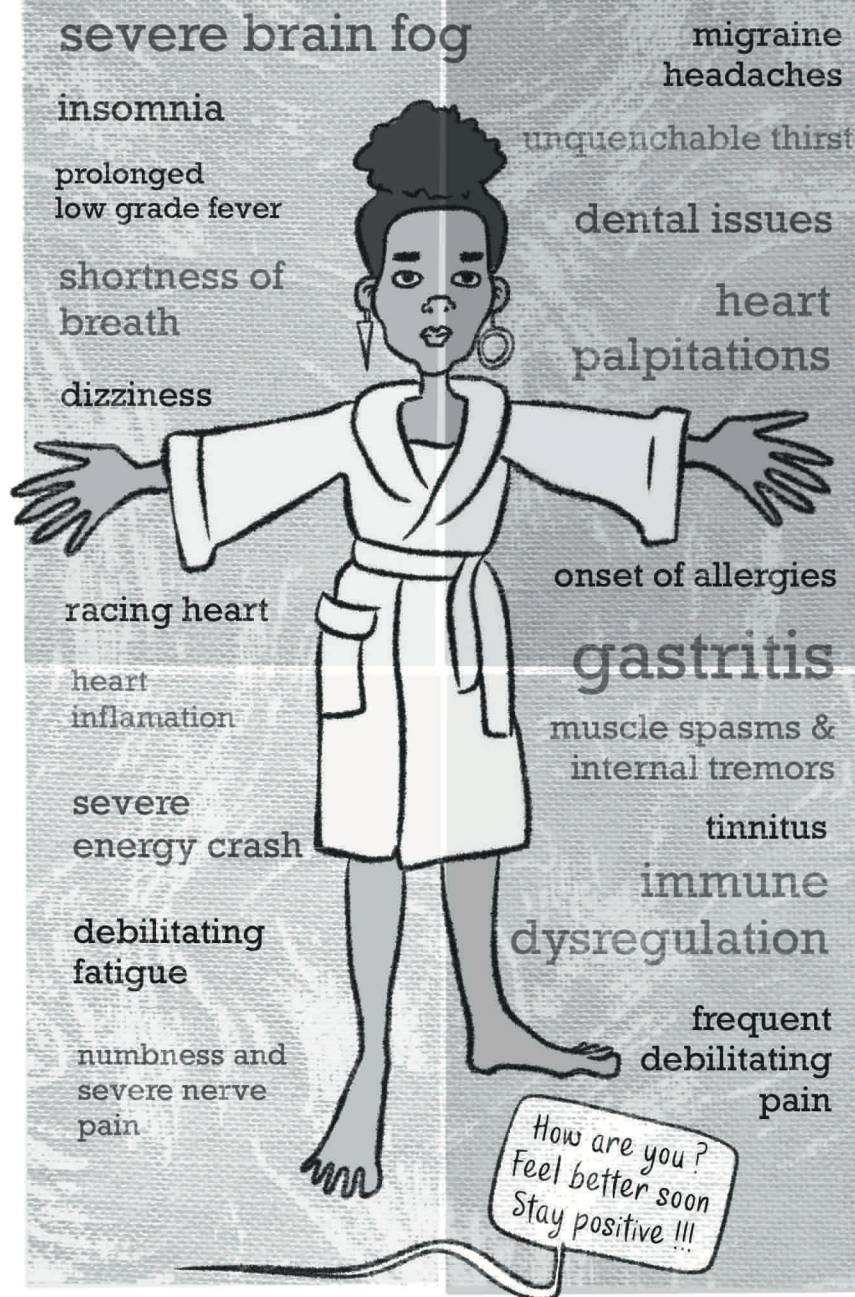
We move
from Palo Alto
to Oakland

SEPTEMBER 2022

Summer
break is over
and Mama
is still
very sick



MY LONG COVID SYMPTOMS



The National Academies of Sciences, Engineering, and Medicine define long COVID as an **infection-associated chronic condition** occurring after an initial COVID infection, affecting one or more organ systems for **3 months or more**. There are over **200** symptoms associated with Long COVID.* I list my most persistent and debilitating health concerns from July **2022** to this very day.

Severe Brain Fog: Research is ongoing, but less than 1% of SARS-CoV-2 causes persistent inflammation of blood vessels in the brain, and immune dysfunction in the brain.

Source: Did the Pandemic Break Our Brains? <https://www.nytimes.com/2022/07/27/health/covid-brain-fog.html>

Chronic Insomnia: A recent study collected data on sleep quality using smart wristbands. Participants with long COVID had less deep sleep than participants who never had COVID.

Source: How COVID can disturb your sleep and dreams <https://www.sleepfoundation.org/covid-19/sleep-disorders>

Prolonged low grade fever, Shortness of breath, Dizziness: Many with Long COVID develop a condition called dysautonomia where your autonomic functions (or things your body does by itself, like blood pressure and heart rate) are disturbed. One way dysautonomia commonly presents with Long COVID is known as POTS, or "postural orthostatic tachycardia syndrome." Blood pressure symptoms often include: headache, "Brain fog" or trouble thinking clearly, racing heart, dizziness or feeling like you might faint.

Source: Dizziness, lightheadedness, racing heart after COVID-19? <https://longcovidjustice.org/2022/07/27/dizziness-lightheadedness-racing-heart-after-covid-19/>

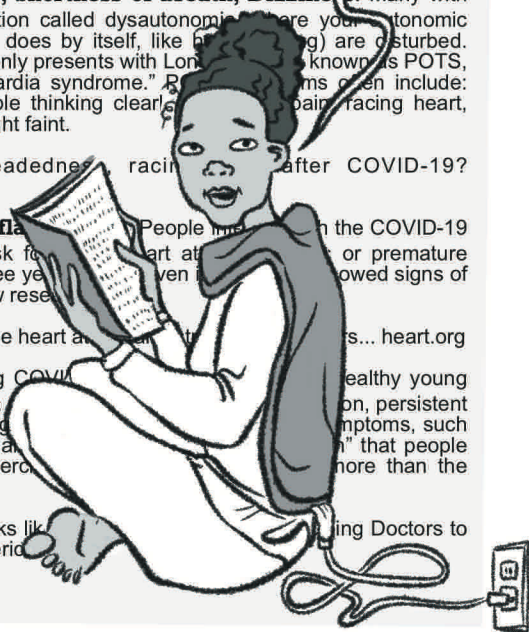
Racing Heart and Heart Inflammation: People who had the COVID-19 virus may have double the risk for heart attack or premature death from any cause up to three years later, even if they showed signs of severe illness, according to new research.

Source: COVID-19 may increase heart attack risk, study finds <https://www.heart.org/en/health-topics/coronary-artery-disease/prevention/covid-19-may-increase-heart-attack-risk>

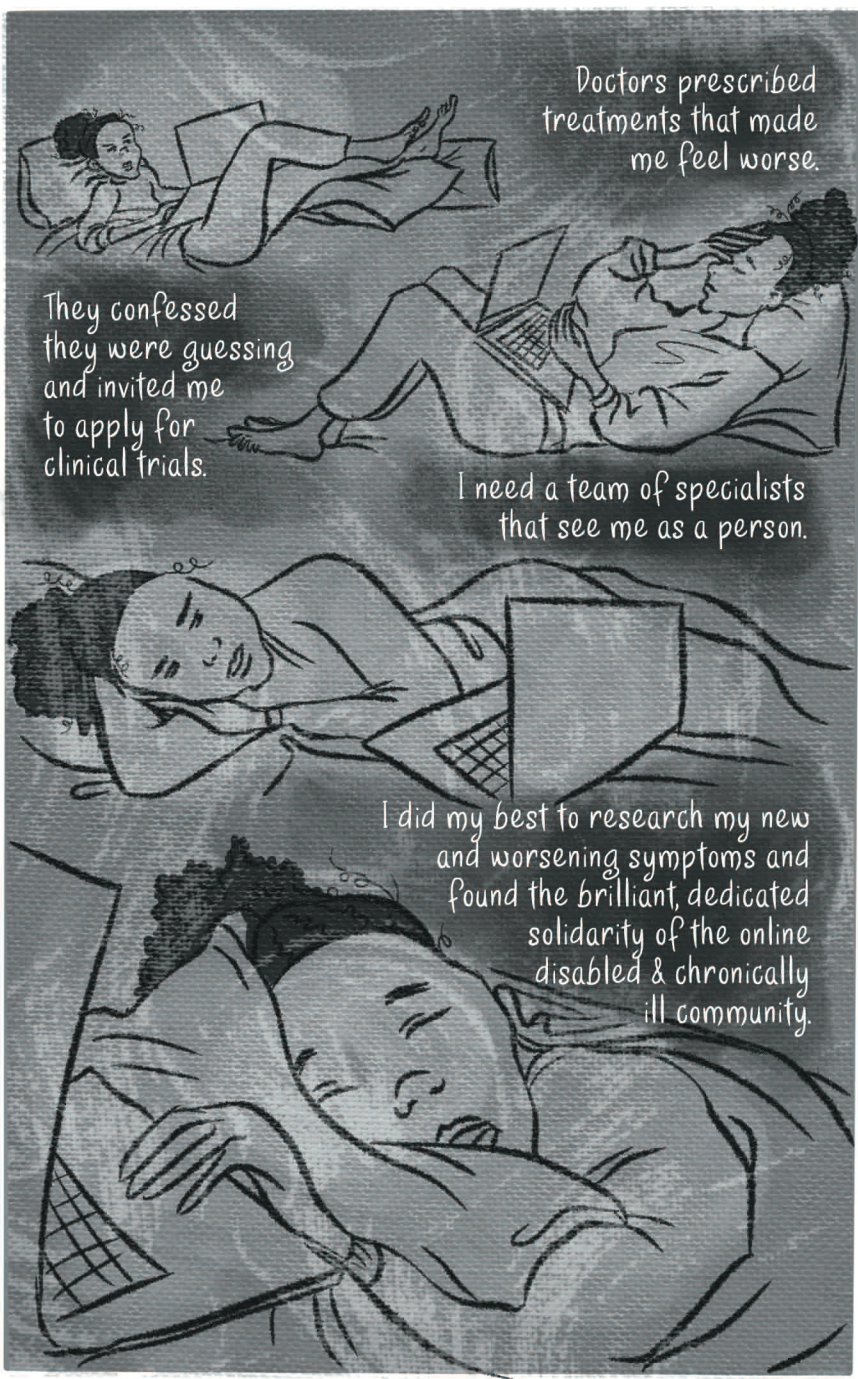
Severe Energy Crash: Long COVID can affect healthy young people, and it can follow even a mild case of COVID-19. Symptoms, such as pain and postexertional malaise, can be debilitating. "It's a crash" that people experience after even light exercise, and it can affect more than the brain.

Source: Long COVID Now Looks Like a Brain Disorder, say Doctors <https://www.scientificamerican.com/article/long-covid-now-looks-like-a-brain-disorder-say-doctors/>

So many words!! I get it. It's overwhelming. You can read about this later in the back matter of this zine.



* Source: National Academies of Sciences, Engineering, and Medicine. 2021. A Long COVID Definition: A Chronic, Systemic Disease State with Profound Consequences. Washington, DC: The National Academies Press. <https://doi.org/10.17716/27768>.



Doctors prescribed
treatments that made
me feel worse.

They confessed
they were guessing
and invited me
to apply for
clinical trials.

I need a team of specialists
that see me as a person.

I did my best to research my new
and worsening symptoms and
found the brilliant, dedicated
solidarity of the online
disabled & chronically
ill community.





So what's the angle
of your documentary
again?

SEXUALITY - kind of
like your poem...



Oh no. My poem
isn't about sex.



See, you got to dig
deeper. People
look at the
surface



My poem
is about
the HIV
AIDS
Epidemic

**BLACK
WOMEN<sup>LIKE
YOU</sup>
ARE DYING.**

DOC. U. MENT. THAT.

Needless to say, I binge watched until I got to episode **23**, The Fast Track and The Furious, written by Susan Wantanabe and Mara Brock Akil. The creative team decided to end the segment with interviews of real women...



Carla Bailey

I was diagnosed in 1989

They try to console you but you don't hear nothin' past "you have"

ALL I CAN SAY IS I DIDN'T WANT TO DIE



One in three



Go to a football stadium and look around - all those people....

One in three

I'm not just gonna die quietly, or not fight this thing

I want to help people know that they can prevent it

Julaun Lewis



So that's my story

Watching that episode,
I can't help but wonder...

Will we learn from our past?

Who
are we willing
to "move on"
without

What groups
are we taught
to care less
about

Am I in
that group?
Are you?

Black Women

Nearly **20** years since this show first aired, but the statements sound eerily familiar. Where is the sitcom Public Safety Announcement for long COVID? Instead, popular media outlets politicize safety precautions and bury the alarming statistics.*

I found an old video where Press Secretary Speakes is asked about AIDS



1 Reagan Administration's Chilling Response to the AIDS Crisis. Vanity Fair Video 2015

As the death toll rose, Speakes cracked jokes amidst gleeful laughter.¹



2 We're Not in Danger Right? Forbes Breaking News Video 2024

Like Biden laughing about not masking while Covid Positive.²

3 to 1

A study shows that Black women are **3** times more likely to die of COVID than white men.³



3 We've only just begun to examine the racial disparities of long COVID. MIT Technology Review 2022

3 to 1

There are differences between HIV/AIDS and COVID, but there are also parallels

I've gotta do something

4 Similarities and differences between HIV and SARS-CoV-2. National Library of Medicine 2021

like advocacy efforts, racial disparities, proposed treatments and certain effects on the body⁴

* COVID-19 Deaths in the US Continue to Be Undercounted, Research Shows. Boston University Viewpoint, Jan 2023 by Stokes, Lindberg, Wrigley-Field, and Chen, buedu

Did you know
the quarantine period
changed from ten days to
five because an airline
CEO made the request to
save money. . .



...even though
it meant sending
contagious
employees back
to work?*



And when
Biden hired a PR
firm to handle the US
COVID crisis, their strategy
was to declare **COVID**
over, even though
it isn't...

...and **never**
talk about how
bad it still is or how bad
COVID will get without
safety protocols **



*<https://www.npr.org/2021/12/29/1068731487/delta-ceo-asks-cdc-to-cut-quarantine>

**<https://www.ineteconomics.org/perspectives/blog/debilitating-a-generation-expert-warns-that-long-covid-may-eventually-affect-most-americans>



Coloring
Playlist



Whew, I don't
know about you but I need
another little break
right about now.

Here are some
coloring pages celebrating
some folks doing
necessary work

Starting with the
cleanair.club

A YEAR of CLEANER AIR WRAPPED 2024

2,686

Purifiers
booked at Chicago
events

1,800

Free masks
distributed

240

Pay-what-you-can
molecular test
distributed



They aim
to raise these
numbers next
year

39%

of bookings
were mask
required

15%

of bookings
had virtual
options

24 PLUS LIFE AND
METRIX TEST KITS

REDISTRIBUTED TO THE
COMMUNITY

73%

of bookings
were wheelchair
accessible



@clean.air.club

Who reaps the
benefits when
we center
accessability?

EVERYBODY!!



@maskblcla

JANUARY 14 - 22, 2025



15 DAYS OF FIRES

14 DAYS DISTRIBUTING

281,690
MASKS

“...But the whiplash between an institutional embrace of social welfare policies “during COVID” and the eugenicist logic required to disavow those policies five years later **show us both what is present and what is possible for the climate justice movement:** we can demand high-level societal realignment in the name of our common welfare, even as we collectively source the knowledge and resources needed to protect our communities in the meantime.”

- Violet Affleck, A Chronically Ill Earth, The Yale Global Health Review, May 2025

What if we only expect
a speed as fast as the
slowest creature?

and actually center
marginalized
communities?

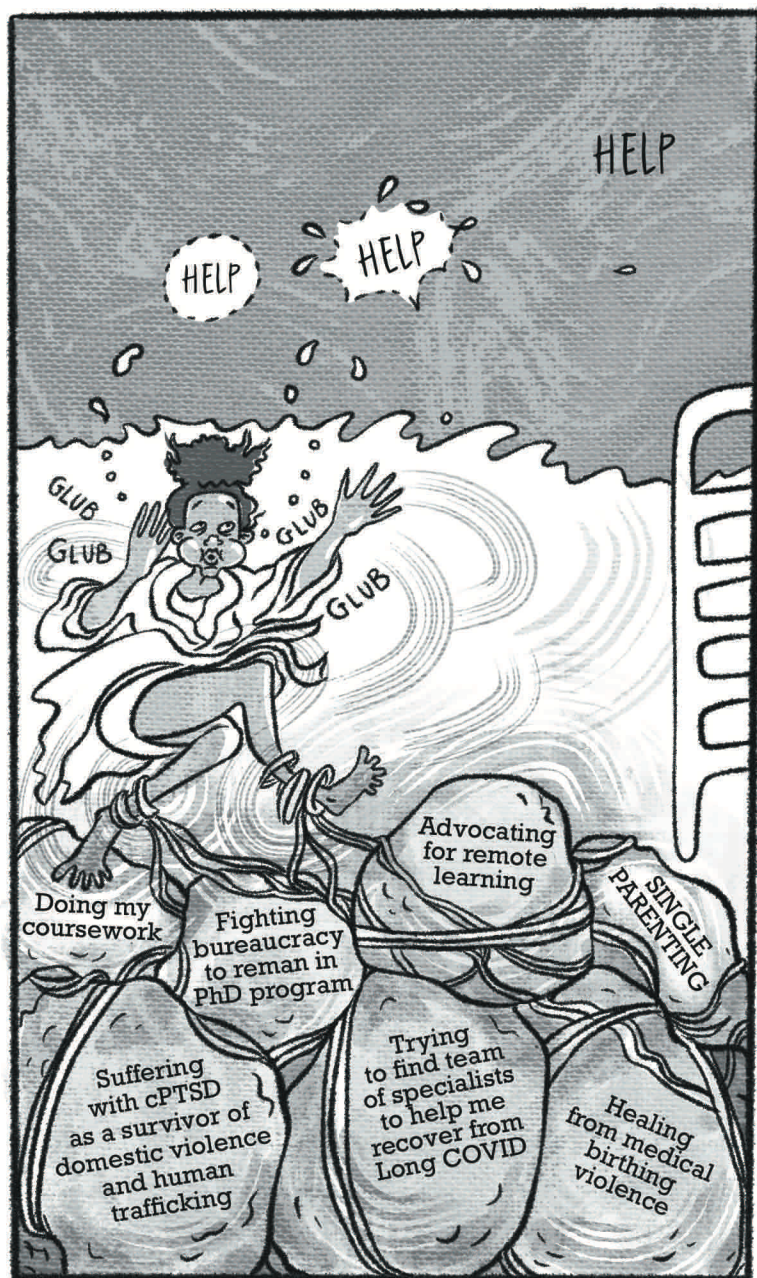
Explore possibility models
that are accessible
for All bodies?



But in my present
lived experience,
I struggle to keep my
head above water...



'Collective Access' is a Disability Justice
Principle coined by Patti Berne and Sins
Invalid—learn more here





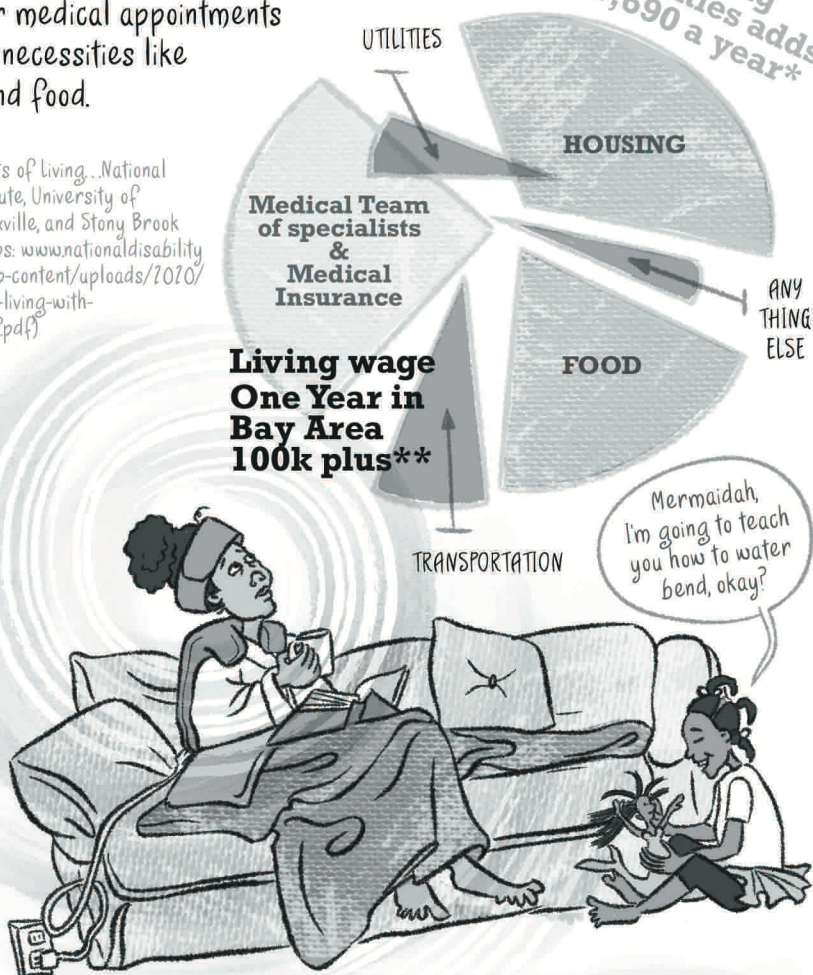




Maybe a medical leave could help me finish my program...eventually. Except being too sick to get a job meant a medical leave would actually cut me off from medical insurance and money for medical appointments and basic necessities like housing and food.

The Cost of managing disabilities adds \$17,690 a year*

*The Extra Costs of Living...National Disability Institute, University of Tennessee Knoxville, and Stony Brook University <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-living-with-disability-brief.pdf>



Witnessing my mother strain under the unexpected weight of helping to maintain our household and figure out Honey's schooling, I knew we couldn't keep up this unsustainable pace.



**Source for cost of living calculations <https://livingwage.mit.edu/counties/06001MITs> Living Wage Calculator For 1 Adult and 1 Child as of February 10th 2025: \$120,551

I slowly launched my GOFUNDME campaign. I quickly found the fundraiser to be more than I could manage without a network of support.

Support A Survivor's Sabbatical



Em Waters is organizing this fundraiser.

Donation protected

"Black woman does not walk on water; does not drown—says 'help' instead."

Letter from Toni Morrison to Toni Cade Bambara



(Image Description: Baby Emily with braids and glasses at around 7 years old. She was excited about new front teeth and becoming an actor and stand up comedian.)

Short Version: TLDR

I have been suffering with long COVID and PTSD and my health has continued to deteriorate. I have been pushing through for far too long and I am in desperate need of a real break to heal and recover...

Though People who hadn't seen me in years gave generously, I didn't reach my goal. But I did reach a decision. For my health's sake, I would stop fighting to stay in my PhD program.

gofundme

\$ 4,115 raised
\$ 100K goal - 23 donations

SHARE

DONATE NOW

This fundraiser is near you

Anonymous
\$ 103

Emmett
\$ 200

Girls for Gender Equity
\$ 1,000

Bolanle
\$ 100

Colette
\$ 200

Joanne
\$ 300

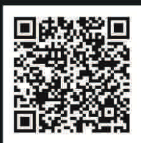
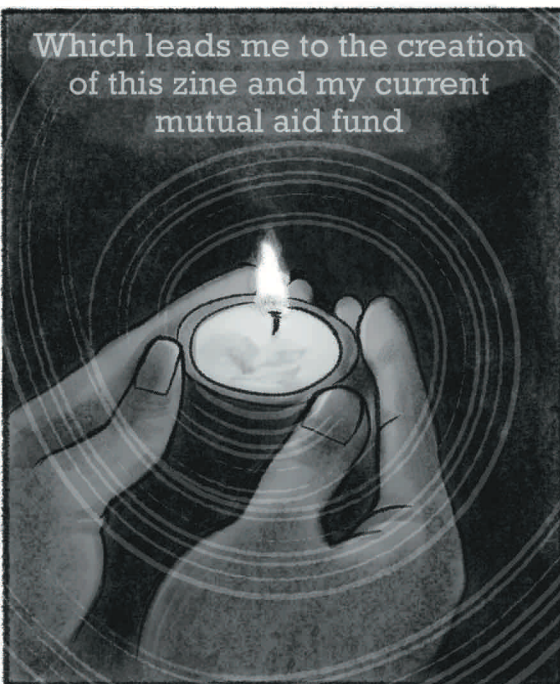
Stiles
\$ 100

See all

See top

The work I'd done
remotely was enough to
earn me a Master's degree
but also prolonged
my illness.

Which leads me to the creation
of this zine and my current
mutual aid fund



Contributions for Urgent Medical Leave

Ever New - song lyrics
by Beverly Glenn-Copeland

Crip Wisdom

What it has been for me
A picture of the full moon
A rose in bloom
To breathe
and be outside
is supposed to be safe
for you too

A beloved sibling
running a saltwater bath
Here is a song that reminds
we are connected

Rapid tests before we gather
PCR if we can
Lay down when you need
Camera off
Silence
Sacred heating pack

I love your cane
With the spikes
Or the sparkles
Or the golden shimmer

Someone is giving away
a shower chair
across the street
right when
I need one

Moving at the pace
of whoever needs
to move the slowest
Ain't no "back to normal"
worth abandoning our kin

By Peace Waters

"...you know, it starts out with,
well, only the disabled and only
the elderly are going to have
problems with this virus.

Hi, that's me, [laughs] okay?
...My life is priceless.

I shouldn't be called upon to sacrifice
my life when we have the resources
to save as many people as we can."

-Tinu Abayomi-Paul

There is a huge, under-documented
tradition of fiercely unapologetic
disabled writing and I am proud to
be a part of it. I am proud to be a
disabled femme of color writer,
writing in a disabled way.

-Leah Lakshmi
Piepzna-Samarasinha

Disabled people know what
it means to be vulnerable
and interdependent. We are
modern-day oracles. It's
time people listened to us.

-Alice Wong

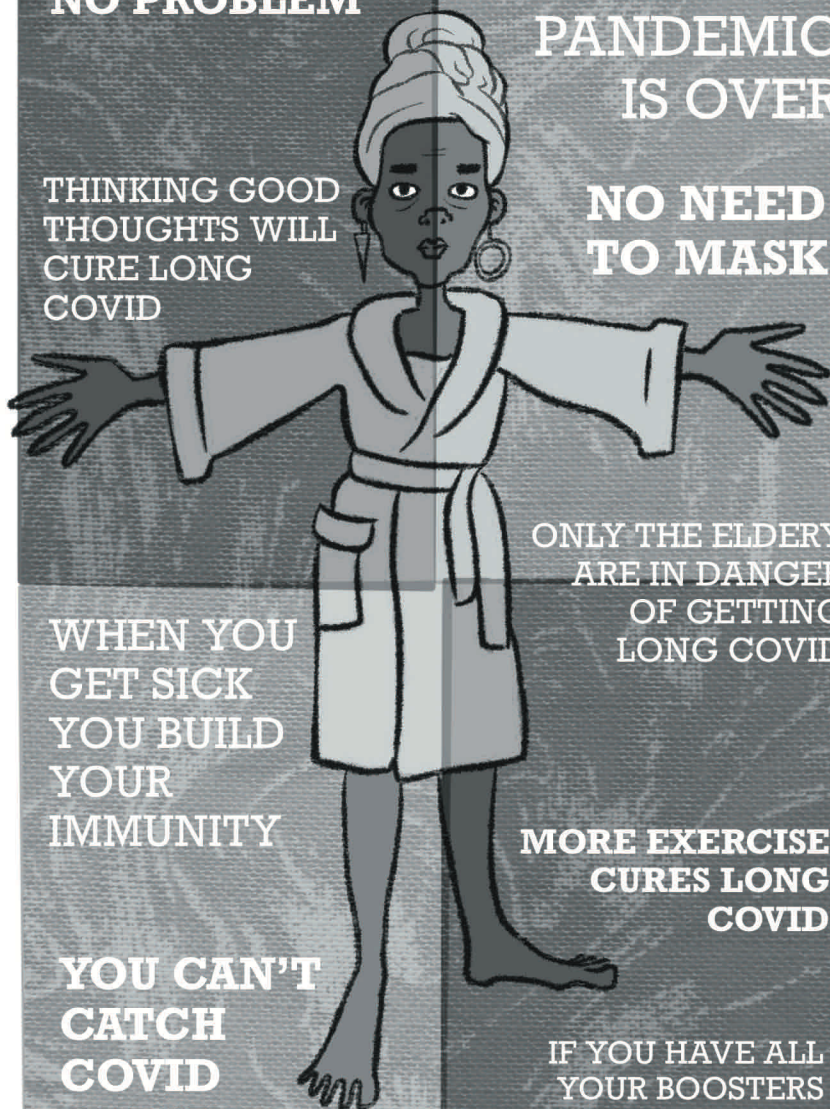
COVID MYTH BUSTER

**NO SYMPTOMS
NO PROBLEM**

**THE COVID
PANDEMIC
IS OVER**

**THINKING GOOD
THOUGHTS WILL
CURE LONG
COVID**

**NO NEED
TO MASK**



**WHEN YOU
GET SICK
YOU BUILD
YOUR
IMMUNITY**

**ONLY THE ELDERLY
ARE IN DANGER
OF GETTING
LONG COVID**

**YOU CAN'T
CATCH
COVID
OUTSIDE**

**MORE EXERCISE
CURES LONG
COVID**

**IF YOU HAVE ALL
YOUR BOOSTERS
YOU'RE GOOD**

Myth Buster supporting articles

No Symptoms, No Problem: False: Recent Studies suggest that about 40.5% of people who tested positive for COVID-19 had no symptoms. If you are not testing regularly you can transmit Covid to people in your community.

Source: <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2787098>
Journal of the American Medical Association (JAMA) Network

The Covid Pandemic is over--its "just" the flu: False: "Debilitating a Generation": Expert Warns That Long COVID May Eventually Affect Most Americans
Institute for New Economic Thinking.

Source: <https://www.ineteconomics.org/perspectives/blog/debilitating-a-generation-expert-warns-that-long-covid-may-eventually-affect-most-americans>

Thinking "good" thoughts will cure Long COVID: False: "I still can't forget those words": mixed methods study of the persisting impact on patients reporting psychosomatic and psychiatric misdiagnoses.

Source: <https://academic.oup.com/rheumatology/advance-article/doi/10.1093/rheumatology/keaf115/8042899?login=false>

No need to mask: False: Masks and respirators for prevention of respiratory infections: a state of the science review.

Source: <https://journals.asm.org/doi/10.1128/cmr.00124-23>

When you get sick you build your immunity: False: re 'Immunity Debt' Claims After Covid-19 Precautions Accurate Or Misinformation?

Source: <https://www.forbes.com/sites/brucelee/2022/11/13/are-immunity-debt-claims-after-covid-19-precautions-accurate-or-misinformation/>

Only the elderly are in danger of getting Long COVID: False: Learn the signs of Long Covid in Children.

Source: <https://longcovidfamilies.org/pediatric-long-covid/>

Here are the ages likely to get long COVID: Americans ages 40–54 had the highest rates of long COVID 2023.

Source: <https://usafacts.org/articles/here-are-the-ages-likely-to-get-long-covid/>

More Exercise cures Long COVID: False: A discovery in the muscles of long COVID patients may explain exercise troubles.

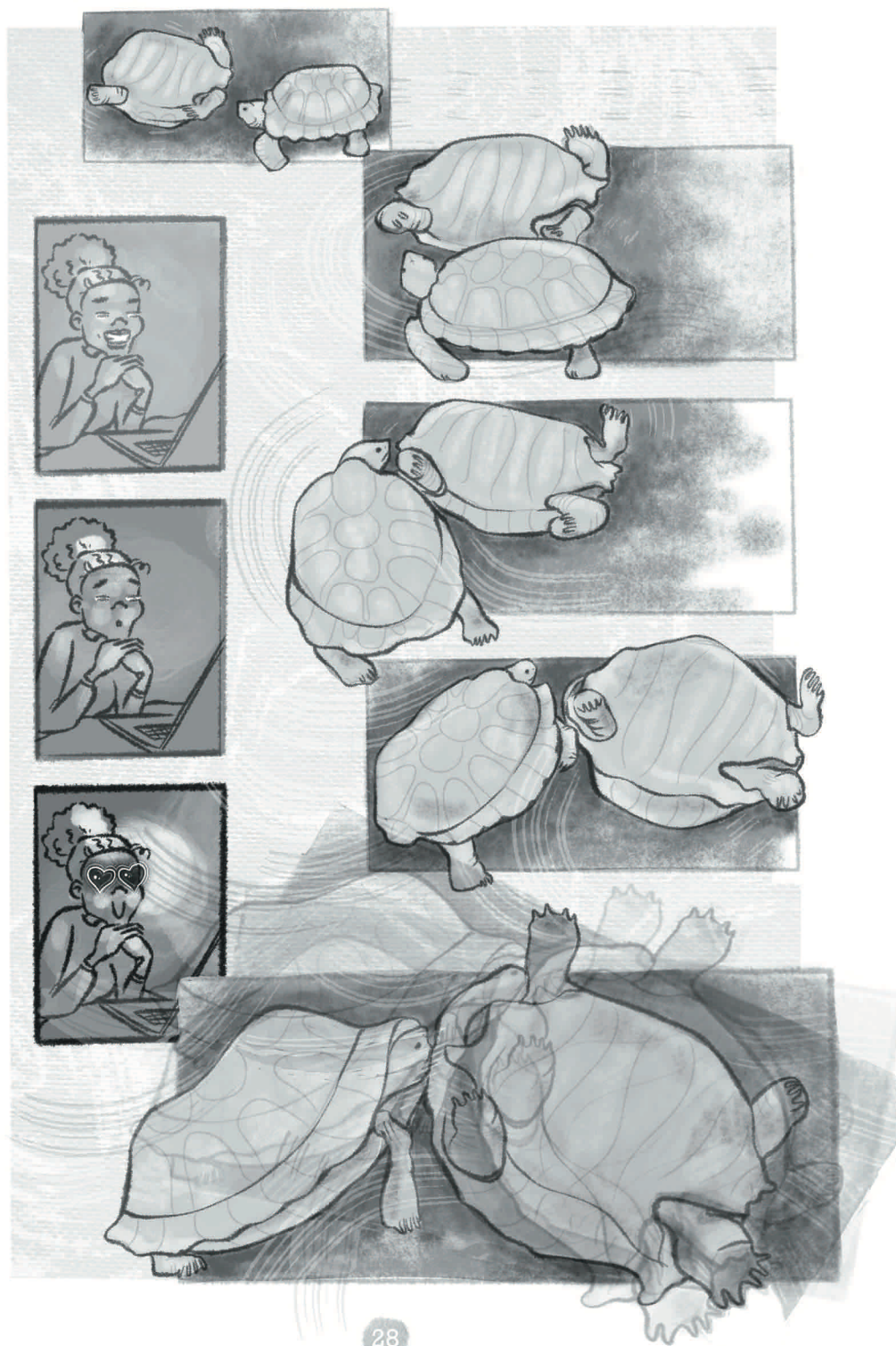
Source: <https://www.npr.org/sections/health-shots/2024/01/09/1223077307/long-covid-exercise-post-exertional-malaise-mitochondria>

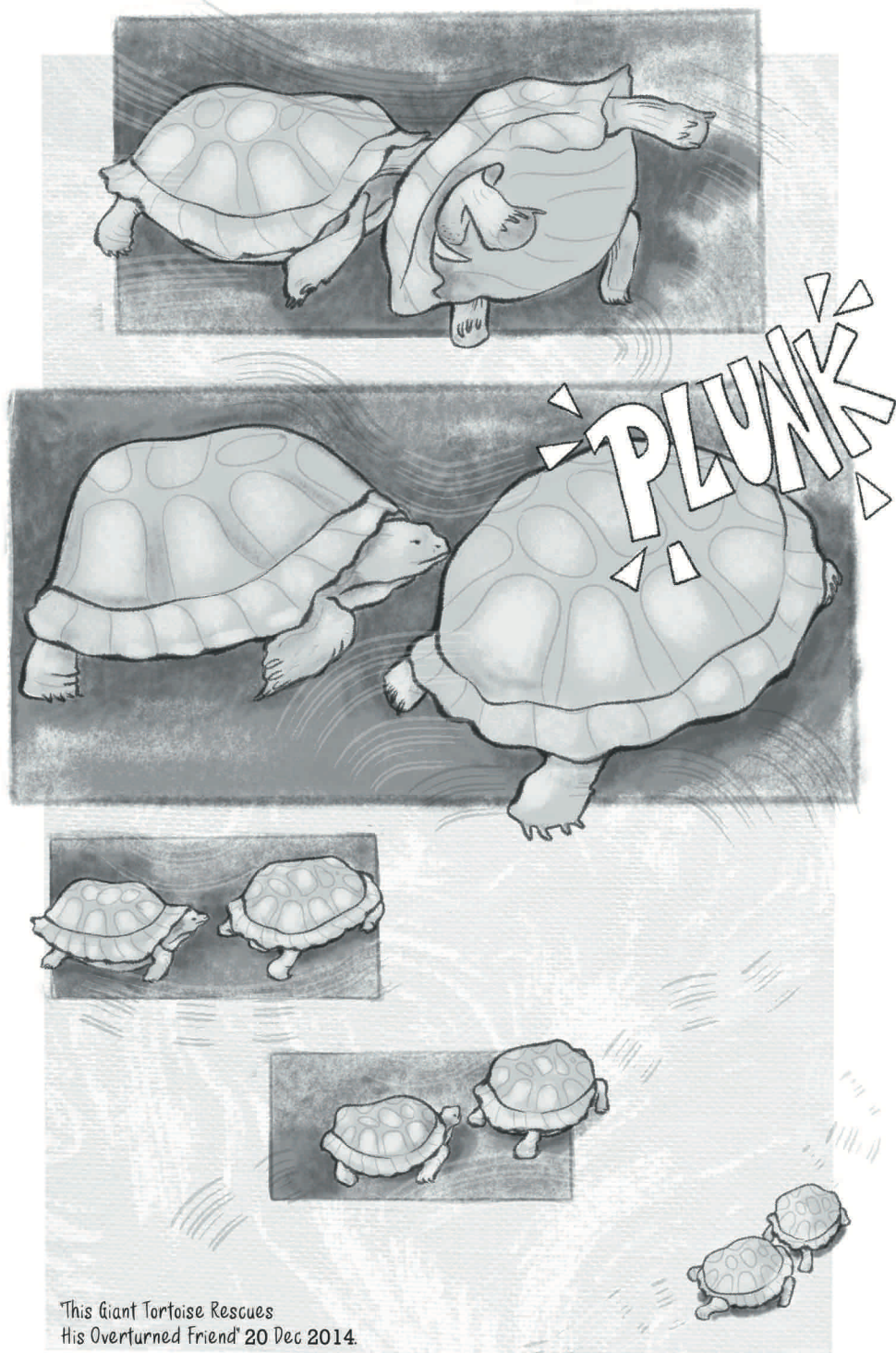
You can't catch COVID outside: False: Your COVID protection outside isn't what it was in 2020. Here's why it's time to think more critically about outdoor gatherings.

Source: <https://fortune.com/well/2022/07/09/can-you-get-covid-outside-outdoors-omicron-ba5-ba4/>

If you have all your boosters, you're good: False: Does the public understand that "variant" means "vaccine resistant"? 2024

Source: <https://www.thegauntlet.news/p/does-the-public-understand-that-variant>





'This Giant Tortoise Rescues
His Overturned Friend' 20 Dec 2014.
Sciencealert.com

Severe Brain Fog: Research is ongoing, but leading hypotheses suggest that SARS-CoV-2 causes persistent inflammation in the brain, damage to blood vessels in the brain, and immune dysfunction so extreme it affects the brain.

Source: "Did the Pandemic Break Our Brains?" [time.com](https://www.time.com)

Chronic Insomnia: A recent study collected data on both sleep duration and quality using smart wristbands. Participants with Long COVID slept less and got less deep sleep than participants who never had COVID.

Source: "How COVID can disturb your sleep and dreams" – theconversation.com

Prolonged low grade fever, Shortness of breath, Dizziness: Many with Long COVID develop a condition called dysautonomia, where your autonomic functions (or things your body does by itself, like heart beating) are disturbed. One way dysautonomia commonly presents with Long COVID is known as POTS, or "postural orthostatic tachycardia syndrome." POTS symptoms often include: headache, "Brain fog" or trouble thinking clearly and chest pain, racing heart, dizziness or feeling like you might faint.

Source: "Dizziness, lightheadedness, racing heart after COVID-19?" longcovidjustice.org

Racing Heart and Heart Inflammation: People infected with the COVID-19 virus may have double the risk for future heart attacks, strokes or premature death from any cause up to three years later – even if they never showed signs of severe illness, according to new research.

Source: "COVID-19 may increase heart attack and stroke risk for years..." heart.org

Severe Energy Crash: Long COVID often arises in otherwise healthy young people, and it can follow even a mild initial infection. The most common, persistent and disabling symptoms of Long COVID are neurological. Some symptoms, such as pain and postexertional malaise (PEM), a kind of "energy crash" that people experience after even light exercise, seem rooted in the body more than the brain.

Source: "Long COVID Now Looks like a Neurological Disease, Helping Doctors to Focus Treatments" scientificamerican.com

Debilitating fatigue: One theory explains why Sars-CoV-2 and other viruses can lead to PEM. Small amounts of virus can persist in parts of the body. Returning to normal activities before the body has fully recovered from its energy debt can cause a crash, during which time the virus can flare up or reactivate dormant viruses and induce further mitochondrial damage.

Source: "Long Fatigue: The exhaustion that lingers after an infection..." bbc.com

Numbness and Nerve Pain: One study found that as many as 56% of COVID-19 patients reported symptoms of peripheral neuropathy post-infection.

Source: "When Nerve Pain and Numbness Are Linked to Long COVID" yalemedicine.org

Migraine headaches: "Most of the time, post-COVID headaches are described as migraine-like headaches," says Dr. Chiang. "The headache can present like a migraine attack." People with post-COVID headache typically experience a throbbing pain on one side of their head. Alongside this pain, some people have sensitivity to light, noise and sometimes to touch or smell.

Source: "Migraine and Post-COVID" americanmigrainefoundation.org

Unquenchable Thirst: "Patients would clinically say, 'I always feel thirsty,' and they think they have diabetes but it's not, it's part of PASC." PASC stands for Post-Acute Sequelae of SARS-CoV-2 Infection and is the term researchers use for long COVID-19.

Source: "Long COVID-19 can make you thirsty" – unmc.edu

Dental Issues: COVID-19 history significantly correlates with severe oral health complications in predominantly Black communities, while vaccination reduced but did not eliminate these issues. The oral cavity serves as a long-term viral reservoir, and periodontal inflammation with increased oral viral presence in COVID-positive patients may increase susceptibility to oral and non-oral viral diseases and identify risk for long COVID.

Source : "Oral Cavity Serves as Long-Term COVID-19 Reservoir with Increased Periodontal and Viral Disease Risk" BioRxiv, Institutionally Funded Pre-Print Server for Biology 2025

Tinnitus/Fluctuating Hearing Loss: New research finds that cells in the ear are susceptible to infection with SARS-CoV-2, causing symptoms that include dizziness, ear ringing, and hearing loss.

Source: "Why COVID-19 Can Affect the Inner Ear..." healthline.com

Heart Palpitations: Some heart problems — like injury to your heart muscle — can show up while you have the COVID-19 infection. Myocardial injury, or injury to your heart muscle, causes cells in your heart muscle to die.

Source: Heart Problems After Covid.. My.ClevelandClinic.org

New onset allergies and sensitivities: People with Long COVID often experience new or worse reactions to foods or other things they could previously eat or encounter without issues...can include sensitivities to foods, fragrances, medications, and other chemicals. Reactions to these can cause a wide variety of debilitating symptoms.

Source: 'Long Covid triggered our MCAS, but doctors didn't believe us' BBC 2023

Gastritis: Not just a respiratory infection, covid can cause symptoms throughout the body. Gastrointestinal symptoms are common in both acute and long covid, with gut issues often persisting long after initial infection.

Source: What do we know about covid-19's effects on the gut? 2024 The BMJ, weekly peer-reviewed medical journal, published by BMJ Group owned by the British Medical Association

Muscle Spasms: "We found that nucleocapsid significantly overlapped with MS-associated proteins, including PLP," the scientists wrote. "Our work suggests that a variety of proteins may be involved in triggering autoimmunity associated with MS [disease development] in certain individuals."

Source: COVID-19 Could Trigger MS Via 'Molecular Mimicry,' Study Shows multiplesclerosisnewstoday.com

Internal Tremors and Vibrations: In some patients, they affect the arms and legs, while others report feeling them throughout their body; the tremors can range from a slight vibration to a feeling of near paralysis and can occur at a frequency of every few hours all the way to a near constant basis. This study helped establish internal tremors as a prolonged and debilitating symptom in some Long COVID patients.

Source: Long COVID Symptoms: Internal Tremors and Vibrations yalemedicine.org

Immune Dysregulation: Individuals with long COVID-19 could develop new onset or worsening of previous underlying multisystemic disorders, ranging from myocardial inflammation, postural orthostatic tachycardia syndrome, abnormal gas exchange, diabetes, pancreatic injury, gut microbiome disturbance, dysautonomia, myalgic encephalitis/chronic fatigue syndrome (ME/CFS), kidney injury, coagulopathy, endothelial dysfunction, stroke, and even infertility, to name a few. In addition, there is also an increased risk of pulmonary embolism, cardiac arrest, heart failure, death, stroke, and new-onset diabetes.

Source: Immunological dysfunction and mast cell activation syndrome in long COVID National Library of Medicine

Frequent Debilitating Pain: With nociplastic pain, some people have what you might call a pain setting turned up in their central nervous system. There's evidence showing that infections, trauma, and stress can be a trigger for nociplastic pain features and related symptoms.

Source: Long COVID-19 is linked to chronic pain...michiganmedicine.org

Other Things People Have Said...

Or just
get a job you'd
enjoy...

Well, why
not just file for
disability?*

Yeah, but
the elderly and
disabled were already
at risk before
COVID, so...

Don't get
a cane you'll
become dependent
on it....

Sick people
were going to die
anyway...

You're young
you will bounce back,
you'll see...

You were
always sickly as
a child so...

OUCH, I don't
think they
realize how they sound
and I am too tired to
correct them



Here's a QR code for a self-advocacy guide for anyone who is homebound or bedbound in the US. Including guides on financial survival and applying for disability.

***Below** are some suggested readings to explain why federal disability programs are not an accessible, easy solution and do not meet survival needs of disabled people...**1.** Nearly 30,000 Americans died waiting for Social Security benefit decision - Newsweek, Sept. 17, 2024 **2.** The requirements of a disabilities benefits program end up hurting those who need it - NPR, Sept. 2024 **3.** Even as a former executive assistant, managing care for Long COVID is a full-time job - The Sick Times, Aug. 2024 **4.** First They Got Long Covid. Then, It Made Them Homeless - Rolling Stone, Feb. 2022 **5.** Living nightmare: Long COVID upends lives and finances - context.news, Feb. 2025



I'd also like to
amplify the work and
voice of birth/postpartum
advocate 4 Black people,
Shishi Rose



Pay Shishi Rose
for their work



Shishi Rose's
GOFUNDME



"Pandemic apathy is a tool of white
supremacy that aids ethnic cleansing, genocides,
racism, and lack of climate emergency awareness.

When you take **pandemic precautions** you are
telling the world that marginalized lives all over it
deserve to be liberated, safeguarded, cared for **AND**
at the center of focus, not pushed out of the bounds of sight."

- Shishi Rose, Pandemic Apathy Allows Genocide, October **2023**



@shishi.rose

ABOUT US

Peace Waters



Peace (they, she) is a Brooklyn-raised, interdisciplinary artist grounded in a Black theater tradition that explores the roles of witness and testimony in collective and intergenerational healing. Their current modalities of focus weave movement, assemblage, film, and poetry.

They earned their BA in Theater from Pomona College and their MA in Performing Arts from Stanford University.

As a Youth Organizer at Girls for Gender Equity, they were featured in the documentary, *Anita Hill: Speaking Truth to Power*, that led to participation on United Nations Status of Women Panel. Peace was an Emerge Fellow 2019 with Hemispheric Institute, where they presented their original work at Abrons Arts Center. They also presented original work at Jack Theater and the Apollo. They are the recipient of the Peace & Social Change Fellowship with Columbia University, where they supervised research on the healing capacity of theater for survivors of sexual assault.

Peace is a 2025 Emerge Fellow with the Paul Longmore Institute on Disability. Reach out to Peace at **Substack** at '[peacewaters](#)'



@peace.waters



Dimitrea Tokunbo

Dimitrea (she, her) is a cartoonist, poet, and teacher. She is honored to collaborate on this project. She made this booklet for people to recognize the seriousness of this ongoing global health crisis and give language, resources and community to folks navigating Long COVID.

She earned her MFA in Comics at California College of the Arts, her BS in Art at SUNY Empire State College, and did some illustration coursework at Moore College of Art & Design.

Before relocating to California, she was deeply embedded in her Brooklyn community and values her time working with Harriet's Apothecary, Center for Anti-Violence Education, Park Slope Food Coop and Brooklyn's Children's Museum. She also had some children's books published with Tilbury House, Boyds Mills Press, Scholastic Press and Cartwheel Books.

She is currently researching and drawing a graphic hybrid memoir about her journey as a Black woman bookmaker raised in America with the biography of the renowned historical figure, Phillis Wheatley. Reach out to Dimitrea at [dimitrea.com](#)



@comix.dimitrea

One more thing

There are many people doing great work

Though we don't mention all of them in this zine, below are more folks helping to keep our communities safe and QR codes. How can you tap in?



Sista Creatives Rising

a 100% virtual project (not a non-profit or LLC!) and concept founded by Black, invisibly disabled mother-daughter duo Claire Jones (age 62) and Amaranthia Sepia (age 25).



"This is our shared responsibility, to fight oppression, to fight injustice, to participate and to show up"

— Tiezst "Tie" Taylor



Tiezst 'Tie' Taylor is a Disabled Black femme who is non-binary trans. They are a radical educator, artist-activist, poet, and storyteller. If you'd like to learn more about mutual aid, check out their video titled, "Mutual Aid, Social Media & Our Shared Responsibility in Social Justice."



Tie's Video



Tie's Fund

Materially support this work here



Black Indigenous Racialized Covid Health

(BIRCH) a project dedicated to distributing graphics about the impacts of a covid infection on mind and body.



"...it took me becoming my best advocate for myself for people to start taking my symptoms seriously."

— Chimère L. Sweeney



Chimère L. Sweeney is a retired educator and Long Covid activist, writer, and lecturer. After facing racism and discrimination while obtaining medical treatment for Long Covid, her clear mission is to empower Black patients to tell their stories about the physical, mental, and financial effects of Long Covid. **Join Chimère** for a 4 - Part Series that supports Black and Latino Americans living with Long Covid in advocating for themselves and others. Also consider becoming a paid subscriber of Chimère's substack, *The Blackest Side of Long Covid*.

4 - Part Series

Substack



"...The Medical Industrial Complex, in nurse's stations, doctor's offices, hospitals...the way Black folks seeking care are treated continues to be unacceptable."

- **Rise,**

Founder of Riotous Roots

"...Each book or story by a disabled person holds a piece of a spell. Eventually when enough pieces come together and fit, there will be a collective harmonic conjuring...and the world will finally see us as we are"

- **Alice Wong,**

*Director & Founder
of @Disability_Visability Project*



The Sick Times posted about an exchange btw Shawn Ross and Solange Knowles, a Grammy award-winning musician, discussing their severe health challenges...

