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Chronic Illness and Disability Narratives

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## Chronic Illness and Disability Narratives

*By Julia Métraux*

**Abstract:** For my master's project at UC Berkeley Graduate School of Journalism, I have reported two features and one profile that highlights the varied experiences of people living with chronic illnesses and disabilities. As someone who believes disability reporting encompasses different subject areas, I chose to report stories that focus on the intersection of chronic illness and medicine, chronic illness and climate change, and chronic illness and labor. As with the disability slogan "Nothing About Us Without Us," it was essential in my reporting to include chronically ill and disabled people talking about their lived experiences. Reflecting on my interviewing experiences, my chronically ill and disabled sources all expressed to me that they appreciated being interviewed by someone else who is also disabled.

### Articles

Title: Some patients say a commonly prescribed steroid triggered mania and suicidal ideation. I should know — it happened to me.

**Word count:** ≈2200

Publication: Insider

Title: With Climate Change, Comes More Potential Complications for People with Lupus

**Word count:** ≈1800

Publication: Richmond Pulse

Title: A former Amazon employee is trying to manage his lupus nephritis without insurance. He doesn't miss his long shifts.

**Word count:** ≈750

Publication: Insider

## **Article 1**

### **Interview Sources**

Medical Expert Source: Psychiatrist [Dr. Paul S. Nestadt](#)

Medical Expert Source: Psychiatrist [Dr. Lorrin Koran](#)

Patient Source: Samantha Reid

Patient Source: Rylie Cooper

Patient Source: Sararosa Davies

Patient Source: Gemma Cooper-Novack

Medical Expert Source: Rheumatologist [Dr. Kristen Young](#)

Medical Expert Source: Rheumatologist [Dr. Alfred Kim](#)

### **Sample of Academic/Secondary Sources**

[US Food and Drug Administration: All Approvals and Tentative Approvals February 1955](#)

[Corticosteroid-induced adverse psychiatric effects: incidence, diagnosis and management](#)

[Psychiatric complications of treatment with corticosteroids: Review with case report](#)

[Corticosteroid-induced neuropsychiatric disorders: review and contrast with neuropsychiatric lupus](#)

[Steroid dementia: an overlooked diagnosis?](#)

## **Article 2**

### **Interview Sources**

Patient Source: Julia Irzyk

Medical Expert Source: Rheumatologist [Dr. Tom Bush](#)

Medical Expert + Patient Source: Psychologist [Monica Blied](#)

Epidemiology Expert Source: [Rupa Basu](#)

### **Sample of Academic/Secondary Sources**

[Prevalence of Adult Systemic Lupus Erythematosus in California and Pennsylvania in 2000: Estimates Using Hospitalization Data](#)

[Potential adverse health consequences of climate change related to rheumatic diseases](#)

[Ozone depletion, ultraviolet radiation, climate change and prospects for a sustainable future](#)

[The Effects of Temperature and Use of Air Conditioning on Hospitalizations](#)

## **Article 3**

*\*For Insider profiles on its health section, there is usually just one profile source*

### **Interview Sources**

Profile Source: Jordan Flowers

Amazon Source: Eileen Hards

**Sample of Academic/Secondary Sources**

[Lupus and Kidney Disease \(Lupus Nephritis\)](#)

[Disability Rights Are Workers' Rights](#)

# Some patients say a commonly prescribed steroid triggered mania and suicidal ideation. I should know — it happened to me.

[insider.com/prednisone-mental-health-danger-suicide-crisis-depression-mania-2022-6](https://www.insider.com/prednisone-mental-health-danger-suicide-crisis-depression-mania-2022-6)

Julia Métraux Jul 30, 2022, 5:54 AM



- Prednisone, a steroid, is prescribed to millions of Americans, often to treat chronic inflammation.
- While mood swings are a known side effect, some patients say they experienced much worse.
- They say prednisone made them manic and suicidal. Some had to check into the ER.

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I was convinced everyone would be better off without me.

It was the spring of 2018, and a few days earlier I had been admitted to the emergency room for a flare-up of vasculitis, a blood-vessel-inflammation disease that causes severe pain, numbness, and breathing issues. Struggling to breathe, I was prescribed 60 milligrams of prednisone, a corticosteroid that would reduce the inflammation.

The drug worked, but within days I fell into such a severe depression that I returned to the same emergency room — because it was the only way I knew I would not be at risk of harming myself. I was ultimately hospitalized for a week to deal with the psychiatric symptoms, which were unrelated to my vasculitis.

My memory of this period is unclear, due to the sudden insomnia the prednisone caused. Before my diagnosis in January 2018, my vasculitis had been dismissed as anxiety, and the resulting medical trauma made it hard to talk to my rheumatologist and pain psychologist about how I was feeling.

As I tapered off the prednisone, my depressive symptoms decreased. At 10 mg of the drug, I began to feel like myself again.

Years later, I now believe that the high dose of prednisone was most likely the cause of my depression and suicidal ideation; the intrusive thoughts that slipped away as I tapered off the drug have never returned. My rheumatologists have agreed, and they now keep me off high doses of prednisone to protect my mental health.

Since then, I've learned that my case is not unique. I've spoken with four other patients who experienced sudden, severe psychiatric side effects after taking high doses of prednisone.

While prednisone is known to have mental-health side effects, these patients — and some doctors — say they can be more serious than most doctors acknowledge, especially for such a commonly prescribed drug. These aren't just "mood swings": They're serious crises leading to weeks of insomnia, manic episodes, suicidality, and mental-illness-related hospitalizations.

Dr. Paul S. Nestadt, a psychiatrist and suicide epidemiologist at Johns Hopkins, said ending up in the psychiatric ward after being on high-dose prednisone was "not an uncommon experience."

"The problem is common enough that when a patient is admitted to my unit with psychiatric symptoms that they have not experienced before, one of the first things I do is check the medication list for prednisone and other common culprits," he said.

## **Prednisone has been prescribed for decades to manage autoimmune diseases and inflammatory bowel disease**

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Prednisone is often used to manage flare-ups for people who live with chronic inflammatory conditions like inflammatory bowel disease, lupus, and rheumatoid arthritis. The drug works by lowering the activity of the immune system, reducing inflammation and swelling.

While prednisone is commonly referred to as a steroid, it's different from anabolic steroids, which raise testosterone levels in the body to promote increased muscle mass and improve athletic performance.

Prednisone, which has been in use in the US since 1955, is a commonly prescribed drug, with an estimated 11 million patients receiving it in 2019. That number has probably gone up during the coronavirus pandemic, as the drug is used to manage some COVID-19 complications.

While prednisone can provide significant relief from inflammation, it comes with notable side effects, including high blood pressure, fluid retention, and weight gain, especially in the face.

The drug isn't contraindicated for people with diagnosed mental illness, as research hasn't found clear evidence that they're at a higher risk of developing profound psychiatric symptoms than those without a diagnosis. Doctors tell patients they may feel "a little out of it," as mine told me, or experience some mood swings.

But according to Dr. Lorrin Koran, a researcher who has studied the topic, mental-health side effects of prednisone actually occur at "a troubling frequency." Koran, an emeritus professor of psychiatry and behavioral sciences at Stanford University, coauthored a 2011 paper that concluded psychiatric side effects of corticosteroids were "not rare."

For example, patients have reported experiencing euphoric mania, "like spending too much money or driving fast or engaging in behaviors that are not typical of them," Koran said. Alternatively, some said they'd experienced depression, or a combination of mania and depression.

Koran said it would be inaccurate for any doctor to dismiss the mental-health risks of prednisone as "low." He cited a 2013 review article in Rheumatology International that draws on a half-century of research, arguing that symptoms could be severe.

"Physicians are not always as open to considering new possibilities or unusual possibilities," Koran said. "Some patients I talked to reported they had difficulty convincing their treating physicians that their new symptoms could be related to high-dose prednisone steroid."

## **Patients say prednisone caused manic episodes, nonstop crying, and trips to the psychiatric ER**

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Samantha Reid, a director of digital engagement at a policy institute in Washington, DC, believes an 80 mg dose of prednisone for her Crohn's disease caused her to experience mania for the first time in 2016. She had previously experienced anxiety and depression, she said, but this was new.

Reid said the only side effect her doctor had warned her about was facial swelling, so she wasn't prepared for the insomnia prednisone caused, which intensified her mania. "I was sleeping probably like four hours a night, and then just like getting up and like boom, boom, boom through the day," she said.

When her dosage was decreased, the mania began to dissipate, but she continued to have depressive episodes, not speaking with others for weeks at a time. While Reid's doctor tapered her off the higher dose for reasons relating to her physical health, she noticed that once she stopped taking prednisone, the mania went away.

In conversations with Insider, some patients who experienced mental-health crises while on prednisone said their doctors warned them they "may feel different" while on the drug. But none were warned by physicians about the possibility of adverse side effects like mania and paranoia. This was despite the fact that several already had a diagnosed mental illness.

That includes Rylie Cooper, a digital director outside Philadelphia who has borderline personality disorder. When they were prescribed 50 mg of prednisone for their Crohn's disease in 2021, they weren't told about the possibility they might experience more severe mental-illness symptoms.

Immediately after starting prednisone, Cooper had a manic episode and began experiencing what they call "brain zoomies." Insomnia kept them mentally exhausted, but their mania and paranoia pushed their mind to overthink nonstop. They felt increasingly unable to manage their borderline personality disorder and ultimately ruined a close personal relationship with constant, impulsive attempts at getting attention, including sending selfies, paragraphs-long texts and frequent calls.

Cooper has since weaned off of prednisone; they said they never told their doctor about their symptoms because they didn't think they would be believed.

When she was prescribed prednisone for her chronic hives in 2018, Sararosa Davies, a podcast producer who has mast cell activation syndrome, expressed concerns about taking the drug. Davies has bipolar disorder, and her mother, who is a nurse with specialized psychiatric training, was concerned that it might worsen her symptoms.

The doctor brushed off Davies' concerns, she said, and the results were disastrous. She was admitted to a psychiatric emergency room for a night. Afterward, she said, she experienced her worst depressive episode to date and couldn't get out of bed.

Nestadt, the Johns Hopkins psychiatrist, said it wasn't atypical for doctors to ignore a patient's existing mental illness when deciding whether to prescribe prednisone. "I have seen patients with psych comorbidities given steroids without documentation of them being told the risks involved," he said.



Even those without comorbidities can be affected. Gemma Cooper-Novack, who works in academia in New York state, had no history of mental illness when she was given prednisone for the first time in 2009, after she was found to have ulcerative colitis.

"Prednisone was just presented to me as the next logical line of treatment," she said, adding that her doctor said nothing about the possibility of mental-health side effects.

Cooper-Novack soon began to experience insomnia and sudden, out-of-control bouts of crying. She kept up with her master's program despite the challenges, feeling trapped on a constant, draining mood roller coaster.

At the time, Cooper-Novack attributed her severe mood disruptions to the emotional toll of adjusting to life with a chronic illness, but she now believes the drug played a role. As soon as she weaned off prednisone, she said, the side effects subsided.

During her time on prednisone, "either it knocked me out fully, or I was awake at 2 in the morning, wide awake, and couldn't do anything about it," Cooper-Novack said. "The impact on the sleep patterns exacerbated whatever it was doing in the first place."

## **Some diseases require higher doses of prednisone, which are linked to higher psychiatric risks**

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Prednisone doses can vary based on a patient's health condition. According to the [American College of Rheumatology](#), people with rheumatoid arthritis are often prescribed 5 to 10 mg of prednisone, whereas people with lupus and vasculitis can receive doses 16 times as high, at 60 to 80 mg.

[Studies have found](#) that the higher the dose of prednisone, the [higher the chance](#) that those in the studies would experience adverse psychiatric side effects. Some medical groups and governmental agencies, including [the UK's National Health Service](#), are investigating whether doctors are prescribing corticosteroids too often or at higher doses than patients need.

[Dr. Kristen Young](#), a rheumatologist in Arizona, said she'd seen both patients with preexisting mental illness and those without it experience adverse psychiatric side effects on doses as low as 10 mg. In some older patients who take prednisone, Young said, she's diagnosed "[steroid dementia](#)," most likely abetted by insomnia. It often reverses when they go off the drug.

But fighting for a lower dose of prednisone, or for a new medication, can be exhausting for people who often have already had to spend years fighting for a diagnosis — or for worsening symptoms to be treated. Young said that's common in the world of chronic inflammatory disorders.

"Every person getting to a diagnosis where they end up on high-dose steroids usually has been through it and been through the mill," Young said.

## **Alternatives to prednisone exist, but they're limited and disease-specific**

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Even though prednisone is more than six decades old, alternative drugs for people in active flare-ups of chronic health conditions are only slowly emerging. Most are disease-specific.

The past five years have seen some major advancements, including the approval of the vasculitis drug avacopan, and research into alternatives to prednisone for Duchenne muscular dystrophy and severe asthma.

But with the journey from drug discovery to pharmacy shelves now taking an average of 10 years in the US, it's a roll of the dice as to which patients will receive alternative options first.

Getting patients on less-risky drugs also requires diagnosing their conditions more quickly in the first place, said Dr. Alfred Kim, a rheumatologist at Washington University in St. Louis who specializes in treating patients with lupus and vasculitis.

By diagnosing and treating patients early in their disease course, doctors can reduce their chances of experiencing the severe, uncontrolled bouts of inflammation that require high-dose prednisone to treat. "There's pressure amongst lupus researchers and vasculitis researchers to be able to figure that out, so that a diagnosis is not 5 1/2 years, but more like five days," Kim said.

## **Doctors and patients are seeking more attention to mental health**

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Getting doctors to acknowledge that prednisone might affect patients' mental health can be difficult, especially for marginalized groups who are already used to having their chronic illnesses dismissed as manifestations of anxiety and depression.

Kim said it was crucial that doctors take mental health into consideration when evaluating a patient's progress on prednisone. He said side effects that might seem minor on paper, like mood swings, could still affect patients' lives.

"Part of that process is going to be a transparent discussion about risks and benefits," Kim said. "It's well beyond the major risk factors; it is also talking about the less-frequent ones. And even the most frequent ones can also be severe."

Young says patients who experience psychiatric side effects from the drug should keep taking it and contact their prescribing physician immediately. Suddenly stopping prednisone without medical supervision can cause severe, sometimes life-threatening side effects, according to the [American College of Rheumatology](#).

In scenarios in which prednisone is the only option to battle a flare-up, many of the doctors and patients interviewed by Insider say the drug should come with mental-health treatment and counseling.

For those who've already had mental illness linked to prednisone, Young advised bringing a psychiatrist onto the person's care team to prescribe antipsychotic or antianxiety medication if needed.

Kim and Young agree that any patient who thinks their doctor is dismissing their health concerns or symptoms should seek a second opinion.

"If you don't have somebody that you really, really trust taking care of you," Young said, "it's probably time to move on to another person."

# 09 Mar With Climate Change, Comes More Potential Complications for People with Lupus

[richmondpulse.org/2023/03/09/with-climate-change-comes-more-potential-complications-for-people-with-lupus](https://richmondpulse.org/2023/03/09/with-climate-change-comes-more-potential-complications-for-people-with-lupus)

March 9, 2023



*(Photo by Engin Aykurt on Unsplash)*

By Julia Métraux

With the clock approaching midnight, Julia Irzyk could not fall asleep. She was playing solitaire, with her feet up on her La-Z-Boy sofa in her home in the Sherman Oaks area of Los Angeles. She was not just experiencing insomnia thinking about the state of the world: Her blood pressure rose to 195 over 110, well above the norm for most adults of less than 120 over less than 80, according to the [National Institute of Aging](#).

That meant she was experiencing a hypertensive crisis, likely linked to her autoimmune disorder lupus. Emotional stress can affect blood pressure, so staying calm was important, yet Irzyk was failing miserably. During this episode in August 2022, her husband — her caregiver — was over 2,000 miles away on a business trip, in Chicago. Her dark gray cat, Disney, seemed to sense something was wrong but could not exactly help her receive emergency healthcare.

*What would happen next?* Irzyk did not know. She took a “crap ton of medications,” as she describes it, including hydroxychloroquine and adalimumab injections to manage her symptoms. Still, these drugs couldn’t shield her against the effects of a heat wave. *Did she*

*need to break her rule of not going to the emergency room during COVID-19? How long would this flare last? Would she have to go back on prednisone?*

With just her cat keeping her company, she needed medical advice. The heat, to Irzyk, felt “like a 40-pound backpack” she was “carrying around all the time.” She sent a message to her rheumatologist; she did not hear back. The doctor was likely asleep. Irzyk also wanted to be asleep. She was exhausted from running a talent agency during the day. But lupus health complications do not run on a convenient schedule. She spoke over the phone with her father, Mark Rothstein, the director at the University of Louisville’s Institute for Bioethics, Health Policy and Law. He told her to go to the emergency room if her 195 systolic blood pressure jumped to 200.

Irzyk, who is 45 and has lived with chronic pain for most of her life, suspects rising heat in Southern California worsens her lupus symptoms. Every summer, Irzyk knows that her body will have a flare-up of debilitating chronic illness symptoms, and she is terrified about how longer and hotter heat waves will affect her health. It took her close to two decades from her onset of lupus symptoms to get a diagnosis. Now, she had to figure out how to navigate that diagnosis with the ever-changing threats of climate change.

That August night, she avoided the emergency room and endured her symptoms until the flare passed. But as someone who has barely left her house during the COVID-19 pandemic, except to go into her office with a good mask, the heat was an unneeded pressure.

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Around one in 1,000 adults, have been diagnosed with lupus in California. Heat waves and wildfires, worsened by climate change, exacerbate cardiovascular and respiratory issues and make managing autoimmune disorders and other chronic illnesses more difficult. And there may be many more undiagnosed, in part due to the ability of infectious diseases like COVID-19 to trigger chronic illnesses.

There are three main types of lupus, all diagnosed through a combination of blood and urine tests. The most common form is systemic lupus erythematosus. Even without heat waves, lung problems, heart problems, kidney problems, seizures, chronic pain and exhaustion can be common complications in people who have SLE. When people with lupus have severe systemic involvement, which includes high levels of inflammation, they can also experience kidney failure.

Dr. Tom Bush, the author of an August 2021 paper on climate change and rheumatic diseases published in the Journal of Climate Change and Health and a rheumatologist at Santa Clara Valley Medical Center in San Jose, says there needs to be more research on autoimmune diseases and climate change. Facing heat waves and wildfires, he said, “at the same time that you have an immune system you’re fighting,” while also potentially being on medications that

increase heat sensitivity, “could be a dangerous situation.” Medications that can make people’s bodies more heat-sensitive, which can include antidepressants and antihistamines, aren’t uncommon.

A small May 2013 study published in the Journal of the American Academy of Dermatology found that of 91 study participants with lupus, 81% experienced photosensitivity symptoms, meaning sensitivity to ultraviolet radiation. Monica Blied, a psychologist who lives with lupus and who serves on the medical advisory board of Lupus LA, tries to stay inside when the sun is at full strength. Photosensitivity is commonly associated with lupus. Climate change is also starting to affect UV radiation, and, according to researchers, “these effects will become more pronounced in the future.”

As a result, people with lupus who experience photosensitivity face a degree of isolation. “This is what the general population got to experience with the beginning of COVID, when we had to quarantine,” said Blied, who is based in Claremont, near Los Angeles, and herself has to sit out of activities that can trigger photosensitivity. To cope with the mental health effects of isolation and other debilitating lupus symptoms, she recommends that people reach out to lupus support groups and mental health providers.

Air conditioning in one’s home can decrease the risk of acute health episodes. A November 2010 study published in the American Journal of Epidemiology found that, when adjusting for socioeconomic factors, people who used AC in California during heat waves were less likely to be admitted to the hospital between 1999 and 2005 with issues like renal failure and acute cardiovascular issues.

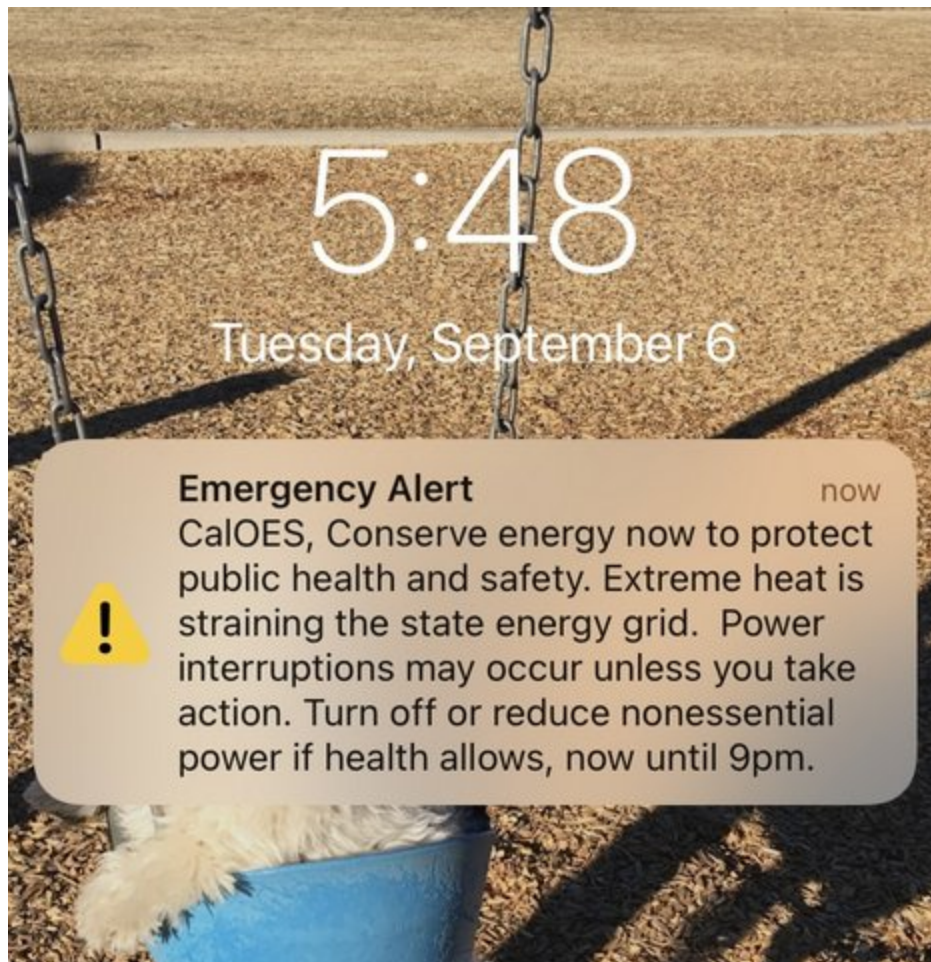
Cooling centers, especially during COVID-19, aren’t a great solution. Contracting this infectious disease, especially multiple times, puts lupus patients at risk of developing more serious complications. Many have also been putting off care — Irzyk, for example, said she’s “never been so desperate to go to the dentist.” Lupus patients faced shortages of hydroxychloroquine at the beginning of the pandemic due to this medication being promoted as possible treatment for COVID-19. The Centers for Disease Control and Prevention did walk back its guidance for this drug to be potentially used to treat COVID-19 in April 2020.

Rupa Basu, a heat epidemiologist at California’s Office of Environmental Health Hazard Assessment and one of the authors of the aforementioned study also notes, “Another thing that comes up is people don’t know that they should be using” AC as the heat rises. Or they cannot afford the cost of their energy bill. Grant and loan programs, such as the Low Income Home Energy Assistance Program, can be difficult to navigate.

When the temperature rises over 100 degrees Fahrenheit, anyone could experience adverse health events. Basu and other scientists, clinicians and public health services need to ensure people are aware of potential adverse health effects.

“It doesn’t really help if we’re just keeping it amongst ourselves and just keep going on with the research,” she said.

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*During last September’s heat wave L.A. resident Julia Irzyk, who has lupus, said she felt “zero guilt about running the air conditioning, because the alternative is that I end up in the hospital, and I don’t see how that helps anybody in the long term.”*

During the early September record-breaking heat wave in California, people across the state received a text urging them to conserve power, asking residents to “turn off or reduce nonessential power if health allows.” In Los Angeles, where the temperature reached triple digits even late into the day, Irzyk kept her AC on and her fans faced towards her, so she could at least minimize her dry-heaving.

“It’s no good if I’m dead,” Irzyk said. She felt “zero guilt about running the air conditioning, because the alternative is that I end up in the hospital, and I don’t see how that helps anybody in the long term.”

Irzyk's plan, if her power got shut off or her AC failed, was to go to a hotel. This would be expensive and a hassle for her. And she already had to do it before.

Prior to the COVID-19 pandemic, when her husband was shooting a commercial in Brazil, the AC went out. Trying to stay upright with a cane, she then had to "wrangle a cat into a carrier."

Back up the California coast, not as many people have AC in their homes, no matter whether they could afford it. Basu, the epidemiologist who studies heat herself, does not have AC in her family's home. "There are usually a few days throughout the year now we're thinking, 'Oh, maybe we should just get it,'" she said.

Some time later, after the brutal heat wave, the truth is, no one knows how many people died due to complications related to the heat wave. As the Los Angeles Times reports, this falls in the pattern of a state that is already hit by acute weather events but struggles to keep track of heat-related illnesses and deaths.

A lot more in-depth research is needed on how autoimmune disorders like lupus respond to rising heat temperatures. As it stands, communities of people with chronic illnesses do their best to check in with each other. On Twitter, many share their journeys, tips, frustrations and hopes using hashtags such as #NEISVoid (the acronym stands for No End In Sight), the political #CripTheVote, and the general #DisabilityTwitter. For instance: It's important to keep some medication around 70 degrees. Some people also send encouraging messages to those applying for programs like disability benefits, telling them it's not unusual to get rejected the first time, for instance.

The lack of chronically ill and disabled people involved in climate change planning is a major problem. The U.S. Environmental Protection Agency notes "climate change effects on people with disabilities have not been studied as much as other vulnerable populations." But this population is especially vulnerable. People face a higher risk of health complications and more difficulty moving when climate change forces displacement. A lack of recognition of the challenges disabled people face is part of the issue. As noted by disability activists at the 2022 United Nations Climate Change Conference, the U.N. still does not recognize the disability community as a group vulnerable to the effects of climate change. How much research is needed before people in power act to protect those who are already struggling due to acute weather events?

Some nondisabled environmental activists say that everyone has a responsibility to limit power, including AC and heating. But this leaves out people who do not have a choice. Irzyk relies on community support to help her take care of her needs. This includes a parking attendant near her office who makes sure she is able to park in an area protected from the sun on hot days.

Public health officials need to do their part as well. Increased attention and research is vital, which groups such as Lupus LA and other patient advocacy organizations push for.



“This is helping to keep them alive, so they can fight another day with their chronic illness,”  
Blid said.

# A former Amazon employee is trying to manage his lupus nephritis without insurance. He doesn't miss his long shifts.

[insider.com/how-amazon-labor-union-co-founder-manages-his-lupus-nephritis-2023-2](https://www.insider.com/how-amazon-labor-union-co-founder-manages-his-lupus-nephritis-2023-2)

Julia Métraux Feb 21, 2023, 2:45 AM



- Jordan Flowers was terminated while pushing for accommodations from his employer, Amazon.
- Flowers lives with lupus nephritis, a type of lupus affecting his kidneys.
- He's spent his time since his termination pushing for the certification of the Amazon Labor Union.

and [Privacy Policy](#).

As a cofounder of the [Amazon Labor Union](#) and its active predecessor, the Congress of Essential Workers, Jordan Flowers has been fighting for workers' rights at the retail giant. At the same time, Flowers, 24, is trying to control his body as it attacks itself — he has lupus nephritis. He was diagnosed with lupus when he was 12 years old.

Lupus is an autoimmune disorder, and lupus nephritis, specifically, "is a type of kidney disease caused by systemic lupus," the [National Institute of Diabetes and Digestive and Kidney Diseases](#) says on its website.

On a day-to-day basis, Flowers experiences fatigue, joint pain, and headaches. A normal week for Flowers includes organizing outside, taking calls in the union's office, filing complaints for Amazon workers, and even teaching some classes on organizing tactics.

"I do get a lot of pains being on my feet, but at the same time — organizing, it's what I do," he told Insider.

Still, the physical aspects of organizing are easier on his health than when he worked at Amazon.

Flowers was terminated from the company on September 27. Amazon characterized his departure as voluntary, which Flowers disputes. In a statement, Eileen Hards, an Amazon spokesperson, said Flowers was "terminated" because he "failed to show up to work and did not provide the required documentation for his absence," a "type of situation is considered a voluntary resignation."

While some parts of organizing are challenging for Flowers, as someone who is chronically ill, he does not miss some aspects of his 10- to 12-hour shifts at Amazon, where he would be on his feet most of the time.

"We make a joke about it that we walk like penguins because that's how your feet hurt," Flowers said.

## **Flowers wants more people like him to be open about their health conditions**

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People with disabilities and chronic illnesses have been a part of workers' rights causes throughout history.

Flowers finds it essential for people like him to be open about their health conditions and struggles, and workers with disabilities and chronic illnesses may need to win certain measures from their employers that workers without disabilities don't, such as comprehensive healthcare benefits and workplace accommodations. Flowers said he was fired as he was pushing for workplace accommodations, which he said he did not receive.

"People think that because we're ill, we're not going to fight back," Flowers said. "We need to be accommodated, and not even just better wages but better health benefits, too."

Flowers recognizes that it can be scary for people relying on a company's health insurance to stand up to it and demand better.

He used to see a doctor once a month to help manage his lupus. But Flowers has not seen a doctor since August, as his insurance was terminated a few days before his then upcoming doctor's appointment in September. Having regular medical care is important for Flowers,

who needs a kidney transplant.

"I'm not even making an income, nor do I have insurance to help me to duck some of that," Flowers said, adding that he did not have the money to pay for kidney-transplant surgery if he were matched right now.

Flowers is spending his time helping organize for current Amazon workers, including a recent victory where a judge ruled Amazon engaged in anti-union tactics.

The work of the Amazon Labor Union and workers' health have been intertwined since the union's founding. In March 2020, Chris Smalls, a cofounder of the Amazon Labor Union and Flowers' former coworker at Amazon, led a strike at a Staten Island, New York, facility over what he said was a lack of COVID-19 safety precautions. This led to Smalls being fired. But the COVID-19 pandemic has been a catalyst for people with chronic illnesses to speak more about the challenges they face with their health.

"People with medical issues need to really be speaking up, especially during COVID," Flowers, who was recently sick for about a week after he got a cold, said.

Still, Flowers is doing what he can to take care of his lupus and associated symptoms, which have recently included some issues with his eyesight. He's taking a long list of medications, including hydroxychloroquine, lisinopril, nifedipine, labetalol, and sodium bicarbonate.

"It's a balance of also drinking water every day and not too much sugar intake to keep the kidneys flushed and clean," he said.

The Amazon Labor Union has demanding that Flowers be reinstated by his former employer. In the meantime, he's doing what he can to support current Amazon employees — and trying to take steps to manage his health.