SICK

ISSUE 4

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Our relationships are

— *Ashna Ali*

crucial to our survival

EDITOR'S *letter*

Recently, for the first time in my life, I began seeing a doctor who specialises in chronic pain that my insurance fully covers. It has taken 13 years of illness for this to happen. To experience this type of care after so many years of seeing dismissive, disbelieving, and cruel doctors has left me unable to fully digest the truth of what this doctor is offering me. Instead, my guard went up, and I began to question if a doctor could really be listening to me this intently; if she really cared at all, or had just come across where all the desperate patients are. Is she specifically helping women with unexplained chronic pain and fatigue because she cares, or because it means she will always have a year-long waiting list and no shortage of patients?

It feels brutal to wonder these things, but it's only something I ask due to experience. Multiple doctors in my past have put me on medicine and never followed up with me after the payments were made. I've become used to managing things on my own; to suffering on my own. Now, this doctor is showing me a new way. I'm on week three of an off-label medication that is supposed to suppress my pain receptors. But, in a way, it feels like being listened to in a medical setting might offer more healing for me than medicine that might work, might not, might work for only a few months, or just cause extraordinarily wild dreams.

When I logged on to my doctor's online portal, I saw notes from my visits that were, for the first time, reflective of what I had said, and not twisted by the doctor's opinions of me. I was shocked to see her write that I had ACEs, which I had to google to find out that it meant Adverse Childhood Experiences. The CDC defines ACEs as 'potentially traumatic events that occur in childhood' that are 'linked to chronic health problems, mental illness, and substance abuse problems . . .'. Below these notes was an accurate account of my experience of illness as a child, and the neglect I experienced with countless doctors in the years that followed. I've been thinking a lot about how much less of a burden I feel when I don't have to prove or convince anyone of the severity of my illness. When I am believed and accepted as I am, there is so much more space left for me to process, grieve, and care for myself. Can you imagine how different our sick lives would be if we had been cared for from the first time we sought it? How much of our time and energy would we still have if we did not have to spend it all on thoughtless doctors, family and friends who don't understand, employers who discriminate against us, and navigating an ableist society?

The truth is that sick and disabled people have been robbed of so much that we cannot get back. As much as we can, and should, imagine what a better world may look like, it hurts to realise how much damage has been done that simply didn't have to be. I wonder how we can continue to carve out spaces for us to exist completely in, and if something as simple as a print magazine can be a step in that direction.

The validation I felt from my new doctor was both beautiful and painful. And while many of the words and experiences in this issue may fill you with anger and sadness, I hope it can also take the form of solidarity, of validation, of being seen and heard and held. In *The Cancer Journals*, Audre Lorde writes " . . . that visibility which makes us most vulnerable is that which also is the source of our greatest strength. Because the machine will try to grind you into dust anyway, whether or not we speak." I hope SICK can be a piece in that visibility — a protest that we are here, and we are speaking to be heard.

This issue is full of urgent questions, important stories, and compelling visuals. Grace Vedock argues against illness as metaphor in a moving personal essay; Kyla Jamieson writes eloquently on intimacy with pain and its distance from language; Emily Chudy asks why outdated methods are being used to determine patients' treatment, and much more, alongside new poetry, artwork, and interviews.

I hope you can find a quiet moment to sit with this work, whether it be under the warm sun, near a babbling stream, on the train next to strangers, or, of course, in bed, wrapped up with words.

With love,
Olivia Spring
July 2022

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Against Migraine as Metaphor

by Grace Vedock

A recent graduate of Middlebury College, Grace is interested in the intersections of disability, advocacy, gender, and law. She plans to attend law school in the fall. On migraine-free days, Grace enjoys hiking with her partner and playing with their two cats.

During the first week of my freshman year of college, I was excited to meet my roommate and the other girls in our hall. I recall popping my head into most rooms on our dorm floor, checking to see whether my hall-mates had opted to loft the bed and where they put the school-issued desk. It was an intimate ritual, seeing how everyone had personalised the small areas which, for the year, we called our own.

I remember welcoming a girl from the end of the hall into my room — I was proud of my lofted bed, which freed up space for my desk and a shag rug below. Rather than commenting on how I'd organised and decorated the space, she stared at my dresser, on top of which I kept a cheap AM/PM pill organiser, and asked, "Why do you have so many pills?" I was mortified.

The shame of needing multiple prescriptions has since subsided. (Incidentally, the number of pills I take on a daily basis has practically doubled.) In its place is a new kind of shame: the embarrassment of requiring help.

Chronic migraine has left me unable to complete most daily tasks by myself. On many days, I cannot rouse myself from bed without sending waves of pain through my neck, shoulders, and arm. I have become accustomed to reading, cooking, and answering emails with one eye closed. Living with chronic migraine has, for me, meant accepting a diminished existence. On my best days, I am able to overcome my internalised ableism. On rare migraine-free days, I allow myself only the slightest indulgence in the thought that maybe I will never have a migraine again.

Inevitably, I am wrong. I do myself no favours by denying the reality of my disability. In fact, I am enraged when others do so. I can count on two hands the number of medical professionals who have diminished migraine — which is a neurological disorder — to *just* a headache. This language undermines the seriousness of my condition and is also not accurate. Hemiplegic migraine, the subtype of migraine I experience, triggers a whole-body response; half of my body goes numb, and the tingling, burning nerve pain running from my neck through my arm sometimes does not subside between attacks. Aura plunges me into a confusing pit of twinkling, spinning visual stimuli. The accompanying brain fog sometimes means that I forget to do basic tasks, like showering and eating breakfast. Migraine makes me fatigued but also wakes me up at unpredictable intervals during the night.

Managing my symptoms brings a different kind of indignation. A past neurologist chided me for taking too much 'rescue' medication, while at a later appointment pointed out that this is precisely why I have rescue medication in the first place. After months of searching, I finally found a more empathetic provider who acknowledged that the medication I currently am prescribed each month covers less than half of my total migraine days. This means that, like many chronic migraine patients, I am forced to ration my medication, making a judgment call about whether my current attack will be worse than future attacks. This also means that to avoid rebound headaches, I use painkillers sparingly for all types of pain, not just migraine-related symptoms. When I had my wisdom teeth removed, I abstained from taking any painkillers except on the day of surgery. My pain threshold has consequently risen, but in turn, I am in pain more often than I am not.

Migraine has given me a new vernacular of pain: pounding, flashing, dull, weak, searing. But it has not given me any insight into the cause of my suffering. Susan Sontag warned in 1978 of the dangers of articulating illness as metaphor; stigma and the myths surrounding chronic illness obscure the reality of patients' experiences and prevent them from seeking proper treatment. Complex and chronic diseases warrant a new vernacular, an articulation of illness that does not posit the subject simply as 'victim' or 'sufferer' and that characterises disease accurately as it affects patients, not simply as a 'battle.' Refusing this language undermines the myth of constant battle, asking us instead to centre patients' needs and adjust access accordingly. Chronic migraine is a disease: a series of disabling, confounding, and often unpredictable attacks. It is not a battle, and I am not a warrior.

If migraine is a metaphor for anything, it is only for patience. It is no coincidence that 'patient' describes one seeking medical care. Migraine patients are forced to endure step therapy: a gruelling process of taking a series of low-cost, off-label medications that may help prevent migraine before qualifying for medications and treatments developed specifically for migraine. This means that years can pass — in my case, two — before someone can access medication for migraine.

Though I am frustrated that providers misunderstand my condition and am infuriated by my insurance company's seemingly endless stream of surprise bills, co-pays, and delay in approving pre-authorisation requests, there is nobody with whom I am more embittered than myself. I avoided requesting accommodations through my university's ADA office until my third year after I had a panic attack during a final exam. When I was taking the Law School Admission Test, I again avoided requesting accommodations until it was absolutely necessary — I had a migraine attack during my first test and scored lower than I had on any practice test. I am not always forthcoming about what I can and cannot accomplish in my work and personal life. For the most part, I do not believe myself deserving of accommodations; I desperately wish that one day my need for accommodations will disappear. This line of thought is both futile and ableist — migraine is a part of me as much as is my need to acknowledge the societal barriers that bar me and other chronic migraineurs from fully participating in society. By internalising ableism, I have made my life unnecessarily harder.

There is an abundance of aphorisms governing humans' relationship to time. For the present: *take it one day at a time*. For the past: *don't dwell on it*. Chronic migraine has so profoundly changed my relationship with time that I do not find comfort in either of these; what difference does it make to take it one day at a time when most days bring excruciating pain? It is difficult not to romanticise the migraine-free past. In the throes of a particularly vicious attack, even the present seems untenable.

Envisioning the future is even harder, but not impossible. As much as I try, I cannot change that the trajectory of my life has been changed by migraine. Though I have tried every mitigation strategy prescribed to me — physical therapy, tracking intake of certain foods, reducing exposure to bright lights and loud noise, neuromodulation, avoiding alcohol, exercising — and undertaken every test recommended — MRI, EEG, blood panels, and even an allergy test — I must come to terms with the fact that there is a not a singular cause nor cure. My life, though different than I may have imagined it, is still mine.

MARIA GRAY

Postictal Sonnet

after Adrienne Rich

the insufferable calculus of
the body shattered on impact have i fallen
from another balcony have
i been good enough to be made better
fever mounted on the basement mantel
of my heart have i kissed death on the teeth window
a television overcome
by static grief the minor chord binding the soul
to the body night a bumper
smeared with blood outside, cowboys and angels
fraternize over cheap beer sirens wail
over the orchestra of storm i think
i would like to fall into the river
i couldn't repeat my name if god asked

The Elephant

Yes, I will be
your bent little teaspoon
if you will have me how I am,
sideways. The body in pain, snakeskin
I cannot shed, wants what she wants.
Obsidian. Bloodsalt. I feed her,
baby her, play Seymour with the promise
of meat. She wants to die. No,
I say, I need you. Lover, I think
I am old now. And I have killed
so many selves to get here.
All my life I learned
to be an ornament, an offering,
a girl. I played dead until
I could not get up. All I had
was my body, and then I had
nothing, and with nothing
I had nobody, only my window
and my bed and the agony
of memory, its anvil
on my chest. I was ill, and so
my room became the elephant,
body a piñata full of blood —
come break me with a bat
and eat my heart.

Maria Gray is a poet from Portland, Oregon, currently based in central Maine. Her poetry is forthcoming from or published in Furrow Mag, The Lumiere Review, Counterclock Journal, and others, and she has received honours from The Lumiere Review and Adroit Journal.

The REST of My Life

by IAW

IAW is disabled non-binary trans man. He's also a Master of Library and Information Science student. When IAW isn't writing and studying, he's reading, cooking, or obsessing over Marvel comics.

Content notes: dysphoria, death, queerphobia, transphobia

I talk excitedly, much faster than I normally do. After two weeks on testosterone (T), I can already see some peach fuzz and fat redistribution. I pause to heave in some deep breaths and wait for my friend on the other end of the phone to similarly celebrate my news. Instead, she inhales sharply and asks, "Are you going to have to take this for the rest of your life?"

My breath catches. What does she mean by that? Why wouldn't I take it for the rest of my life? It's already making me feel better, more like myself. Why isn't she happy that I've found something that helps me, 14 years after I first questioned my gender?

I stumble through an answer and change the subject, asking her about her knitting projects. The following week, I'm organising my injection supplies in a three-tier cart full of my various medications, mobility aids, and assistive devices when I think about her question again. I realise I've heard that question before.

Family, friends, and even acquaintances have quizzed me about my medication regimen for my chronic conditions for years. They always want to know if I'm going to have to take my medications 'for the rest of my life.' The implication behind this question is always negative — as if it's heartbreaking, shameful, or a personal failure to depend on prescriptions. I quickly learned that in social settings, I should excuse myself and take my medications in private if I wanted to avoid this question and the pity or scorn I'd receive after I give my answer. (Which is: I will be taking these for the rest of my life.)

So, why did my friend's question catch me off guard when it was related to my gender? Why did I feel defensive and disappointed that my friend wasn't supporting me? Why do I expect and accept these invasive questions when related to my chronic conditions, but perturbed by them in relation to my trans identity?

• • •

After much reflection (and a bit of therapy), I realised I have some cognitive dissonance about this question because my experiences with disability have been tied to me being seen as a 'woman.' I know what it means for me to be trans, to be a man. I do not know what it means to be a disabled man. Until very recently, when I sought gender-affirming medical care, doctors have solely perceived me and treated me as a 'woman.' I've experienced misogyny from doctors that has affected the level of care I've received. Even now, with T on my medication list, a masculine preferred name, and he/him pronouns in my chart, I'm called my deadname, she/her, ma'am, a lady, and a woman in doctor's offices.

This feminisation is even more heavily forced upon me because most of my health conditions are associated strongly with cis women and 'womanhood.' My endometriosis, positive BRCA2+ mutation, and family history of breast cancer all affect the parts of the body which have often been associated with women. My hEDS and MCAS are more common in those assigned female at birth. The doctors' offices I visit the most are decorated in pink, with images of cis women and 'inspirational' messages about how these conditions don't lessen your femininity. If you're in this office, you must be a strong, brave, feminine woman.

There's a certain way people have always expected me to act when I'm questioned about my disabilities. Presenting as female for most of my life, I was raised as a 'good girl' in a white, middle-class, predominately-Christian community in the American Midwest. I was told I must unquestioningly accept and please authority, not take up too much space, smile, be agreeable, and think of everyone before myself. When people asked me invasive questions about my disability, if I did not answer with a smile, I was being rude.

Now, as a non-passing trans man, I'm still held to those same expectations. So I still expect and accept those questions related to my disability. It's a habit. I have had to put up a mental barrier that separates my trans identity from any medicalisation; my health being treated as something entwined with 'womanhood' erases my trans and male identities. At this moment, when I do not pass and haven't been able to legally change my gender, I am not given the space socially to be my authentic self and be disabled/chronically ill.

My friend's response to my excitement with T confused me because I never viewed my medical transition as a medical issue, I just viewed it as part of my transition. (Though, of course, trans people do not have to medically transition to be trans.) I changed my clothes, my hair, my name, my pronouns, and my dominant hormones in this process. When my friend questioned my medical choices related to my transition, it felt like she was questioning the core of my identity. But being disabled/chronically ill is also a core part of my identity.

• • •

Even though I don't always consciously honour my identities' intersections, they do impact each other. I'm able to get all of the surgeries I want to get for my transition due to my other health conditions. My endometriosis is allowing me to get a hysterectomy, my mutated BRCA2+ gene allowed me to get a mastectomy; my hEDS and MCAS made getting on T easier, since T has drastically improved some of the symptoms from those conditions, like pain and fatigue.

Both my disabled and trans identities are also linked in how they have shaped my outlook on life itself. The phrase 'the rest of my life' from my friend's question used to be something nebulous to me — a very abstract concept that I didn't really believe in. I used to think I wouldn't be alive by my mid-20s. Really, it was that I hoped I wouldn't be alive by my mid-20s.

Before I got a mastectomy and reduced my breast cancer risk to almost nothing, my BRCA2+ mutation and family cancer history meant I was very likely to get an aggressive type of breast cancer in my early 20s. Obviously, I knew there was treatment, and I knew I'd be taking steps to detect and prevent cancer. But I didn't want to grow up into a woman, then an old woman. I was so deep in the closet, despite having wanted to be a boy since I was nine, that I mistook my deep discomfort with ageing due to dysphoria as being apathetic toward living. I latched onto the risk of illness and possible death as a young person to help me dissociate from a future I didn't want for myself.

I only ever admitted these hopeless feelings out loud to anyone once. A high school club I was in had a 'bondfire' (bonfire for bonding) my senior year. As the night drew on and we got a noise complaint to turn down the music, someone suggested a round of truth or truth, where one person asks a question and everyone has to answer it. One of the questions was, "What's something you've never told anyone?"

People were brutally honest, revealing brokenheartedness, parental problems, class anxiety, and severe depression. I had been privately questioning my gender and sexuality, but I knew I couldn't be open about that in this group that often made queerphobic jokes and harassed those who were

transitioning has allowed me to access a life so much more fulfilling than I ever thought I could have

more visibly queer. The thing I really wanted to say, I couldn't. So I revealed my genetic risk and lack of future plans.

In this group, I was a student leader and seen as extremely self-assured. They all offered support and sympathy, dogpiling me with hugs while tears streaked all our faces. But what really would've supported me would have been an environment where I could be totally honest. I could've saved so many years and so much agony if I simply felt like I would've been accepted back then.

* * *

Discovering my identity and coming out was a journey I had to take on my own, and not just because it's a personal issue. It was something I had to have the internal courage to claim and decree because, even when I grew older and found (cis) queer spaces, I rarely saw celebrations of trans joy.

After I accepted my identity and started medically transitioning, I was able to allow myself to envision my future for the first time. I didn't want to walk down the aisle in a dress, I wanted to be at the end of it in a suit. I could imagine myself as a husband, a father, an old man. These were futures I never let myself dream of. Joys that I never let myself imagine.

Though my friend who asked if T was lifelong is not queerphobic, her question wasn't supportive. My friend's question had a tone that implied pity, shame, and tragedy. Taking T 'for the rest of my life' would be a trial, a loss, a burden. These feelings are often projected onto disabled, trans, and disabled trans people. Being trans, from the view of many cis people, is condemning yourself to a life of misery. Being disabled, from the view of many non-disabled people, is similarly morose. Her question was just another reminder of how much overwhelming ignorance and subtle transphobia and ableism exists in the world.

Why can't joy — from the physical changes with hormones to the mental healing in seeing one's future — be celebrated more than the possibility of lifelong medication?

For me, transitioning has allowed me to access a life so much more fulfilling than I ever thought I could have. Accepting my disabled identity has helped me grow as a person, understand the world in new ways, and experience pride that I don't think I ever would have if I was non-disabled. Being both disabled and trans meant I could reimagine and reclaim my relationship with my physical body, giving myself so much more grace and love than I ever did when I thought I was cis and non-disabled.

Am I going to keep honouring my body's needs and doing whatever I can to contribute to my own happiness? Yes. People may think disabled and trans lives are marked by sadness and sacrifice, but the shots and pills I take allow me to thrive. My life is not a tragedy. My life-long medications aren't something to pity — they're something to celebrate.

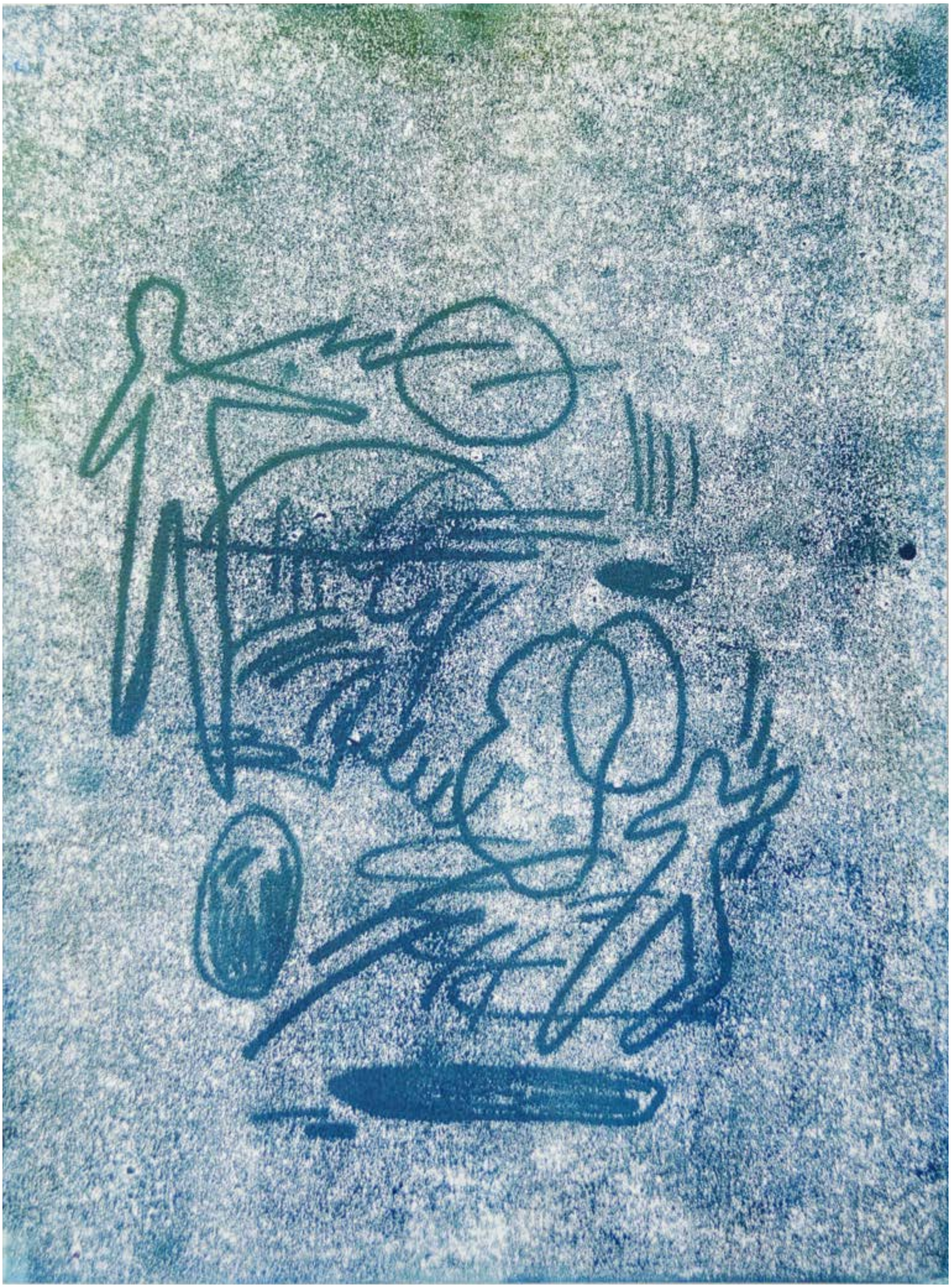
ARIANA MARTINEZ

A body moving through space is a continuous transmitter and continuous receiver. My sounding-searching body is parsing through paresthesias and petrichor, electrical hum and visual snow, barometric pressure and refracted light. I turn to material processes that can mirror or translate my own sensory and emotional experiences as well as the environmental conditions that provoke them. As a printmaker, my sensory noise translates into layers of granulated texture, optically-mixed colour, and offset line. Through my work, I've become attuned to the transient, atmospheric collisions of mood and weather, story and touch, memory and movement that create relationships to place. Concerned with the ways physical environments receive or resist non-normative bodies, my work engages feelings of placeless-ness, disorientation, and the inventive place-making that emerges from necessity.

Ariana Martinez is a multimedia artist based in the United States. They work across printmaking, sound, and video, and their work has appeared on BBC Radio 4 and at the Open City Documentary Festival (UK), LUCIA Festival (Italy), HearSay Festival (Ireland), among others.

A Bright Wish Burning

Over Exposure (Summer Haze)



Soft Contours

Soon Soon Soon

I Couldn’t Sleep

Seeking Safety While Visibly Disabled

by Grace Quantock

Grace writes narrative non-fiction at the intersection of creative arts, social justice, and marginalised bodies. Shortlisted for the Nan Shepherd Prize, Writers' & Artists' Working-Class Writers' Prize, and a Curtis Brown Breakthrough Award winner, Grace is writing a memoir, Madwomen Are My Ancestors.

Content notes: physical and sexual violence, harassment, abduction, stalking, ableism

At my first self-defence class, the instructor, Matt, asked me to choose training goals. I wrote a list of things I feared could happen, or happen again. I emailed him 15 scenarios, which included how to escape attempted abduction, how to stop someone from running with my wheelchair, and what to do if I'm held at knifepoint. I was the first wheelchair user to attend the self-defence class and one of just three women in a class of 15. Matt looked over my goals, but instead of basing my learning around my fears, he took another route.

"It sickens me to do it, Grace," he said. "But look, I'm going to approach you like a bastard would, right? Like I want to hurt you. If I saw you in the street, if I were a prick, what would I try? Let's work from there." He circled me, approaching me as a predator. I sat in my sea-foam green wheelchair in the centre of the crash mat. Matt was tall, bald and muscled, wearing a black gi. He shoved his foot flat against the spokes of my chair wheel, rocking his weight into it. Is it possible to throw me sideways?

"You're most likely to be attacked by someone grabbing your handles, dragging you away or tipping you forwards. We'll focus on escaping attacks from behind, break-falls, and on defending yourself from the ground."

I got a one on one mentor — a black belt who specialised in restraints — and was taught how to escape them. I appreciated how the trainers instinctively recognised the world I live in as real and risky. I got boxing gloves and pads and learned to block and punch; jab, right cross, left hook, uppercut. I felt stronger, but the undermining fear remained. There's no way to make me safe. I can try to disguise being a woman, but I'm unable to transform into a shape people find unnoticeable. Still, I benefit from white and gender-conforming privilege, and I know that living with a visible disability is much more challenging for Black, Asian and minority ethnic (BAME) disabled people, as well as trans and visibly queer disabled people. Statistics show that BAME people are over nine times more likely to be targets of stop and search by police in London.[1] My mentor told me that if I was attacked by someone trained, like a police officer or a person with a martial arts background, there would be no defence — nothing I could do. I think about that comment each time news breaks of another woman harmed by police; each time the media cycle gears with more nonsensical advice on how to not be attacked, while failing to confront the responsibility of the perpetrators.

I went to self-defence classes every week after my therapy session. It was a surprisingly good fit — moving from talking about trauma to fighting back. My self-defence lessons were split into two categories, which I named Gone To Hell and Overreacting to Men Near Me.

Gone To Hell was where I learned how to protect my spine and belly if someone threw me from my wheelchair. How to bring an attacker to the floor, so he couldn't kick me. These defence moves are for the times I hope will never come, when we have moved beyond de-escalation tactics and I am trying to stay alive. The risk is real — globally, an estimated 736 million women (almost one in three) are subjected to physical and/or sexual violence at least once in their lives.[2] In Overreacting To Men, I learned how to stop situations from escalating and getting people's hands off me when I felt unsafe. We played out all the creepy ways people touch me non-consensually and how that can escalate into an attack. The hand on my knee on the bus that inches higher, "to see if I'm really disabled". A grip on my shoulder or arm that drifts where it shouldn't under the guise of "helping". I used to worry it was something about me that caused people to keep touching me, even when I said no. I felt both less alone and more scared when I read about *Private Places, Public Spaces*,[3] a research project by Dr Kavanagh and Dr Mason-Bish at the University of Sussex on the rife non-consensual touching of disabled people.

I called the second category Over-Reacting to Men Near Me as a private joke, because that's how many people will see it. But those are people who believe violence is rare. Disabled women are almost twice as likely to be sexually assaulted than non-disabled women, and are also twice as likely to experience domestic abuse.[4] I'm at risk from the same kinds of violence non-disabled women face, but I'm also at risk of abuse specific to disabled women, which can happen in "a wider range of places and is enacted by more kinds of perpetrators" according to the Centre for Disability Studies, University of Leeds.[5] This violence can include hate crimes, attacks on disabled women when they are most vulnerable (such as during pregnancy or after a new diagnosis), and institutional violence from carers or assistants required for help and support at home.

The advocacy group Stop Hate UK revealed that over 9,208 disability hate crimes were reported to the police across England and Wales in 2020-2021. They point out that disabled people face exacerbated difficulties in an already inaccessible society. Inaccessibility in housing, transport, infrastructure and information impacts social protection[6] and puts disabled women at further risk. Violence against disabled women has increased

It doesn’t matter how assertive I am; as a disabled woman I am seen as a victim, and no matter how many caps I stuff my hair under, I can’t hide being a disabled woman, nor should I have to.

by a third since 2014, yet Disabled Survivors Unite, a UK support and advocacy group, point out there has been a drop in rape prosecutions and called for changes in the treatment of disabled survivors who report sexual violence to the police. Many disabled women have spoken of the traumatising experience of being harmed by ableism, interrogation, and dismissal by police during their complaint process.[7] I'm aware every time I am harassed of how much further harassment I could experience after the event.

I learned chokeholds because it was a way I could immobilise an attacker much stronger than me, whereas throws and kicks weren't accessible. I saw how seriously my trainers took my safety when I was practicing chokes on my mentor. He was on his back on the crash mat and trying to teach me how hard my grip needed to be to actually limit his air supply. Necks are thicker and harder to grasp than I would have supposed, so I couldn't grip that hard, nor get my hands around his neck. Instead, he taught me to use his t-shirt collar to choke him. His neck was red, skin inflamed, his voice horse from my repeated attempts. But he kept going until I got it because he wanted it to be that he would fight me with all his strength and not be able to hurt me.

Some of my fears might seem unlikely, like learning to defend against abduction. This wasn't a fear of mine until it happened. I was on the train station platform, trying to get to my train when a male staff member appeared behind me, grabbed my wheelchair handles, and ran. He swerved in the direction of the station shelter, shoving me head first towards the metal support posts. He veered away at the last second, made a noise like squealing race car wheels, and slammed me towards the next post, averting at the last possible second. He was laughing. I didn't find the prospect of being slammed headfirst into a steel post amusing. When I made a complaint, the complaints team admonished me for complaining, explaining claims were stressful for their workforce.

During another train journey, a stalker was able to locate my whereabouts from the passenger assistance list — train stations insist on disabled passengers confirming their journey times at least 24 hours in advance. It wasn't some high-tech data breach — it was just a clipboard on the wall of the staff room, after all. The station master advised me to protect myself in future by using a pseudonym when booking assistance. My favourite was Florence Fentiman-Hardy (the formula for this name is your favourite European city, plus drink, plus late author). But the distraction of concocting aliases didn't diminish my fear. I pointed out to the station master that a false name is a flimsy shield when I was targeted as a disabled woman. I can't hide my wheelchair. As the only wheelchair user on the train (there's only one wheelchair space per train), who could be easily located in 'the wheelchair space', I was highly visible and vulnerable, no matter what name I gave.

It doesn't matter how assertive I am; as a disabled woman I am seen as a victim, and no matter how many caps I stuff my hair under, I can't hide being a disabled woman, nor should I have to. As many disabled women consider how to live during a pandemic, we are also considering how to exist in a world that we may have — through lockdown and/or shielding — been absent from for a significant period. There's a re-entry to more than physical contact but also to risks of violence outside the home (as well as the domestic violence many experienced in lockdown). I feel increasingly unsafe when official responses to women's safety often focus on avoiding violence by increasing women and marginalised people's invisibility. But what happens to those of us whose otherness is always visible and never deserves to be hidden?

Notes

1 Stop and search up by almost a third in England and Wales. *The Guardian.* N.P. Web. 2019. Retrieved 9 June 2022.

2 Facts and figures: Ending violence against women. *UN Women*. N.P. Web. 2022. Retrieved 9 June 2022.

3 Mason-Bish, Hannah & Kavanagh, Amy. Private Places, Public Spaces: *How Disabled Women and Non-Binary People Experience Non-Consensual Touching*. University of Sussex. Web. 2022. Retrieved 9 June 2022.

4 Disability and crime. *Office for National Statistics*. United Kingdom. Web. 2022. Retrieved 9 June 2022.

5 Shah, Sonali & Wooding, Sarah. *Violence Against Disabled Women.* University of Leeds, University of Glasgow. 2015,

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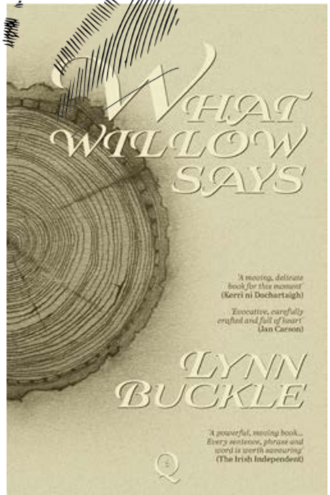
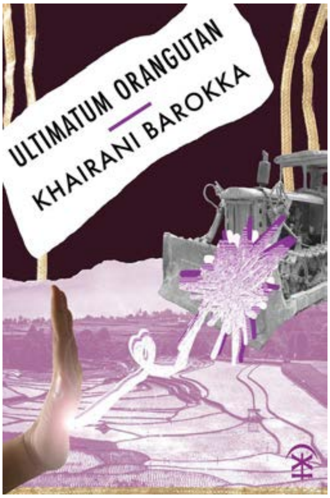
The Barbellion Prize 2021 shortlist

Book summaries written by Eleanor Franzén



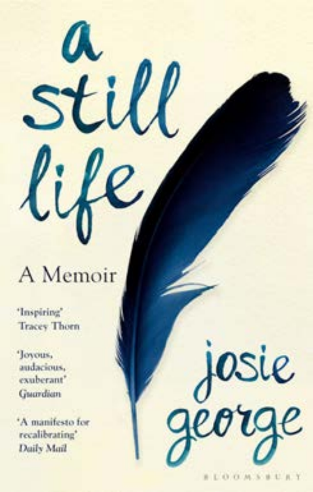


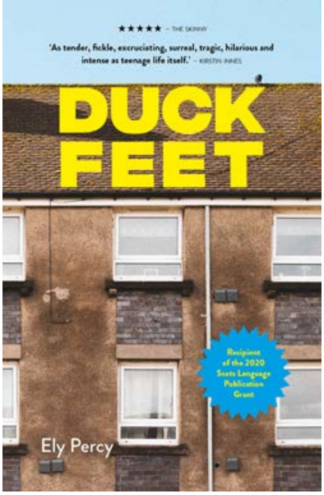
WINNER: What Willow Says by Lynn Buckle (Époque Press)
A slim novel with a lyrical, almost dreamlike quality, following a hearing woman and her deaf granddaughter in modern-day Ireland. With each chapter headed by meteorological information, What Willow Says is firmly grounded in the phenomena of nature — of which deaf experience constitutes a part — and in individual perception. Buckle both disorients and reorients the reader in a world where, far from being a deprivation, deafness opens doors to identity, self-expression, and belonging.

Ultimatum Orangutan by Khairani Barokka (Nine Arches Press)
In poetry that embraces the surreal and the lyric, Barokka places the disabled body front and centre in a shout of resistance to colonialism, ableism, climate crisis, and exploitation. Linking the way human and animal bodies are valued or devalued with the fate of the earth itself, her work harnesses and champions the power not merely of difference, but of strangeness. Unlike any other poetry collection you'll read this year, or perhaps ever.

Created by Jake Goldsmith, The Barbellion Prize is a book prize dedicated to the furtherance of ill and disabled voices in writing. The prize is awarded annually to an author whose work has best represented the experience of chronic illness and/or disability.

The awarded work can be of any genre: fiction, memoir, biography, poetry, or critical non-fiction from around the world — whether it is in English, in translation, traditionally published, or self-published. The prize is named in tribute to English diarist W.N.P. Barbellion, who wrote eloquently on his life with multiple sclerosis (MS) before his death in 1919.





A Still Life: A Memoir by Josie George (Bloomsbury)
George's memoir of life with chronic illness is an extraordinary homage to attentiveness: seeing, observing, connecting. Through her work, fierce and gentle, runs an emphasis upon choice, even — especially — in the very smallest things. A Still Life argues passionately that the body does not limit the mind, that pain and suffering and difficulty are never all that there is, and that a person can decide what stories to tell themselves about their own life.

Duck Feet by Ely Percy (Monstrous Regiment)
Imagine Adrian Mole had been a girl living just outside of Glasgow in the mid-'00s, and you've got a sense of what it's like to read Duck Feet. Hilarious, occasionally heartbreaking, narrated in an uncompromising and beguiling Renfrewshire dialect, Percy's novel-in-stories is a delightful account of working-class Kirsty's coming-of-age that handles topics from exam pressure to false friends to teenage pregnancy with wit and verve.

Submissions for 2022 are open until October 31st 2022. For more information, visit www.thebarbellionprize.com.

KYLA JAMIESON

PAIN IS A SENTIENT ENTITY

no, you wouldn’t know by looking
as if looking is knowing
—Teva Harrison

pain watches my body from another planet
transmits dialogue as radio signals
plays my body like a marionette
everyone believes is actually me
look, she’s kissing her partner
look, she’s washing the dishes after dinner
whatever it looks like I’m doing
know I’m doing something else
know pain is my most intimate relation
the one I’m always dancing with
even when it looks like I’m on earth holding
my own hand or moving my fingers
across the keyboard to write a poem about pain
like I know anything about it
like pain would allow itself to be known in language
like the vessel would be permitted to perceive
the mechanism of control

THE BODY SAYS HELLO

I wish I could ask Instagram
who borrowed my copy of
Leave Your Body Behind
& whoever I lent it to would give
it back, but nobody I knew
before I stopped reading
still watches my stories.
I stopped writing sentences
& editing & being useful
to the literary scene. I stopped
being productive in the ways
society defines it. I did not stop
being beautiful. In fact, I became
more beautiful than ever
in a way selfies can't capture.
My current projects include
remembering to feed myself
lunch before 5pm & embracing
rest with my body, not just
my intellect. The intellect buys
a book called *How To Be Idle*.
The intellect follows @okaytorest
on Instagram. The body breathes.
The body unfurls. The body holds
the phone. The body says *Hello,*
these words are coming
from a new place now.

THE INTAKE QUESTIONNAIRE FOR THE PAIN CLINIC ASKS IF PAIN HAS PREVENTED ME FROM HAVING A FULFILLING LIFE

All year the line between inside
and out has been hard to cross
but spring opens the gate.
I hear the sun calling. I hear
the magnolia tree down the block
calling. I go to the tree. I go
to the grocery store for coconut
I Left My House Today ice cream.
I think I see an ex waiting
in the line outside when I leave
but she has a mask on and last
I heard lived in another city.
I don't want her to see me
because I don't want to go back
to being the person I was
when she loved me. I want
to keep who I am now
despite my deep exhaustion.
Time reinvents itself so often
I forget I've always lived
in this body, on this planet. Inside,
I fantasize about going back
to the patio chairs in the middle
of the still-sunlit street and calling
Libby, but after climbing the stairs
to our apartment's front door
I need the couch to hold me up.
I'm so used to shedding
my ambitions that it almost looks
graceful when I do it now. In all
my daydreams I have the energy
to call my friends. Rest my body
in a river of their voices.

THE FUTURE REWARDS OUR LOVE

for Afuwa

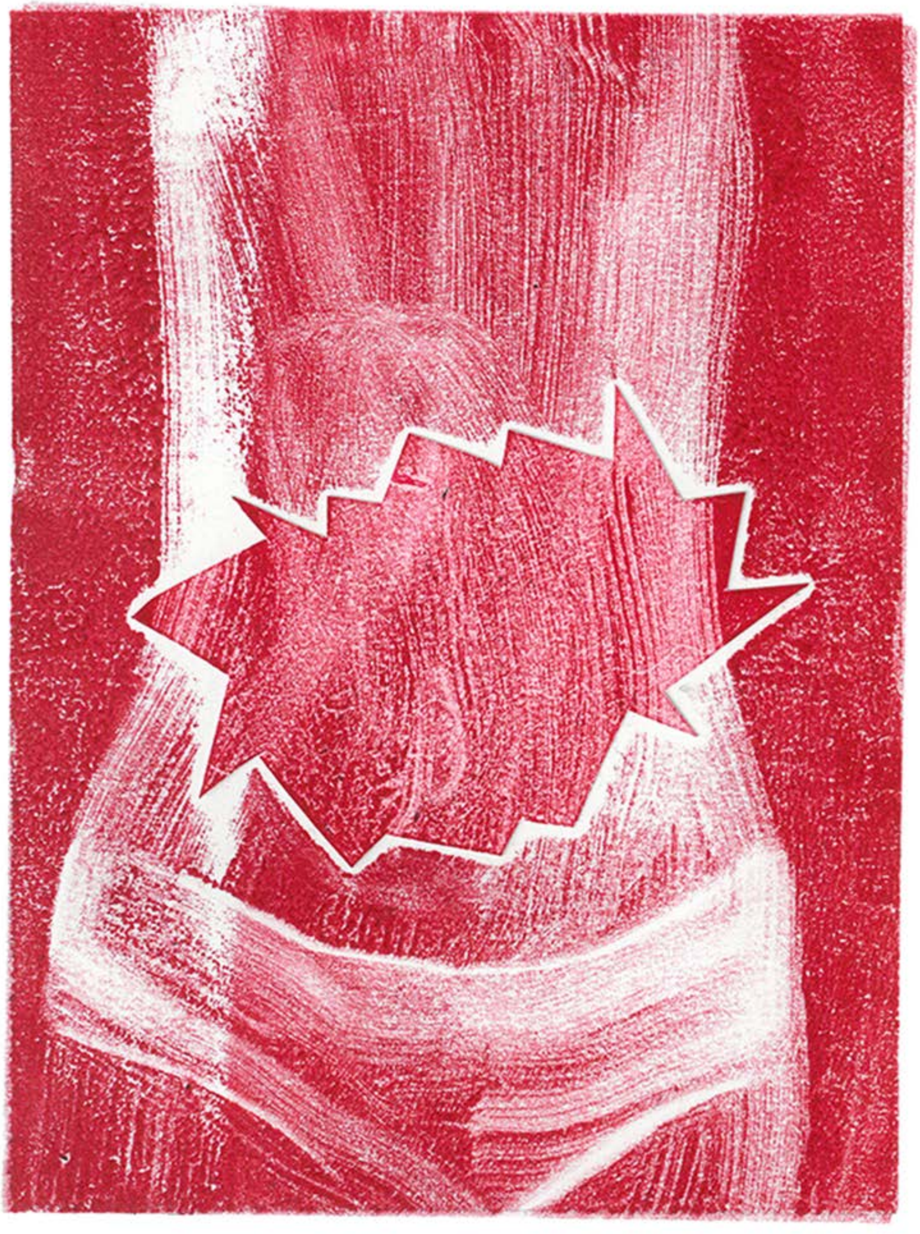
I keep waking
in the early morning dark
because my arm is numb,
asleep—is it dreaming?
What can it tell me
about our future?
About the reimagining of care—
who participates, and when,
and with how much joy?
With how much love?

Kyla Jamieson is a disabled poet and the author of the poetry collection Body Count. Her writing reimagines time, embodiment, care, and intimacy in the aftermath of a brain injury.

TAMSIN GAUL

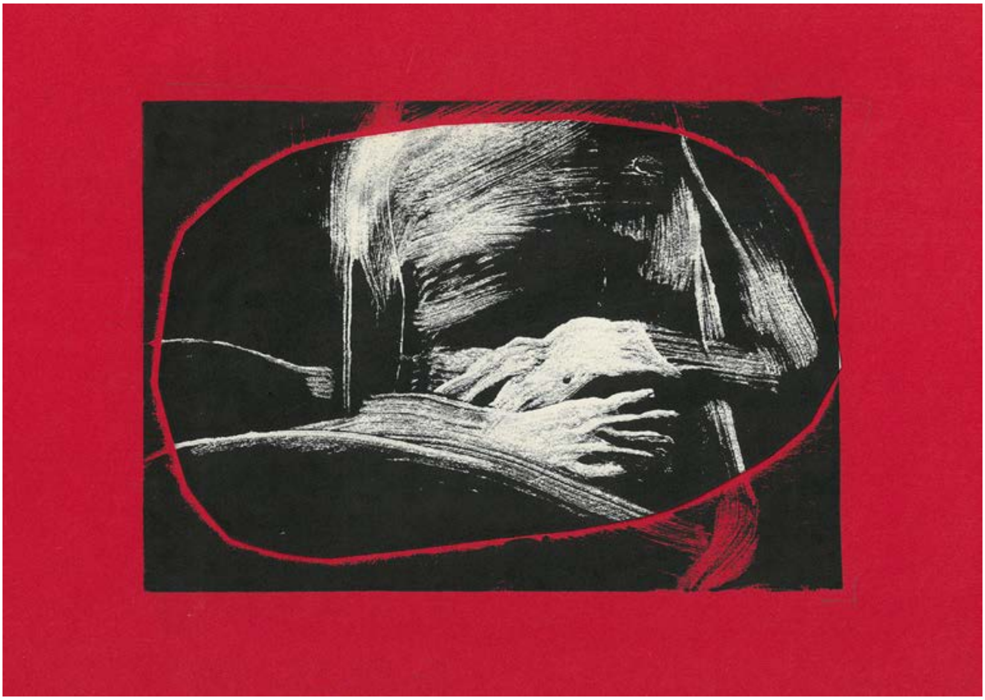
In this body of work, I respond to some of the words that are used to describe pain. Often this language fails to adequately reflect the emotional aspect of experiencing pain. I attempt to find an alternative visual language that allows me to express both mental and physical feelings in a creative way.

Tamsin Gaul is an illustrator and printmaker who is inspired by quiet moments, self-reflection, human connection, and music. Her practice combines experimental use of media and unpredictable processes with a slow and intentional manner.

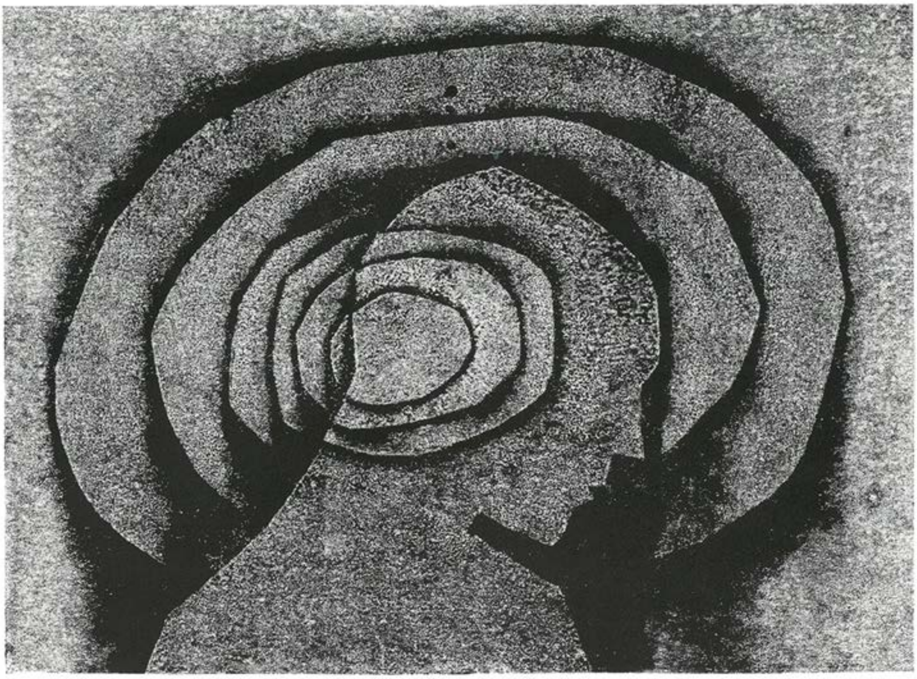


Flashing

Tummy Clutch 2



Tummy Clutch



Headspace

Tearing

Life in the Body: Poetic Memoir, Crip Kinship, and Living Well

Ashna Ali interviewed by heidi andrea restrepo rhodes

Ashna Ali (she/they) is a queer, agender, disabled, and diasporic Bangladeshi poet, writer, and educator raised in Italy and based in Brooklyn. They are the author of the chapbook *The Relativity of Living Well* (The Operating System, 2022) and their poetry has appeared in several journals including *Sun Dog Lit, Nat. Brut, Zoeglossia*, and *Kajal Mag*, among others. They hold a PhD in Comparative Literature from The Graduate Center, CUNY, and facilitate a series of workshops through Liminal Lab called “CripLit4Spoonies” on the literature of disability and illness.

In an interview with heidi andrea restrepo rhodes, Ashna speaks about illness under capitalism, historical memory, sick and disabled queer community interdependence, and their new chapbook, *The Relativity of Living Well*.

HR: One of the most central themes in *The Relativity of Living Well* is the contention with the fiction of ‘the good life’ that we are conscripted into through the false promises of capitalism and western individualism. What has writing this collection during the COVID-19 pandemic and its ongoingness illuminated for you about what it means to ‘live well’ as a sick and disabled queer (SDQ) diasporic poet of colour in the face of capitalism’s compulsory able-bodiedness?

AA: I wrote this cycle of poems between March 2020 and July 2020 documenting my experiences of pandemic. I did this, in part, because of the phases of unreality that I didn’t know how else to capture, but had to. All of the things I thought were important in the past — achievement, upward mobility, having *things*, being bigger, better, faster, stronger in all the ways that we are hailed to be by capitalist consumer culture — just fell away. I realised, perhaps for the first time, that my health and well-being matter more than all of those things, and also realised that this should not have been a radical thought or realisation. Living well became about having and making the space and time to nurture my mind and body, choosing my relationships carefully and cultivating them deeply, and living a life of curiosity and creativity rather than ‘achievement’ and ‘success’. One of the ironic gifts of disability is that it teaches you not to take things for granted. A day when the body does not hurt is a gift. A day when one is excited to get out of bed is a gift. A day when there is time, energy, good will, and money enough to go out for dinner with a dear friend and enjoy their mind, participating in their

Documentation of the grief and rage of the moment allows us to ensure that these feelings don't get stamped out by exhaustion or state erasure.

life — that kind of access to joy that so many think mundane reveals itself as profound joy to value deeply. Gratitude has more to do with living well than almost anything I've known.

HR: I also see the work in this collection as poetry of witness, social documentation, and archiving of the present as rendered into specifically queer, crip practices.

AA: Thank you so much for that — I certainly hope so. I think documenting the present from the lens of the personal and the social at the same time queers the notion of what has political and historical importance. I'm committed to the notion of narratives of the moment as both social history and art. These are expressions of the series of states in which so many of us live that acknowledges the solipsism of that moment, too. The inside of our homes became our only version of reality outside of our social media engagement. Those of us who were partnered experienced things one way, those of us who were single experienced it another, those who left town or lost people vs. those who didn't. There is such pressure now to force amnesia of the impact of Covid on our lives that this kind of documentation feels crucial to remind ourselves and each other what we've survived and what we continue to have to put up with until we choose not to, anymore. Another way of addressing so many of the problems that arose from Covid were possible, and many other countries approached the pandemic without anywhere near the degree of human loss or economic exploitation. Documentation of the grief and rage of the moment allows us to ensure that these feelings don't get stamped out by exhaustion or state erasure.

HR: I've been spending a lot of time in recent months with Aurora Levins Morales' essay, "Mountain Moving Day" from her book, *Kindling: Writings on the Body* (Cambridge: Palabrera Press, 2013.) She maps critical connections between the histories we carry from colonisation and capital's destructive force upon life and land, and the illnesses we contend with. What particular histories of body and place do you find yourself mapping out in your own writing about or from chronic illness?

AA: I've been thinking about this idea a great deal myself. My particular set of conditions are all associated with trauma and dysregulation. My parents lived through the Bangladeshi Liberation war, immigration to the United States and then again to Italy. Their parents before them suffered the ravages of Partition, and their parents before them, colonisation. Extreme forms of patriarchy run through these histories and the present, not to mention struggles with poverty, illness, and our various human dramas — so many untold stories. Though my immediate family is now removed from many of those more immediate struggles, from the Global South living in the Global North in comparative safety and security, but under fascism, capitalism, and several interlocking social forces that socialise us into silence, compliance, consumerism, and a degree of amnesia. The crushing pressure of normativity imposed on the so-called model minority in the Global North ultimately expresses its damages on the body when the psyche refuses to yield. I think this is particularly true in the United States, which is a toxic and sick place due to state traditions of neglect and abuse. My personal traumas, my intergenerational traumas, and the pressure of our political and social present are absolutely speaking through my body. It's absurd to assume that life experience has no impact on our bodies' regulatory systems, but the Cartesian divide has for centuries been one of the most useful fictions for colonial white supremacist heteronormative patriarchy.

HR: In both your chapbook and in your poem "Top Secret Club Abjection" (published on Zoeglossia), community interdependence is documented and celebrated as a vital element to collective sick and disabled queer survival as well as the mediated pleasures we access. How has this sense of interdependence shaped your poetry as specifically "crip"?

AA: American individualism is a toxic ideology that drains the joy from our lives and distance us from the truth of who we are as animals. We're a social animal that thrives in community and collaboration. Our relationships are crucial to our survival. I think the huge increase in the presence and ethic of mutual aid since 2020 is exactly the kind of effort that we need to see more of. The same is true of our poetics. I think often of Aracelis Girmay's "You Are Who I Love" and the way Yanyi writes the names of his friends and the authors that are shaping his mind directly into his poems. I feel an ethical responsibility to be transparent about

> **My personal traumas, my intergenerational traumas, and the pressure of our political and social present are absolutely speaking through my body.**

The idea of a revolution of care is ultimately not so radical or that difficult to achieve.

how much disabled folk rely on each other for support of all kinds. People need to be aware that we are actually *unable* to survive without each other, and that we are failed more often than not by the medical-industrial complex. I also want to contribute to the normalisation of chosen kin for all manner of love and survival. We should be naming our loves — all the different kinds of kinship and interdependence that support and uplift our lives that are often unrelated to the nuclear family or the monogamous romantic pair — and showing the world who we love, why we love, how we love. The more cultural production represents these relationships and lifestyles, the more we are exposed to the reality that the state is uninterested in taking care of us, so we have to take care of ourselves and each other in defiance. The idea of a revolution of care is ultimately not so radical or that difficult to achieve.

HR: Which sick and disabled kin and kindred writers, poets, and texts, are nourishing you right now?

AA: Leslie Jamison is always an important and rich point of return. And frankly, you! Also my dear friend Leigh Sugar, whose erasure poetry in particular is gorgeous. Anthony Thomas Lombardi's poetry on addiction and recovery always moves me deeply. I just received Sarah Manguso's memoir *The Two Kinds of Decay* and *I Am Your Book: A Poetic Journey Through CFS/ ME/ Fibromyalgi*a by Charlotte Jones in the mail, and I'm very much looking forward to diving in. I return over and over to the folio of poetry on disability and chronic illness on *Nat. Brut* curated by Kay Ulanday Barrett, in which we were both featured. What an incredibly powerful collection of poems! A non-literary but exciting book that I recommend, too, is Gayle Backstorm's *I'd Rather Be Working*, about how to survive work and money while disabled.

HR: With this first collection out in the world now, where do you find yourself on the other side of having written and published it? What is on the horizon for you? What are you dreaming up next?

AA: When I return to the chapbook to read from it, I am staggered by all the things I would not have remembered about that period of my life had I not written them, and this has helped me understand myself as a poetic memoirist first and foremost. It is a form of memoir that benefits from metaphor, simile, collected or found language, to express the dimensions of the unsayable that poetry offers while documenting experiences private, public, individual, collective, and cultural. Though every poet's experience and style is unique, every poet's story has resonance with a number of readers out there who desperately need to hear it in order to feel less alone, to feel empowered, or less ashamed, or, hopefully, to be inspired toward core truths of their own. In that vein, I am working on my first full collection of poetry, both collecting older work into its shape and writing into it. It aims to show exactly these overlaps — personal trauma, intergenerational trauma, illness, state neglect and social illness — and how art, community, and shifts in perspective toward nurturing the self and the world yields joy. Teaching a series of workshops with Liminal Lab titled "CripLit4Spoonies" has influenced the process greatly, and created a beautiful community with which to think and write. Still, it's both an exhilarating and terrifying experience so far. Wish me luck!

The Relativity of Living Well is available to purchase at your local bookstore or at www.theoperatingsystem.org.

heidi andrea restrepo rhodes (she/her) is a queer, disabled, Colombian/Latinx, poet, scholar, educator, and cultural worker. Her poetry collection, The Inheritance of Haunting (University of Notre Dame Press, 2019) won the 2018 Letras Latinas Andrés Montoya Poetry Prize. You can find her on Instagram: @vessels.we.are

LATIF ASKIA BA

The Little Me

I got up at 5:30
to heat, water,
and reggae:
Gregory Issacs telling the slavemaster,
“I’m accustomed to your whip.”
I fought with my hair
and won,
my shoulders burning.
I fought with the gate
and won,
my shoulders burning.
I got there and waited,
the sun pulling itself over a low building.
A member of the sangha found me
in the shade of a car.
He let me in, not forgetting,
how to.
I had forgotten his name and he had forgotten mine.
But we remembered each other,
the things people remember,
the silent subtleties, renoted
in the long white halls of a factory.
I squeezed through the metal door,
took off my shoes, and heard the clacking
quickening. I passed through the little library
and held my body quiet.
Tattooed ivy grew up the arms
of a practitioner
like a fence post.
I saw my things in my usual spot:
a zafu on a zabuton,
and an extra zabuton
leaning against the wall,
a small black bastion flooded
by the familiar scent of burning incense.
A priest greeted me
in the blackness of his robes.
The ancient laugh in the eyes
dispelled some confusion about
where I was to sit.
I sat
and wavered

like a carwash inflatable.
We sat
and wavered. We sat,
and we wavered. I
forgot we were wavering.
My breath swelled in my ears.
My spine bent, straightened for a moment,
then resettled into its former scoliosis.
I looked around at the beautiful bodies,
so quiet, so committed—
little mountains in black beds;
I grasped at them.
My hands—like skipping stones
or tyrannical twins
coveting each other—
found their place on my throat,
my throat all stuck with fingers.
I taught them myself: “Choke. Choke.
Count your choking.” Nail in flesh
and cushion. How the breath cuts out,
how the nerves fire militia-rifles, how
there is smoke
and then nothing.

Later,
at the front of the ferry,
wind picked at the roots of my afro
and rendered all words inaudible.
An island of sun-flooded hills,
I climb them and count
a stranger’s breath
drawn from plastic tubes,
choking beautifully on each number.

Waiting

I’m high on waiting.
This is what they built us for:
a man like a mule,
darkness as his fur;
we were built like our pyramids—
tall, wide, and waiting.
The smoke is of us,
of the midnight waiters,
of the corner swayers,
of the soothsayers,
of the switch players.
Our smoke clings
to the insides of our bones; our flesh
long deceived us.
It oils the bolted joints
that stood in fire,
to the holes of faces
as they curled their lips
in felicitation, in anxiety.

I write this in waiting,
in smoking, in hoping—
the dealer praying to his mother.

Gregory Isaacs
chants through a small speaker,
his voice an electric cradle. The record
I’ve spun endless times in Rilke’s solitude
tries to dislodge from its orbit,
plays once again in an attempt
to catch what it keeps lunging for,
dark and trembling.

I wonder what they’ll think of me:
whether this was the body they were looking for,
whether dark and trembling will suffice,
whether they will fear me
like a savage
that looks warily at the elder savage.

I’m still half-savage,
a thing for society to iron out.

My ancient culture drowned
in swampland and desert.

I wonder what the chalice will make of us:
the borders of our bodies,
their coasts and frontiers.

I wonder if these extraneous movements
will be perfectly necessary
like the winding to a slow dub
set in summer sweat. The melding
of two broken things: two bronze souls melting
in Plato's shadowy fire.
I wonder what they'll make of us:
a sword, a shoulder pad, a faucet—
the decadent inefficient ones
poor people buy to remind them of dreams.

They turn on our faucets

I Always Danced

I always danced
in the empty lecture halls,
in the crypt-like waiting rooms,
in many chairs.

In the empty lecture halls,
I'd listen and squirm
in many chairs,
uprooted by the faintest wind.

I'd listen and squirm
like a strung-out fiend,
uprooted by the faintest wind,
trying to sink my nails into my skin.

Like a strung-out fiend,
with my spasms and baggy eyes,
trying to sink my nails into my skin,
my eyes dug dharma out of pages.

With my spasms and baggy eyes,
I sat on a zafu.
My eyes dug dharma out of pages
in an obscure zendo.

I sat on a zafu;
I always danced.
In an obscure zendo,
I always danced.

Latif Askia Ba is a poet with Choreic Cerebral Palsy from NYC. He's currently an MFA candidate at Columbia University and an author at Stillhouse Press, who will be publishing his next collection, The Machine Code of a Bleeding Moon in the fall of 2022.

‘TOO BIG’ *for Help:*

Are eating disorder patients still being rejected from treatment due to the BMI scale?

by Emily Chudy

Emily Chudy is a freelance journalist from London. Her work has been featured in PinkNews, Stylist, Gayming Magazine and more.

content notes: eating disorders, BMI, medical neglect, self-harm

The number of young people with eating disorders (EDs) in the UK has skyrocketed since the pandemic hit. A combination of being isolated from family and friends, as well as the feeling of having little control, has understandably taken a toll on mental health. After a decade of funding cuts, the NHS has been stretched past its breaking point trying to care for the many people suffering.

While new NICE (National Institute for Health and Care Excellence) guidelines have stipulated that a person's weight should not be the sole diagnostic criterion for ED treatment, and several medical experts have dismissed the reliability of using BMI for diagnosis, are patients still being rejected from receiving further treatment because of it?

The most well-known EDs include anorexia, bulimia, and binge eating disorder, with a disordered outlook on food, body image, and health being common characteristics of most EDs. While medical experts believe EDs may have a number of different causes — such as genetics and brain chemistry — my ED came about after a number of traumatic events in my personal life.

In my experience, weight has been a huge barrier to receiving ED treatment. I went to my doctor in 2021 concerned that lockdowns were affecting my recovery from the dangerous ED I suffered through university. However, since my BMI — combined with my blood tests — presented as not concerning, my doctor said I would not be referred for further treatment. In 2012, at a drastically different weight, I was also rejected on the grounds of BMI.

When it happened in 2012, I could almost feel myself shatter. I had spent a year thinking the worst thing about myself was how much I weighed, only to have someone in a position of power judge my suitability for treatment based on it. In 2021, I was simply confused and disappointed. My ED had been a mental illness causing self-harm, isolation, and poor self-esteem for years, regardless of all the different ways my body had looked, so why was I still being denied treatment based on my physical health?

According to NHS data from March 2022,[1] over 10,000 children and young people started ED treatment between April and December — up by almost two-thirds since before the pandemic. But this number is not the full picture. If 10,000 young people are being treated, what about people like me, whose ED was never officially recorded? What about those on the ever-growing waiting list?

PhD student Erica, 22, says her ED began when she was around 12 years old, along with depression and anxiety. She was only referred to talking therapy for depression and described having to recover from her ED on her own after being rejected from further treatment.

"I started off by going to my GP, and she weighed me," says Erica. "She said that 'you might be a little bit too heavy' to get treatment for it." Erica was then referred to therapy to be assessed for depression and anxiety, in addition to an eating disorder.

> "Again, she weighed me and took my measurements. She said, 'I'm really sorry, but you need to lose more weight' before they could hospitalise me or give me any treatment. When she told me that, I kind of felt determined. I guess I was like, 'okay, I can lose more weight then'. But I also felt so terrible and very guilty because at the time my parents had made me go to the doctors and go to therapy to

> try and help myself. Because [doctors] weren't allowing me the treatment, I felt like I'd failed them."

After being dismissed by her GP, Erica and her family were forced to find their own coping mechanisms and deal with this complex illness without medical guidance.

The BMI scale may form a further barrier to care for women and people of colour with EDs. Initially called the 'Quetelet Index', and invented in the mid-19th century by Belgian mathematician Lambert Adolphe Jacques Quetelet, the BMI scale was created using data collected primarily from white European men to create a height-to-weight ratio thought of as 'ideal'.

The index doesn't take into account differences in age, sex, race, or a person's fat-to-muscle ratio, which means the measurement system may not accurately say much about the health of a person's body. This baseline measurement being used — along with other medical biases — could contribute to women and people of colour being assessed wrongly when it comes to ED treatment. A recent YouGov poll found that Black, Asian and Minority Ethnic (BAME) people feel less confident in seeking help from a health professional for an ED than white people,[2] with just over half (52%) of BAME respondents saying they would feel confident doing so compared to almost two-thirds (64%) of white British respondents — despite people with Black African backgrounds being the fastest-rising community to be admitted to hospital for an ED in recent years.[3]

Dr Giles Yeo, a geneticist at the University of Cambridge, wrote for Science Focus that BMI is an "inherently flawed"' measure that "shouldn't be used by healthcare professionals . . . as a be-all and end-all to inform treatment" for patients. In theory, BMI as a diagnostic tool for EDs should be a thing of the past since NICE guidelines were updated in 2017. However, many patients are reporting that without specific training for healthcare practitioners on how to deal with EDs, some may still slip through the cracks.

One ED patient, who wishes to remain anonymous, says that even if BMI is not considered, certain stereotypes about ED patients remain, which means bias may still affect people's ability to receive help.

> "I know my local team no longer has the BMI criteria (although I was rejected because of BMI in 2018) but they kept rejecting all my urgent referrals this year, and I just wonder whether they now use vague language, such as 'not stereotypical enough' to cover up the fact that they are doing the same thing," they said.

Dr Agnes Ayton, chair of the eating disorders faculty at the Royal College of Psychiatrists, added that another side of the issue is chronic underfunding in ED treatment. She explains that while BMI may not be used in every case, "decades of underinvestment" in EDs have resulted in services having to treat patients who are at "high risk due to extreme malnutrition" first, leading to those with higher BMIs having to wait for care, despite being a demographic with higher rates of EDs.

"This is dangerous as it could encourage already seriously ill patients to lose even more weight to get the treatment they need," Dr Ayton says. "According to the NHS Digital Health Survey in 2019, 16% of adults over 16 screen positive for eating disorders, but the rate is 41% among those living with severe obesity."

While it is essential for those in

need of emergency care to receive it, ED charity Beat explain that early intervention, such as in cases like mine last year, actually improves a person's chance of long-term recovery. The charity said in a statement: "Sadly, we hear from the people we support that there are instances when people with eating disorders cannot access treatment, because their BMI is not deemed 'low enough'. This is really concerning, as the sooner somebody accesses treatment, the better their chances of recovery."

Erica now volunteers with Beat, and believes 'old-fashioned' BMI should not be used at all when it comes to assessing and treating EDs.

> "I feel really good about it [BMI's role being reduced in NICE guidelines]," she says, "because at the end of the day, an eating disorder isn't to do with weight at all, it's to do with your relationship with food . . . Personally, I think that there should be a training programme for everyone that goes into medical practice . . . I went to the hospital a couple of weeks ago for my skin, and they were telling me to restrict my diet to improve my skin. I know they were coming from a skin-focused approach, but if they said that when I was still struggling, it would have been really damaging to me."

For me, I now have enough of a support system that I was able to pull myself out of a potential relapse, and thankfully have people around me that are knowledgeable and empathetic about EDs. It is a shame, though, that despite the care society has taken to dispel myths about EDs and the tremendous efforts of the body positivity movement, some people are still being left behind for the way they look. ED patients have a tendency to reduce themselves down to a set of numbers; I believe we deserve better than being treated as a number when asking for help.

Notes

1 NHS treating record number of young people for eating disorders. *NHS England*. 2022. Web. Retrieved 9 June 2022.

2 New research shows eating disorder stereotypes prevent people finding help. *Beat Eating Disorders*. N.P. Web. Retrieved 9 June 2022.

3 NHS hospital admissions for eating disorders rise among ethnic minorities. *The Guardian*. N.P. Web. 2021. Retrieved 9 June 2022.

MEGAN WILLIAMS

My practice consists of documenting my illness experience through college. I am drawn to images of surrealism and body horror in my works because they express an emotional truth about my life with ME/CFS. In my collages, I explore emotions and experiences of being young and largely absent from the world around me. Grief and loneliness are ongoing themes in my works.

I consider collage itself to be a kind of disabled medium: unmaking and remaking, transformation, adaptation, limitation, unexpected outcomes. I am inspired and emboldened by radical disability theory and my own search for disabled joy.

Megan Williams is a bed-based artist and full-time sick person. Her work explores the embodied realties of her life with severe ME/CFS. Working across collage, print, and textiles, she celebrates the mundanities, absurdities, horrors, and unique joys of her disabled life.

More than one way to bloom


NOUVELLE ICONOGRAPHIE
T. II PL. XLV.
CLICHÉ A. LONDE
PHOTOTYPIE BERTHAUD
ATTAQUE DE SOMMEIL HYSTERIQUE

escape

slow lane

HLR

HLR (she/her) is a prize-winning poet, working-class writer, and professional editor from North London. She is a commended winner of The Poetry Society's National Poetry Competition 2021. HLR is the author of History of Present Complaint (Close to the Bone).

Twitter - @HLRwriter

Out of the Mouths of Doctors

The following statements were made directly to the patient by medical professionals and mental health workers in various hospitals in North London between 2014 and 2019.

Your blood is highly uncooperative.

If you were my daughter, I honestly wouldn't know what to do with you.

I've decided that you are not currently in crisis because you're wearing clean jeans, so you're fine.

Well I guess, going forward, the plan is: keep taking your meds and try not to kill yourself or anybody else, and we'll reconvene in six months. Sound good?

You have a very shy cervix.

I would let you borrow my pen, but you'll probably steal it.

Either my blood pressure monitor is broken or you're on the cusp of death right now.

Prison might be good for you. Would you be willing to commit a few crimes, some theft, perhaps? Or fraud? You'd get help there, and three meals a day, and then you wouldn't have to worry about housing! It's a win-win for everybody. Think about it.

It's funny because you look normal.

You can live without water, stop complaining.

Look at the state of you. It's such a shame, you'd be really pretty if you made a bit of effort.

We've run out of vegetarian options, so I've brought you four pots of jelly.

Yeah, you don't seem stupid enough to fall pregnant.

You can press this buzzer any time you need help, but please don't press it, it's annoying.

I had a girlfriend like you once. Proper psycho she was. Loved her to bits.

At least when you're mentally ill, life is never boring.

Baby Boy

content notes: suicidal ideation, description of imagined death

The last time I walked this far I was a wine-drenched wreck,
class A in my veins, suddenly off venlafaxine after a decade

spent ingesting the highest dose daily. Pubs shut, lockdown, streets empty,
desperately despairing—Suicidal Sunday & nobody was coming for me.

I had the baby boy waiting for me at home. I'd left him because I didn't want him
to see me crying, shaking, frightened, so insane. He'd already escaped a small hell

when I whisked him away from that crack den flat on that sinkhole estate, when he fit
in the palms of my cut-up hands. Still, in pain, my brain pushed the image of him away

for a tiny second & I launched myself into the path of the bus careening
down the hill. It swerved around me & the driver stuck two fingers up at me

& called me a *fucking idiot* & I screamed back, *I KNOW*, because I remembered
the baby boy again, how he was expecting me back. Yes, if I didn't have the kitten,

I'd have made sure I'd died splayed under the wheels of the oncoming 144. What was left
of the flesh of me would have been dragged down Park Road & up The Broadway.

The bus would’ve been hosed down at the depot, then turned around to retrace
its journey & crawl solemnly past the scene of my crime, up & down the hill,

on repeat, repeat, repeat. Or maybe the driver who ran over me would refuse, would demand
to work a different route. I’d have made the pages of The Evening Standard, granted,

another casualty of the pandemic, they’d say, *isolated, MH issues exacerbated,*
though that wouldn’t have been true & anyway, I had the baby to get home to.

I ran back, choking apologies, *I’m so sorry, I’ll never leave you again, I promise,*
I’m so sorry. We were both small & hungry but in different ways. I was shrinking

into nothingness & he, the runt of the litter, rejected by his mother, was growing
bigger, stronger, fiercer every day. I was starving for love, safety,

something resembling peace, but he had all that in abundance.
He just wanted chicken liver pâté on his special little plate.

When I got home, he didn’t eat.
It turns out he just wanted me.

The Beautiful Sick Man

by Jodie Noel Vinson

Jodie Noel Vinson's essays and reviews have been published in Ploughshares, The New York Times, Harvard Review, Literary Hub, The Rumpus, and Electric Literature, among other places. She lives in Providence, RI, where she is writing a book about the creative expression of chronic illness.

I stretch out on the jewel green lawn of the Champs-Elysée. You pull out a journal and begin to sketch. Last night your subject was my body, which, at 29, retained the angular, broad-shouldered build of a high school athlete.

A few time zones and a day before, beside the Concord River, we'd said our vows, including in sickness and in health, and we'd meant it. But we also didn't know what it meant.

• • •

The other night, when we didn't have breath to speak, I found a journal and handed you a pen. This is how we'd communicate when the illness took away our words.

• • •

"Words only come when everything is over, when things have calmed down," Alphonse Daudet observed during his long suffering from syphilis. "They refer only to memory, and are either powerless or untruthful."

Daudet's unfinished record was curated into a staccatoed opus on illness, with swaths of sick time passing wordlessly in the white spaces between broken passages. The translator, Julian Barnes, called the book *In the Land of Pain*.

• • •

Beneath that bright Parisian sun, you'd traced the sculpted angles of Daudet's statue residing over our picnic: pensive, dashing, head cocked in a winsome way. His jaunty charisma, apparent even in stone, makes it clear why Proust referred to the author as 'the beautiful sick man.'

• • •

A decade after the honeymoon, we plan a different journey. As our flight to India lifts off from the East Coast, the first American life is lost to the virus out West.

Though it erupted with violence on our return flight, it must have begun upon arrival. A slight tickle spidering through sinuses, a strange malaise. Then, as if building toward a crescendo, a throb like an ominous drum deep within my cranium that night I ran across the palace square.

• • •

Daudet contracted the disease in his youth, but it lay dormant for decades until it reared its head in the 1880s, manifesting in an excruciating tertiary stage, an anguished finale.

"Warning signs going back a long way," he observed. "Strange aches; great flames of pain furrowing my body, cutting it to pieces, lighting it up."

• • •

When we met, everything aligned, alight with the synchronicity of story. We'd grown up within 50 miles of each other, in Iowa City and suburban Cedar Rapids. I'd played basketball in your high school gym. You'd shopped at my Barnes and Noble.

We arrived in Seattle within months of each other, worked at different branches of the same bookstore for two years by the time you walked into mine. Our apartments lay a mile apart.

• • •

You'd known all along, in your quiet, perceptive way. You looked at me with sadness the night I hissed at you not to be paranoid; it was just jet lag. The pandemic had barely begun.

• • •

By the time illness became the dominant focal point of his life, Daudet had asserted himself as a man of letters, admired for his ceaseless storytelling. Given this oeuvre, this penchant, this personality, it makes sense the sick man would bend what creative force he had left toward the shrinking circumference of life encapsulated by illness.

• • •

At first, I attribute my stomach's churn to turbulence on the small plane we took from Udaipur to Delhi, en route to home. I leave you at the baggage claim to buy bottled water. By the time I find you, wrangling backpacks, I know in that awful, inevitable way: *I am sick*.

On the plane, I watch the nausea hit you with something more than empathy — I'd just been there myself. I could still hear the roar that filled my ears as the stall door slammed behind me and my body convulsed. I don't know if the white-hot noise was something I made audibly, or only filled my ears from the inside. I felt possessed.

• • •

I remember you then: lanky and lean, with touches of feminine beauty — long lashes, deep brown eyes. I worried I might fall inside them that night our gazes locked. I had a premonition, something you'd known from the beginning.

Uh oh, I thought, as my stomach leapt: *This is it*.

• • •

His usual form, the novel, doesn't seem sufficient; but, like a good memoirist, he worries about the truth's effect on his family, considering his desire — when the pain is at its worst — for death.

Daudet's compromise: couch the truth in fiction, in which the character takes notes on illness. "This notebook allows me a fragmented form, so that I can talk about everything, without the need for transition," Daudet tells his friend, the publisher Edmond de Goncourt.

Pain calls one into the present; pockets of time pulled into sharp focus by the aperture of suffering. The reader is left to draw the moment's connection to everything else.

The result is a searing account of the minutiae of Daudet's illness, meted out over a decade, compressed into small doses. Between one entry and the next, untellable years of suffering are present on the page.

• • •

When we wake, it's like rising from the dead. Fourteen hours have passed since we were last conscious. The nightmare flight, the incompetence of the CDC at the airport, the Uber ride through a whitewashed world after the vibrant colours of India — all seen through a haze.

What's present now is you and me in our apartment, and that's all there will be for quite some time.

You notice it first, in the shower: the chest pressure, the shallow breath. I stay in bed and call my mom, and then there it is, just as you said. A "web," then, when it tightens, a "corset." Impossible to describe, but I look in your eyes and know you feel it, too.

• • •

Fatigue was the first sign Daudet's illness was returning. Then: "The 'breastplate': my first awareness of it. Suffocation, sitting up in bed, panicking."

• • •

We lie on our backs after folding laundry, without energy to stand. In the face of caring while being cared for, we are patient and nurse, often in the same moment.

This is so hard, we tell each other.

From then on, our symptoms are synchronous. And even when they diverge in the way they manifest — a vise around the back of your head, while it grips me about the ribs — they flare in tandem, as if we are two ships tossed by the same sea.

• • •

“My friends, the ship is sinking, I’m going down, holed below the water-line,” Daudet wrote. “Beginning of the end.”

• • •

Our symptoms might be aligned, but our response to them is not. You are the perfect sick man, lying on the couch inert and lifeless, still as a log. I heap blankets on top of your shivering torso, heat bags of sweet-smelling rice, or rub an ice pack into the back of your head where the pressure persists, unrelenting.

When my symptoms flare, I resist and carry on, controlling what I can of the situation by checking another thing off my list. *Put on a bathrobe*, you urge as my pain mounts with each task. *Stop cleaning the bathroom*. You sneak an item onto my endless to-dos: *Let my body rest for four hours*.

• • •

The servants watch as Daudet hides his agony from his wife Julia, standing in her presence, collapsing when she leaves.

• • •

When the pain passes an unnamable threshold, you drive me to the ER. The hospital is so close I could walk, if not doubled over by the blades twisting through my lungs. Barred by Covid restrictions from entering, you sit in the parking lot, fielding texts from family. Sometimes you leave the car to pace the pavement, but it never occurs to you to go home.

Seven hours later, I emerge, disoriented by the sudden darkness. Headlights flash from the lot. You are there behind the wheel.

• • •

Proust remembers Daudet medicating himself in the midst of conversation. The sick man leaves the room, talking through the doorway as he administers the injection without breaking his flow of thought. He rejoins the others.

Even when pain made him absent, Daudet made sure to be present.

• • •

With no answers from the ER, we begin to research. Along with our notebook, we purchase a stool so we can rest while washing dishes; we buy compression tights in men's and women's sizes, and gallons of Gatorade, all recommended for the 'orthostatic intolerance' that can follow a viral infection, making it difficult to stand.

• • •

A statue of the author in Nimes tells a different story than the sculpture that looked down on our bliss in the Champs-Elysée. Daudet's head seems too big for his body, which appears shrunken beneath an overcoat. The facial features have a haggard, drunken look, accentuated by the weary tilt of the head as he leans, the crook of one arm supported by the stone he is carved from, as if it is holding him up.

"I've suddenly turned into a funny little old man," Daudet notices. "I've vaulted from forty-five to sixty-five. Twenty years I haven't experienced."

• • •

What we assumed would take decades to arrive manifests from one day to the next, compressed into thresholds: the desire for sex eclipsed by the demand for sleep; my productive drive utterly usurped by sickness. Where there had been energy, there was lethargy; where the skin was taut, a release; where we once felt joy — exhaustion.

• • •

Clearing a hard drive, my brother-in-law sends video clips taken on his digital camera a decade before. A few are from our wedding, which he officiated. The camera frames the three of us beneath an old oak. When invited to read our vows, I recite Whitman, and you read me Yeats.

When you are old and grey and full of sleep…

• • •

From the top of my part I catch flashes of silver laced into blonde. Then my hair begins to fall out, spiralling in the cyclonic tides of the shower floor. “Hairicanes,” we dub the swirling snarls, sometimes rescuing them from the drain and then forgetting them in the soap dish until it looks like some creature has nested there.

• • •

Another depiction — this time a daguerreotype: Daudet’s hair is dishevelled, beard untrimmed. A monocle obscures the shadow under one eye, a half-moon darkens the other. “I’ve felt this strange collapse of my face and my whole body,” he writes, “a sort of hollowing-out that doesn’t go away.”

• • •

Our eyes have sunk like ships with heavy cargo, a crescent water line etched above cheekbones by some unseen freight. On bad days these lunules tinge lavender, giving us a bruised, damaged look by which we are able to measure the minute gradations of each other’s pain.

• • •

Daudet’s vision is not always turned inward. He begins to look around the rest cures where he is sent to “take the waters.” At the thermal station of Lamalou he writes of the “astonishment and joy at finding others who suffer as you do.” He notes a grotesque spectacle of diseases, records ailments and treatments. He quotes a proverb: “The illness of a neighbor is always a comfort and may even be a cure.”

• • •

After months of symptoms, I join an online support group. I discover the relief of recognition. Of comradery. Of Schadenfreude.

• • •

Daudet looks for “the fellow whose illness most closely resembles your own.” At Lamalou, he pieces together two cases: an Italian painter and a member of the Court of Appeal. “Between them, these two comprise my suffering,” he writes with satisfaction.

• • •

You come home from seeing a client, whose Covid infection has left him with a daily pressure at the back of his head. *It’s in the* exact *same place,* you say with awe, indicating the base of your own inflamed skull.

You feel awful for him. You are gleeful.

• • •

Within the support group, I'm more or less silent, lurking at the edges. Part vociferous voyeur, part heady empathiser, I am drunk on companionship, on our collective sorrow.

When sickened with it, I break away.

• • •

"The man who watches the others suffer," Daudet writes, murkily self-referential.

• • •

One day, I come home from an appointment I'd been looking forward to for months with the assumption that I'd be, if not healed, at least helped. But neither was the case. Because my illness did not appear on any tests, I'd been disbelieved and dismissed.

• • •

When the season is over and the baths close, "this whole agglomeration of pain breaks up and disperses," writes Daudet. "Each of these patients turns into a loner . . . a strange creature with a funny illness, almost certainly a hypochondriac."

• • •

When I reach the top of our stairs, I crumple. In the exam room, beneath the fluorescent lights of science, it had been as if the illness didn't exist. But here in our apartment, with its reminders of struggle: the stool standing sentinel at the sink, compression socks drying limply on the rail, your face, socked in with exhaustion — it comes roaring back, along with a realisation: we are alone.

• • •

"Only at Lamalou is he understood," writes Daudet, "only there are people truly interested in his disease."

• • •

When I couldn't convince the doctor I was ill, I'd told her about the support group. At the time, thousands had joined, reporting symptoms lingering long after Covid. Their stories, I thought, corroborated my case.

I think you'd better stay off those groups, the doctor said, eyeing the tears beginning to soak the top of my mask.

The specialist had mentioned the medical archives she would've turned to, had my diagnosis been, say, West Nile, and not a novel disease. I hadn't realised how different the support group's archive of anecdotal experience was from cases that bore the stamp of science.

• • •

Away from the baths, Daudet turns to the annals of history. Without contemporaries, there are always predecessors — those who've already succumbed. He pours over their letters and poems as if they are mirrors. He calls these men — Baudelaire and Flaubert among them, "my forebears, my doppelgängers in pain."

• • •

You bring a Zoom meeting to an abrupt end and rush to help me stand. Sobbing, I let you wrap me in a robe. Lay me down.

When, four hours later, I get up, I sign back on to the support group.

• • •

Along with the validation of history, in Daudet's observations there's acknowledgement of what is to come. He spots a professor with a more advanced case, and prophetically records his tremulous condition.

Goncourt: "He knows what will happen to him next year, and what will happen to him the year after."

• • •

On occasion, the light returns. I step out of the shower, peer into the mirror and there's a flicker of recognition; something — a self — is back. You might simply call it health.

I'm not sure you've noticed. Our love no longer relies on sparks, perhaps because amidst all the fierce dependency something has been forged in the blaze of our feverish passion, or in the hot flame of our fevers themselves. Something immune to disease in ways our bodies are not.

• • •

"I've been nervy and bad-tempered all day. And then Julia sight-reads a folio of gypsy music for me. Outside there's a storm, hail, thunder — inside, I relax at last."

• • •

And I recall the words you said, before this sickness altered us: *One man loved the pilgrim soul in you, / And loved the sorrows of your changing face…*

Poem as prophecy, a pledge made truer by time: not that the promise was empty before, but it had yet to be fulfilled.

• • •

“I walk with more confidence when I can see my own shadow,” wrote Daudet, the disintegration of his spine making his step unsteady: “just as I walk better when someone is alongside me.”

Notes

Daudet, Alphonse. *In the Land of Pain*. Translated by Barnes, Julian. Knopf, 2003.

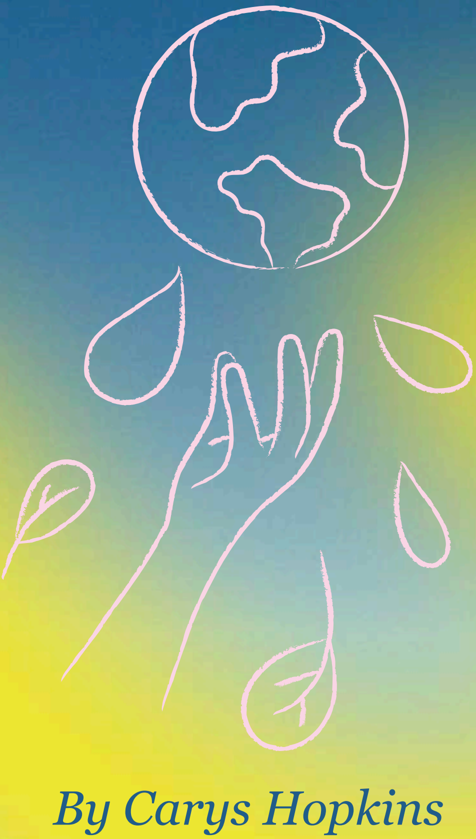
Yeats, William Butler. “When You Are Old” in *The Collected Poems of W.B. Yeats*. Collier Books, 1989.

MEGAN KENNEDY

As vessels of reflection and comfort, the objects in this ongoing series are constructed through concentrated acts of repetition as a means to help ease the effects of chronic illness. Created through the investment of already diminished energy, the Worry Stitch series is an inquiry into my own somnipathy, psychology, illness, and the soothing quality of physical repetition culminating in visually dense artefacts.

Megan Kennedy is an artist based in Canberra, Australia. Megan's textile practice focuses on the incidental and deliberate interventions or transmissions of experience to objects and materials in a given environment, and how this is often reframed in the context of her own chronic illness.

Burning Questions: why does big oil pretend to care about disabled people?



By Carys Hopkins

Carys is a Welsh freelance writer. Her interests include, but are not limited to, climate change, climate and social justice, and environmentalism. She uses her voice to question power structures that continue to abuse our people and our planet.

The past two years have been defined by the global experience of living through lockdowns, quarantines, isolation and adapting to life in a pandemic. As COVID-19 continues to disrupt our lives, we must not forget that we are currently in the midst of another crisis — a climate crisis.

Excessive human activities, namely the burning of fossil fuels, have proven too much for our planet and as a result, we all face dire consequences. By 2050, it is estimated that up to 200 million people will be at risk of having to leave their homes due to climate disasters.[1] Some of us, however, face these consequences at greater intensity and frequency than others.

The United Nations Human Rights Committee found that during climate emergencies, disabled people disproportionately experience "higher rates of morbidity and mortality, and are among those least able to access emergency support."[2] The majority of countries do not have climate emergency plans in place that meet the needs of disabled people — which is a breach of human rights and is also known as Eco-Ableism. People that aren't disabled may find it difficult to truly understand how damaging the lack of plans for preparing for climate-related events is. For example, during climate emergencies, assistive devices that help people function physically often get damaged or lost and are more often than not left out of emergency relief aid. This is effectively breaking The Paris Agreement in which member states agreed to "respect, promote and consider their respective obligations on human rights, the right to health . . . persons with disabilities and people in vulnerable situations."[3]

As part of this marginalised group facing serious consequences due to the actions of fellow humans, it was shocking to see a company that perpetuates this announce their support of an event that centres disabled people: the Paralympics. Not only did big oil company BP become a sponsor of the Paralympics, but they also joined the #wethe15campaign. I couldn't help but wonder — *what are their true intentions?*

#Wethe15 is a human rights movement which fights for justice for disabled people. Fifteen percent of the global population is disabled, yet more often than not, we are left out of the climate conversation. But when 1.2 billion of our people are facing constant discrimination and barriers in all aspects of their lives, we absolutely must be a part of the conversation. We have the potential to provide insight from our personal experiences to create plans and measures, but instead, ableism continues to prevail.

In August 2021, BP came out with a new campaign joining the #Wethe15 movement. It was part of their sponsorship of the Paralympics — though after severe backlash from the public, youth protests, and numerous petitions pleading Channel 4 to cut ties with the corporation, they were dropped as a sponsor just days before the Paralympics began, but failed to answer why. However, BP did not remove their campaign from social media, and they are still an international partner of the International Paralympic Committee (IPC).

It was a well-crafted marketing campaign to remind disabled people that BP sees them. But when big oil targets a marginalised group of individuals, it is always very calculated. The campaign was great — strong, powerful and really makes the viewer believe that BP cares about disability rights and justice. But the fossil fuel industry's product is quite literally killing our planet and our people, and perpetuating inequalities that people who are already considered unequal disproportionately face. What we should be asking is, *what does big oil stand to gain from an advertising campaign about disabled people?* In short, they stand to gain a lot.

There is no good reason for big oil companies to be on social media. It is a free tool for them to share advertising and to greenwash. Greenwashing is something we all see on a day to day basis. It is public relations, and an intense marketing campaign based upon lies. For example, today on BP's website at the top of the page it says "Our purpose is reimagining energy for people and our planet. We want to help the world reach net zero and improve people's lives". But this is not true. Since 2016, BP have spent $3.2 billion on clean energy (renewables such as solar and wind). In comparison, they have spent $84 billion on oil and gas exploration and development during that same period. They do not reimagine energy, they have kept to oil and gas since 1909 and predict to continue to use fossil fuels beyond 2050. This is past the target date for net-zero as set out by scientists in the Paris Agreement, and several IPCC reports in the past decade. It's a bold claim from one of the leading companies destroying our planet and our people.

Social media for them is merely another vehicle to drive their reckless advertising and PR campaigns. As they took their recent campaign to social media, they once again remained unchallenged. I took a deep breath and a long eye roll before commenting on their post with a link to an article titled 'Climate Darwinism Makes Disabled People Expendable', by disability inclusion activist Imani Barbarin. My intent was to challenge their new stance on supporting disabled people, as they'd seemed to forget that they make our lives a lot more difficult in the midst of climate change. They sadly went majorly unchallenged, which is unfortunately the way it goes with most of big oil's social media propaganda. But I challenge you, if you are someone that is fighting for climate justice and your justice doesn't include disabled people, to consider if it's really justice you are fighting for.

When your company is one of the top players in the game of climate change, can you really care about disabled people? The evidence is clear — from their decades of perpetuating climate change, they too have been perpetuating social injustice. And their new campaign is just further evidence of their greenwashing.

If big oil were to stop burning fossil fuels and pay reparations to society, which would be seen through changes to the law and regulations in each continent in addition to cleaning up the mess that they have made, then maybe disabled people would benefit from their support. But as it stands, the future will still be engulfed in the fumes spewed by big oil. Social injustices are rife and are predicted to continue in the coming decades — especially since big oil expects to continue to choke us and our planet for the foreseeable future.

Notes

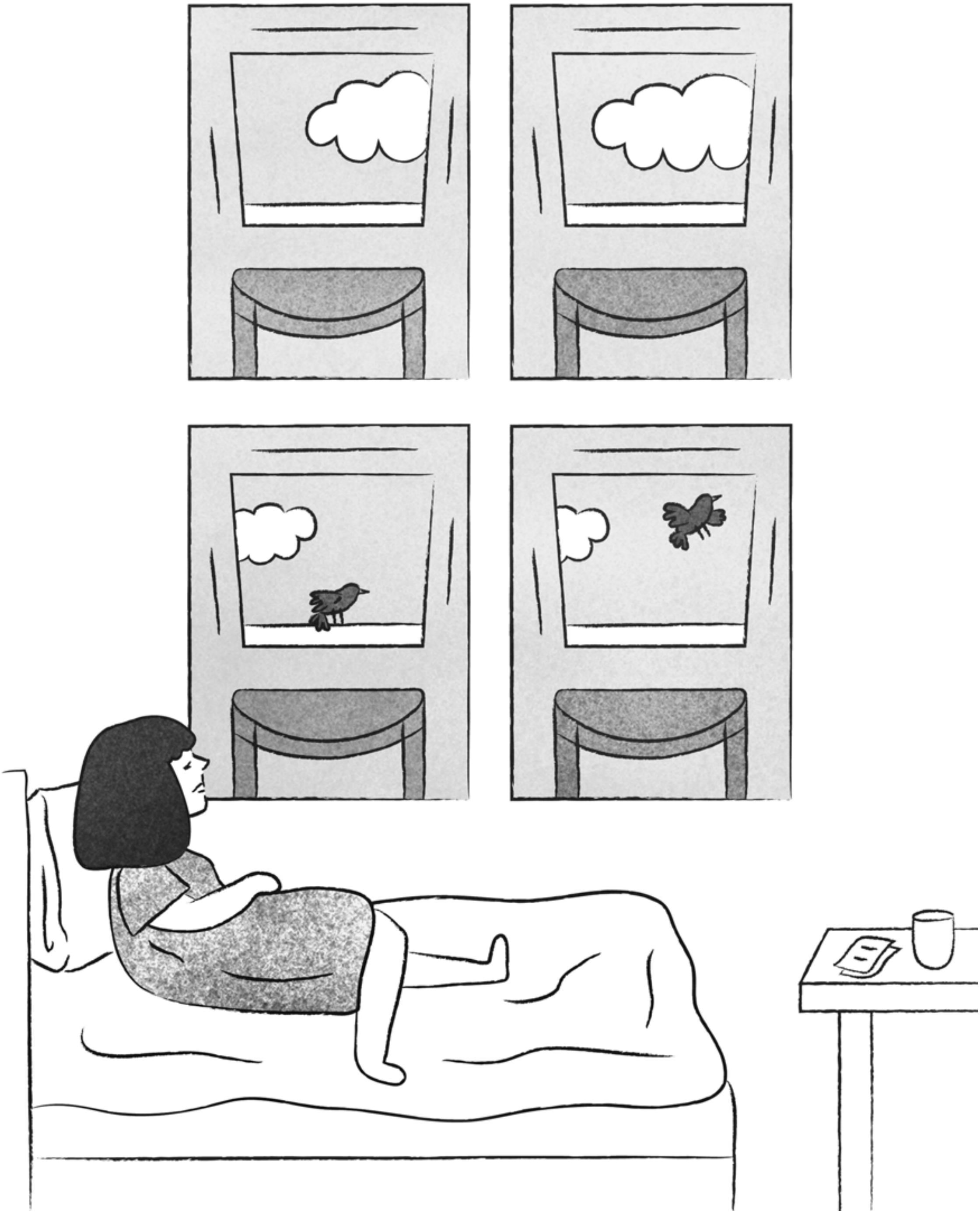
1 The Human Impact of Fossil Fuels. ClientEarth. N.P. Web. 2022. Retrieved 9 June 2022.

2 The impact of climate change on the rights of persons with disabilities. United Nations Human Rights Committee. N.P. Web. 2019. Retrieved 9 June 2022.

3 Adoption of the Paris Agreement, 21st Conference of the Parties, Paris: United Nations. United Nations / Framework Convention on Climate Change. 2015.

cover artist:

Hello! My name is FLORENCE BURNS (FLOSS)
I am 24 **years old and from** MANCHESTER.
I am currently in MY SOCKS & SANDALS ERA
and feeling MY BARBEQUE DAD FANTASY**. The
song I listen to most is** ST VINCENT & DUA LIPA'S
LIVE PERFORMANCE OF MASS SEDUCTION & ONE KISS
but I also love SOUNDTRACKS FROM MUSICALS.
TAMARA DE LEMPICKA **are the artist(s)
who inspire me most. I started making
art because** I THINK I HAVE AN INNATE DRIVE TO MAKE
ART. IT'S HONESTLY NEVER FELT LIKE AN ACTIVE DECISION.
**Something I wish I knew when I was
younger is** THAT ABSENCES, RESTRICTED PRODUCTIVITY &
STRUGGLING TO KEEP UP WITH MY NON-DISABLED PEERS
DOESN'T MAKE ME A FAILURE OR DIMINISH MY WORTH
and something I wish I knew now is I'M
ATTEMPTING TO LEARN GERMAN. I ALSO INTEND
TO LEARN BSL (BRITISH SIGN LANGUAGE).
You can keep up with my work here:
📷:FLOSSBURNS.ART ✉:FLORENCEBURNSART@GMAIL.COM



featured artist:

Hello! My name is Hatiye Garip

I am 29 years old and from Turkey.

I am currently in Iceland for an artist residency and feeling curious. The song I listen to most is the sound of wind, birds, and waterfalls but I also love Japanese ambient music nowadays.

The book that has had the greatest impact on me is always changing because I am changing too.

Nature is ~~are~~ the artist(s) who inspire me most. I started making art because I had to stay at home when I was little after having many surgeries.

Something I wish I knew when I was younger is taking care of myself first

and something I wish I knew now is not thinking too much.

You can keep up with my work here:

hatiyegarip.com

Meet the Editors: Olivia Spring & Kaiya Waerea

Hey Kaiya!

How are things with you this June? Have you had any hot days in London yet? When I lived in London I was always astonished by how consistently everyone wanted to throw parties/have bbq's/gather in parks when it was warm out. There was such specific energy and excitement on those days that I can so vividly remember, and it was so different from anywhere else I've lived. You would have thought it was the only sunny day of the year! I guess it was funny to me because everyone always said summers were grey and rainy, but I found them to be pretty averagely warm. Do you find that weather affects your symptoms? For me, the heat is pretty unbearable.

Hey Olivia,

Yeah, we have just come out of a hot week here in London, and I know exactly what you mean, summer here is like nowhere else. I always think London has such a particular smell in the heat – probably the pollution, but I love it haha. My health is usually a lot better in the summer, but this year has been different. It hasn't really changed since the winter. After spending all last week unable to really get out of bed I found out the meds I am on at the mo make me prone to overheating, which explains a lot. I have been so unbelievably exhausted (6 years with ME and it is still a surprise to me) that even talking out loud was enough to feel like cardio exercise. Still, the temperature has dropped and I am feeling a lot more able today; I spent the afternoon in my studio, and in the evening I went to the private view of my students' degree show. The latter has left me in a lot of pain (from standing up) but I have a massage in the morning!

I know exactly what you mean about being surprised by your own fatigue, even after having it for so long. For me, it's weird when I feel so comfortable inside of my illness, like I know all its secrets and how to deal with it all, and then I wake up to a big smack in the face. This feeling also ties into disbelief in the sense that if I go a while without a flare or any super bad days, I often find myself thinking my illness isn't that bad. Then when I do inevitably have an awful day or week or month or year, my mind is like, *see, you really are this sick, stop doubting yourself*. I hate this feeling because it reminds me that I really have been sick for 13 years, and so much of that time is defined by me being disbelieved, and feeling the need to prove my illness. I also got sick at such a young age, and I feel the damage done to me from the ages of 11-14, in particular, can never be undone. I'm curious what it was like for you, getting ME when you were a young adult. Were you already at uni? Did you encounter a lot of disbelief in both medical and social settings?

I totally do the same where any moment of feeling well (or *less*-bad) becomes an opportunity to disbelieve myself. I told this to my therapist once and she said, if you don't believe yourself how can you expect anyone else to? I got ME when I was a term into the first year of my undergraduate degree. I had to interrupt for a year while I figured out what the hell was going on. I find doctors believe or disbelieve depending on what is most convenient – if I ask to be tested for other things they are determined I have ME, and when I ask for help with my ME they doubt my diagnosis. It took me four years to see an ME specialist, and the specialist appointment has since mysteriously disappeared from my medical records, so GPs never believe it happened. In London, the few GPs that do care are too exhausted to do anything.

That is so frustrating! A similar thing happened to me where I waited ages for a specialist appointment, travelled from Norwich to London to get there, only to have the most pointless appointment ever. After they ran a bunch of tests and sent me their summary, it never showed up in my records, and other doctors would ask me for it because they couldn't see it in the system. It just makes me never want to go to a doctor again (which I definitely go through phases of doing)!

Anyway...

It's incredible that we are now on our fourth issue and have been working together for three years! I remember when we were first put in touch through a mutual connection — I was so excited because finding a designer was one of the most difficult parts of starting the mag — and we first met in London in the spring of 2019. I'm curious what your initial thoughts were on the project when I first reached out, and how they have changed over time?

Only three years! It actually feels a lot longer than that to me. I was still an undergraduate when we started working together. My main first impression when we first met was how totally sure you seemed that this was going to happen, of how upfront about your hopes and intentions you were, what you wanted SICK to be, and where you wanted it to go. Particularly at Goldsmiths, where we both studied, people seemed prone to starting magazines and dropping them after the first issue, and while I immediately believed in what SICK was all about, I was waiting to see how sustainable it was going to be I guess. What made me realise this was really going to work was after the first issue you asked me, of your own volition and without anything having gone wrong, what we could do differently next issue to work together better. I think I gave you some feedback about scheduling, workflow, that kind of stuff, but that let me know you were really invested in our working relationship for the long haul. How do you think your understanding, intentions, and dreams for SICK have developed over the last few years?

It's interesting, and nice to hear, that you could see how sure I was about SICK, because it is exactly how I felt. It was very much a 'I am *DOING* this' feeling. So, so much about my understanding and intentions for the mag have changed over the years, but I find it hard to put into words. I've always loved and read a pretty wide range of magazines and my initial thoughts for SICK included things like fashion shoots and favourite runway looks and affordable fashion picks. (I always hated spreads of cute clothes that were all designer — they were outrageous prices, but in affordable magazines, and I wanted to look at things I could actually afford.) It feels weird writing this because it feels so out of place for SICK now — but I think that's natural, and I'm glad things unfolded the way they did; certain things just presented themselves to me and made sense.

I remember while we were working on the first issue, I was so embarrassed by how unprepared I was for the design process, and was so worried you wouldn't want to work with me again. I sent you so many corrections because I hadn't properly proof-read everything, or even realised there were things I needed to make decisions about style-wise that I hadn't. I had never worked with a designer before and never put together a publication, so there were so many things that I just didn't know and the only way to learn was through trial and error. I do feel like, for the most part, the process has been easier and smoother with each issue, and it's something I know will always have room for improvement. Do you feel like it has gotten easier each time?

While the process of the first issue might have been a little messy, we were both feeling our way through! I was very much learning how to work with someone as a freelancer, how to communicate boundaries, how to organise a workflow with a 'client'. You have no idea how many people are 10 times more all over the place and rude to me to boot. Every issue we have learned and actioned our learning, and this issue was a dream.

You also do so much brilliant work that I'm a fan of, and I'm curious how or if your projects influence one another. As you know, I love Sticky Fingers

Publishing, which has grown and expanded a lot over the years. You are also an associate lecturer in graphic design and a member of Access Power Visibility (APV) collective. How do you manage freelancing and balancing different projects with chronic illness?

I do have several long-term projects and different jobs at the moment, and there isn't really anything that makes managing it all with my illness easy except for working with people who get it. I am lucky enough that I don't have to work in unpleasant or unsympathetic workplaces anymore. Sophie Paul, who I run Sticky Fingers with, will pick up anything I need to drop; as will Ben Redgrove and Arjun Harrison-Mann, who I work as Access Power Visibility with. It is with teaching I have really lucked out, having politically engaged co-workers who will cover me at short notice, accept my cancellations at face value, and know that it is part and parcel of what also makes me good at my job, which is my experiences of marginalisation. The students seem to understand this too, and I think it is important to set an example to them that it is okay to cancel things if you need to. Alongside these things, I also work as a support worker for artist and writer Abby Nocon. That has really made me realise how much internal shame I feel about my illness. She wanted me to work for her because I am also disabled, and have a political understanding of what that means, but I struggle with guilt around being inconsistent as someone who is supposed to be supporting her. Still, in all these relationships and scenarios, we manage them through communication, honesty, good faith and solidarity.

It's great that you are setting an example to your students that it is okay to cancel things if you need to. I cannot stand 'hustle culture' and people who pride themselves on never missing a day of work, or 'not letting anything stop them'. Like, you should totally let things stop you! We are human beings; complex, strange animals, not machines. Work-wise, did you always have an interest in design, writing, and publishing?

I've always written. I always made things too, and when I was a teenager I became more interested in design than art because I value what comes from how design is expected to act in the world — there is more risk involved to me. Not to say art-making isn't ever risky, and certainly in some contexts s art-making can be life-threatening. But to me, design is about the vulnerability of putting something directly *into* the world, and it touching the ground. Artwork is often let off the hook or allowed to float just above the surface. People ask art what it means, and people ask design what it does for them. I don't think they are necessarily the right questions to be asking either of those practices, but that's my observation. When peole ask what design does for them, it is producing futures, and I love that. Other practices develop thoughts and ideas about things, but design is the point where you act.

I have always been a big reader (I am an only child lol), but I became really interested in publishing when I got ME. Prior to that, I was more engaged with 3D making, participatory installations, sculptural interventions, and so on. When my health changed I couldn't use a lot of the workshops and methods I previously would have, and I had to develop my thinking into new mediums and scales that were accessible to me.

Last time we talked about books, I remember you saying you were going through a period of not being able to read/focus on book-length works. What are you reading/listening to/thinking about at the moment? My reading has painfully slowed down, almost to a complete stop, since we opened for submissions. I think because I'm reading so many submissions, and I'm in such a specific frame of mind when reading them, it's hard to read anything else with a fresh mind. It's also hard to find the time because when working on an issue, I work considerable more than I do any other time of year, so I feel fried. But! I just recently read *Girlhood* and *Bodywork*, both by Melissa Febos. Have you read any of her work? I think you would like both of those. I was also entranced by *A Ghost in the Throat* (such a good title) by Doireann Ní Ghríofa, which had such an interesting blend of essay and autofiction.

Reading... yeah haha that thing! To be honest, the only thing I have really read properly recently is the *Secret History* by Donna Tartt, which I read the other week while recovering from a laparoscopy. I needed something long and easy, and I love anything set in an academic context (I obviously just can't get enough!). I have been watching a lot of easy things too, *Heartstopper, Derry Girls, Drag Race*, the types of shows which are a bit like being on social media, are written for short attention spans. I am also having a bit of a pop revival music-wise. There is a trend here, which is not wanting to engage with anything too meaningful. I am tired and everything is terrifying. The books you mention sound much more interesting, I haven't read any of them. At the weekend a friend put some shelves up for me and I am mid-reorganisation though, and am coming across lots of things I bought ages ago but never got around to read, so maybe one of them will take my fancy. I know exactly what you mean about the way one reads submissions, reading as an editor. It is taxing because you are not only reading as yourself but you are reading as all of your imagined readers too. What is it about the processes of editing that you are drawn to?

I'm not entirely sure what initially drew me to editing. As a teenager, I always just thought it seemed like such a cool, fun job. I liked the idea of being more than just a writer, but one who decides what stories are important or worth publishing. I used to want to be a features editor and a profile writer. I love reading profiles, and the idea of carving out a narrative. When I interned at Marie Claire, I would eavesdrop on every over-the-phone interview and editors talking about their upcoming celebrity interviews, and I just thought it was so interesting. Now, I'm not so interested in the celebrity aspect, but like that I can decide myself what I believe is worth focusing on, rather than having to pitch it or convince someone why it's worthy. As I write that now, I wonder if that has anything to do with the fact that I have spent more than half of my life constantly proving my illness and my own worth, and that I have for so long felt that I was never in a position of power or authority, but rather having my body be subject to approval from people in power.

Editing SICK definitely feels like a unique and special experience that I can't imagine getting tired of. I would love to find a way to receive funding of some sort, because I really want to pay everyone more, be able to give out free copies, have a larger print run, be in more shops, and hopefully someday pay myself. Do you have any long-term goals or dreams?

My dreams for the future: I would love me and Sophie to be able to pay ourselves a part-time salary to do what we do, and in a dream world, an assistant or two as well. A bigger studio, more equipment, to be able to produce bigger runs and more varied outcomes. I would love my teaching work to become permanent, to one day be writing my own units and curriculum. I want a cat, and to live somewhere which isn't crumbling to pieces. I want to have books of my essays published and to stumble across them in bookshops. I want to be able to give disabled writers, artists and designers lots of money. I want to be like one of Octavia Butler's protagonists: one who knows how to deal with crises, how to build and grow on the other side.

Let's hope some of these things can happen before London becomes a floodplain and I have to move back to New Zealand to live in a nuclear safe bunker haha... how about you?

I dream of my memoir being published and someday doing a little book tour. I want someone who believes in SICK to give us lots of money to redistribute with no strings attached. I want to go to a funded writing residency every year. I would love to have a studio, or office of some sort for SICK. I dream of having enough money and energy to own a lot of land and fill it with goats and horses and dogs. I dream of universal basic income and free healthcare, and unlimited hours of guilt-free rest.

Olivia Spring (she/her) writes about illness, trauma, and disability. She lives in Maine with her dog, Black Bean. Follow her work at olivialeoraspring.com and @olivialspring.

Kaiya Waerea (she/her) is a chronically ill writer, publisher and design educator from Aotearoa, now based in London. She is interested in crip feminist methodologies, science fiction, and bodies of water. You can find her on Instagram @kaiyawaerea

SERAP ŞAHIN

Magic and feminine bodies are a through line threading through my work. Childhood memories and dreams have also a tremendous impact on my work and I use thread as a sketching tool to explore relationships, self-perception, and cultural and internal conflicts in psychological landscapes. All in all, my work represents the meeting of psychology and art. Being an artist is the only way I can relay my thoughts and experiences effectively to those who were never part of any of these experiences. It's the challenge to bring reality and imagination together and produce something that will make the viewers think deeply and feel like they are part of that story.

Serap Şahin is a Turkish self-taught artist based in Eskisehir, with a background in American Studies. She was diagnosed with depression in 2016, and started to explore embroidery art as a creative way to find her own visual language. She has been included in various group exhibitions in Europe and the USA.

Untitled

Double Date

3 Sisters

Disabled FEMINITY

by Megan Baffoe

Megan is an emerging freelance writer currently pursuing English at Oxford University. She's big on feminism, fashion, and fairytales, and keeps track of her published work at https://meganspublished.tumblr.com.

Receiving my epilepsy diagnosis at age 14 was something of a surprise. I'd always struggled with concentration and coordination, but in year 10, something started to change. My memory, always unreliable, now seemed to be genuinely faulty; I kept missing instructions and conversations, misplacing things at a rate that was abnormal even for me. I woke up with strange aches in my muscles, which often seemed to move without my consent.

Although at this time my physical symptoms hadn't escalated to a truly dangerous point, this pre-diagnosis period probably took the most significant emotional toll on me. Being 14, my aches were 'growing pains' and I was often in trouble for what was perceived as clumsiness and disorganisation, considered old enough to know better. Although I tried everything from sticky notes to timetabling to phone reminders, I simply couldn't remember all the different equipment required for the six lessons I had every day. I felt stupid and incompetent next to my peers, who didn't receive constant detentions for not having the right equipment. Eating in public made me feel anxious and overwhelmed because I was sure to be scolded or embarrassed for dropping or spilling something. I became frustrated, frightened, and resentful.

These stressful emotions peaked at a weekend destination wedding, which now — for the most part — I can no longer remember. In a cab with my family on our way back to the airport, I had my first tonic-clonic seizure. Tonic-clonic seizures are the ones that you're probably picturing: I lose consciousness, drop, and spasm. Upon waking up in the hospital bed, it was explained to me that I also suffered from absence seizures and myoclonic jerks. Absences are sudden lapses in consciousness, which were what made it seem like I was forgetful or inattentive, and myoclonic jerks are involuntary, shock-like twitches in the muscles. After a week on medication to ensure I wouldn't have another tonic-clonic seizure in the air, I was allowed to fly back home.

Prior to being diagnosed, my only real knowledge of epilepsy was what a tonic-clonic seizure looked like, and that it can be photosensitive. I was soon to learn that actually quite a small percentage of epileptics are triggered by flashing lights; in my case, the doctors identified stress, tiredness and air pressure as triggers. I was given medication to take every morning and evening — luckily, this worked to subdue my symptoms and didn't cause any unmanageable side effects, which isn't the case for everyone. I was also advised to adhere to a strict sleep schedule and to avoid anything that affects the brain such as drugs and alcohol. These restrictions have definitely affected my life more now that I'm at university. Although it can feel quite isolating, watching people suffer through hangovers or sleep deprivation eases the blow a little bit. I manage my triggers as best as I can, but sometimes, stress and tiredness are unavoidable — and air pressure, obviously, more so. Although my medication keeps the worst at bay, I still suffer a lot on 'bad days' from absence seizures, myoclonic jerks and muscle pain.

More seizures were to come, alongside restrictions, including bathing with the door locked and no more than one cup of caffeinated tea a day. I was emotionally and physically exhausted. GCSEs were fast approaching, and the work was ramping up. I decided after an assembly that I wanted to try for Oxford, which provided additional pressure to perform well. I was still very ill — with attendance so poor that I had already been advised to drop a subject — and the sheer effort required to wake up for school every day meant that I spent most of my afternoons and evenings with fatigue.

By 15, certain social routines seemed to be expected — the stigma around female body hair, for example, was well ingrained. Our school uniform code strongly discouraged us from wearing makeup, but it did little to offset the pressure from elsewhere. If not a full face, my classmates were beginning to feel uncomfortable coming into school with dark under-eyes and patchy skin.

Conformity, realistically, would never have been an option for me. My shaky hands and lack of coordination would have made makeup a remarkably drawn-out, frustrating process, and I was too tired to think about anything but the bare minimum in the morning. By this point, I had already understood what it meant to have a myoclonic jerk with a razor in hand and had no desire to scar my legs any further. (Although unrelated to epilepsy, my eczema also meant shaving wasn't comfortable.) I had already developed a healthy interest in feminism, so I felt quite indignant that these were alleged issues at all. Especially with all my other, far more pressing worries, I had no problem putting that particular brand of performed femininity to the side.

Bafflingly, other people — even adults, who I remember thinking had a lot more to worry about — didn't seem to agree that wearing makeup or shaving should be low-priority. From politely voiced 'concerns' to genuine disgust or outrage that I didn't want to engage with such things, there was at some points quite significant pressure to focus my very limited energy on my appearance. I even remember being told that not doing these things was 'dirty' or 'unhygienic.' I still find it somewhat surprising how invested people are in the idea of 'proper' female presentation — even from those who consider themselves as overall quite progressive. But, like most responses to my illness, I learned to simply use it as a solid personality detector.

Adults also complained that I didn't appear to be engaging with any 'interests' – I'd always been an avid reader, but I didn't have the cognitive space anymore. I enjoyed running, especially long-distance, but now it was considered a danger for me to participate even in ordinary PE. So I spent most of my time resting, content with my own thoughts, and often relieving my boredom with social media. Surprisingly, this was what would lead me to my much-needed hobby, as online, I found myself drawn to 'aesthetic' pages — virtual spaces devoted to cultivating a specific style.

The world these accounts created was pretty, perfect and pink — a lovely escape from the grim exhaustion of my daily life, and indulging in it didn’t require too much energy. This, I soon discovered, meant that a lot of the people running these blogs were also sick, or attempting to cope with something similarly distressing. I had accidentally stumbled upon a community. Enchanted, I began blogging as well, and soon, I was buying clothes that emulated the images I loved to consume.

The world of fashion unfolded for me from there. I became familiar with different brands — the majority of which were far out of my budget — and experimented with different styles. Although femininity held very little attraction for me as an expectation, as an aesthetic it had by far the strongest pull on me. Social media is often critiqued as a purely performative space, creating an unrealistic and unattainable bubble of people trying to outdo one another. But for me, it was far less about trying to live an enviable or admirable life and more about retreating into a less difficult world. Years later, I’m still using it as an escape.

When I started wearing pink a lot, I realised that, too, comes with its own expectations of femininity. I’m used to people underestimating my intelligence or patronising me, but again, it’s a good personality detector. Since epilepsy is invisible, I heard quite early on that ‘I don’t look disabled,’ but I’ve noticed that the sentiment is definitely likelier to come up if I’m well-dressed. Other opinions (such as ‘too much pink!’ called out to me from a bus stop) are less offensive, but I’m happy to discard them as well. My wardrobe holds a lot of significance for me now — far more than the respect of someone I have very little respect for in the first place — so I feel no need to change the way I dress.

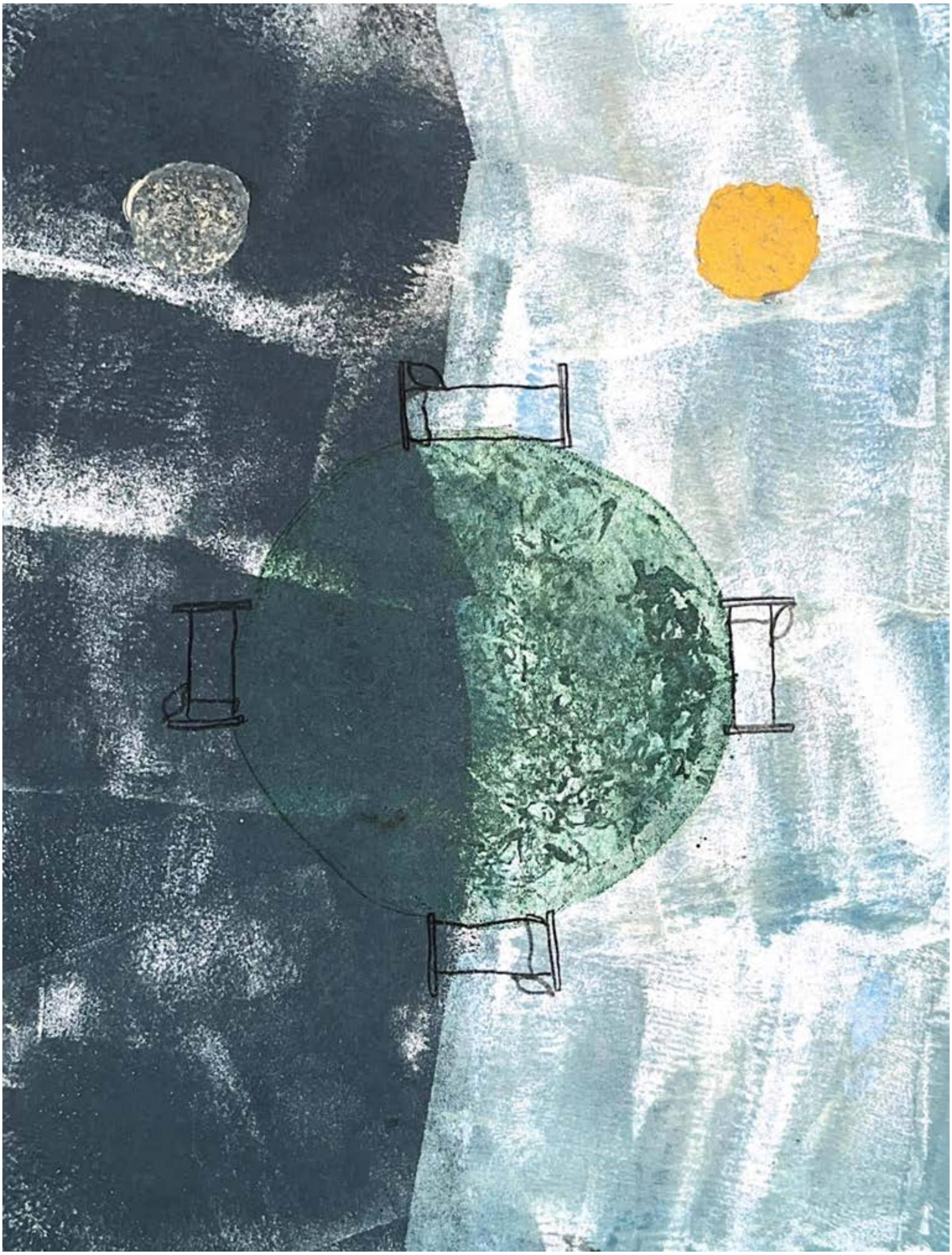
Judging by appearance, though, is a terrible thing. I wish we still didn’t live in a world where gender roles create not just restriction but even violence. Pink is still considered a ‘girl’s colour’ by many in 2022; this in itself is long outdated, as is the idea that everyone has to neatly slot into the categories of either male or female. Fashion has made me friends all across the gender spectrum — some, quite literally through spontaneous compliment sessions on the street — and I know first-hand just how significant having that outlet can be. People of all genders should have the freedom and safety to dress how they like without ridicule, speculation, or harassment.

I recently developed a new muscle condition that seems to be eluding diagnosis. Although I’ve never been one for loungewear, I now wear it a lot for comfort when I’m dealing with pain and fatigue. Even in pretty pastel colours, I’ve been finding jogging bottoms quite depressing, and sometimes I wish I could wear heels, which are simply not practical on my bad days. But the best part of fashion is that boundaries are only there to be crossed — I’ll continue to invent ways to express myself, even if it means ripping up the rule book.

EL PENBERTHY

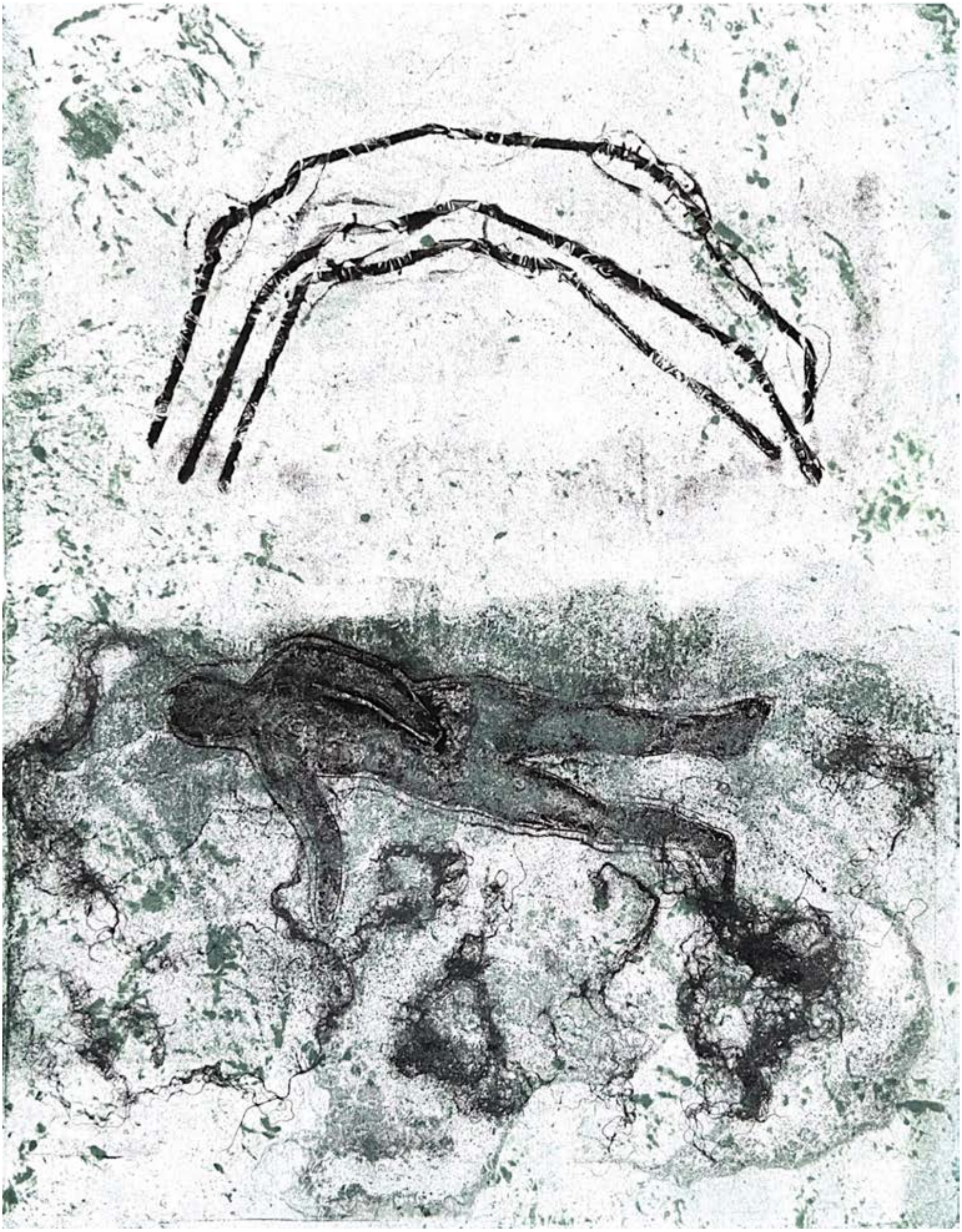
Created by layering textures, cutouts, and coloured pencil, these monoprints are part of a series exploring the suspended states of chronic fatigue. So often fatigue pulls me into hazy dimensions where slowness rules and the world revolves around bed. *Overgrown, Bed World* and *Dreamtime* attempt to make visual these abstract wordless temporalities.

El Penberthy is a sick/disabled queer artist and writer from Portland. Their work delves into the nebulous, achey realms of the sick.



Bed World

Dreamtime



Overgrown

Grieving CARE & CARING Grief

By Courtney Felle

Courtney Felle (she/they) lives between Western NY and Washington, DC. You can find their previous writing in Monstering Magazine, Glass: A Journal of Poetry, and other publications. Keep up with them on Twitter @courtneyfalling.

Content notes: grief, death, opioids, medical neglect

In my favourite memory with my aunt, I am eight years old, disabled but not yet aware of my disabilities or what they will come to mean. My mom's side of the family gathers around my grandmother's kitchen table, gossiping about their coworkers and clicking spoons against ceramic mugs as they mix too much sugar into their tea. I am not supposed to receive a mug — my mom thinks I'm too young for caffeine — but my aunt passes me one anyway, with an exaggerated wink. *We can break the rules together,* she seems to be saying. *In small acts of resistance, there is care.*

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It takes until I am 20 to receive a proper diagnosis: hypermobile Ehlers-Danlos Syndrome (hEDS). After more than eight years filled with dismissal, disbelief, partial (mis)diagnosis, and mistreatment, to have a name is a relief. To know what has happened, and to know what is continuing to happen.

"It means 'connective,' in my case, is a suggestion," I explained to my mom a few days after my diagnosis. I was trying to break it down but still felt tentative, ironically not unlike my own body's response to collagen. I showed her a few online articles. "You can think of all the science as explaining why and how I have neck pain, wrist stiffness, or any other symptoms," I said. "It gives a cause and a history."

"Huh," she said. "I always thought some people were just double-jointed. Your aunt was. She used it as a party trick, but it grossed me out so much."

Somewhere in the loosely structured lore of my aunt, I know how often she cracked her knuckles, how twisty and stiff her fingers became. Somewhere. She died right after I turned 13, still too young to feel like I had ever really known her person to person, rather than as a small observer watching a large, fascinating icon.

All my cobbled-together stories recreate her vibrant personality and warm chaos. At my family's housewarming party, she tried to microwave chicken wings on aluminium foil and narrowly avoided setting the new place on fire. She dated a radio DJ and had a brief stint of hometown fame. She shocked her sisters by getting a large, gaudy Tweety Bird tattoo across her stomach, and when she became pregnant with my cousin, Tweety Bird stretched into a muted and misshapen blob, which she later covered with an even larger, gaudier butterfly. She filled her apartment with Marilyn Monroe memorabilia. She exuded charm and an effortlessly hot persona.

And, of course, I can never consider her life for too long without my looming knowledge of her death. She had several car accidents and unsuccessful back surgeries that left her in constant, chronic pain. A fibromyalgia diagnosis and a few others layered over as her non-recovery stretched out. Her doctors prescribed opioids, and she developed a dependence on them, then became addicted to other substances and sellers, too. Loved ones tried to intervene for years; she clung to this option, and she died from an overdose. My aunt deserved so many better options for her pain than what she received.

I am still trying to understand how the political forces around opioid use and pain management swirled into such individual harm. There is no easy truth here, or even one, complicated truth to find and hold. There are a lot of small, contradicting, important truths, and beneath all of them, there is a real person. I am still trying to balance the darkest, most vulnerable details I know about her with her humour, joy, and

> as a queer, disabled, chronically ill, neurodivergent, Mad person, I cannot recall having any role model that would allow me to imagine my own possible future.

care, all as part of someone I loved and wish I could have loved longer.

When my mom called her ‘double-jointed’ and flagged her ‘party tricks,’ I knew what this might mean. With similar genetics connecting us, the question is obvious: what if my aunt also had hEDS? But how do we understand her life and death, and our own grief, differently, with information she never had the chance to learn?

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I don’t know how to discuss hEDS with my extended family. I spent the first several reunions avoiding any mention of my new diagnosis until my mom started mentioning it instead. Even now, I hesitate, waiting until someone else makes a comment so relevant that my explanations feel like small additions. As much complicated grief as I have for my aunt, I also know that her daughters, sisters, and other nieces and nephews might not want to confront the same difficult questions involved in any retroactive diagnosis or new revelations. Most of them do not come from the same perspective within the disability and chronic illness community already. I want to respect their privacy, space, and healing when my aunt’s death has already caused so much suffering and consequence.

This is an easy excuse. A harder one involves subjectivity. My illness is my illness — it is not universal, not even necessarily similar to my aunt’s experience. My diagnosis can point to probabilities and inheritance patterns, but I’m not a glowing Rosetta Stone for someone else’s potential misdiagnosis. My aunt can no longer agree or disagree with our attempts to re-contextualise her life. “Yes, this sounds exactly like me,” she might have said, had she known about hEDS. Or she might have said, “No, I’m not sure this is right.”

I want to honour her agency. I also fear, with rage and terrible sadness, that misdiagnosis killed her, like it has killed millions. This is not a coin toss — maybe my aunt had hEDS, maybe she did not, on an equal plane. If my aunt had undiagnosed hEDS, it suddenly becomes all too apparent why some pain management techniques did not work. Doctors could have used this information to offer better options and better support. My aunt could have used this information to understand and adapt to pain, fluctuating mobility, and even substance use. My aunt could have, might have, stayed alive.

And meanwhile, I am alive. I am diagnosed. I am not supported, exactly, amidst the very real cruelties of the medical-industrial complex, but I am surviving. In this context, it’s almost impossible to avoid viewing myself as an alternate timeline or reflection of her.

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I barely know how to view my survival anyway. I have spent nearly my entire life feeling like I am living on borrowed time, like a milk carton far past its expiration date. In my worst depressive flares, often triggered by erratic medication side effects (one could, based on their position, say substance use), I am still filled with that emptiness.

More bluntly, I feel like I've lived past when I was supposed to, and I'm constantly confused about what to do and how to feel now. I'm only 22 years old, but as a queer, disabled, chronically ill, neurodivergent, Mad person, I cannot recall having any role model that would allow me to imagine my own possible future. My formative years were lonely, and my lonely years were formative. My existence has felt like a mismatch with the entire world for as long as I can remember.

Examples of pitiful sick kids and angsty sick girls certainly clutter media, and with their easy cultural recall, many adults latched me to these stereotypes. But I cannot remember meeting any casually chronically ill adults who signified that I, too, might be able to live as I was, let alone ones who embraced continued vulnerability and radical compassion into adulthood. I needed community, even the hopeful promise of it, and I needed people.

I know now that these adults do exist — many more than I realised — and I am becoming one of them. But many others — an unfathomable, terrifying amount of others — have passed on to the world of disabled ancestors. Public policy, societal norms, and systemic violence have left disabled people behind, and the result is that huge numbers of us are continuing to die every day. Medical neglect, police brutality, punitive social insurance design, and sheer poverty and despair kill us all the time. Cruel inaction during the AIDS crisis stripped an entire generation of queer, chronically ill ancestors away, and similar apathy during the COVID-19 pandemic is still causing massive, irreparable death.

My aunt, of course, is one intimate example of this violence. And selfishly, I want to know what might have happened if I could have admired my aunt — my beautiful, sarcastic, energetic, headstrong aunt — as a chronically ill kid looking up to a chronically ill adult, in a world that believed in us both. I am haunted that she didn't get to live; that widespread and systemic ableism did not let her.

• • •

Back when my aunt was alive, she was my mom's immediate concert invite. They called radio stations incessantly to win free merch, tickets, and VIP passes. Once, my mom jokes, they almost ran away to become groupies. They danced all the time, and she had enough vibrance and verve that any dimly lit grocery store could've become a dance floor, too.

Grief has meant letting go of surety. I know some of what has happened, and I know some of what is continuing to happen. But other parts I can never know, not perfectly or permanently. The process of figuring out how to feel is called life.

I never attended a concert with my aunt, but my mom often invites me now. Each time, I close my eyes between songs and imagine my aunt with us. I want to hear her excitement, her bad singing voice, her gossip. I want to offer her a world of possibility in return, a world of justice and joy. *Here*, I want to say. *I still have more for you*. More simple, unmemorable moments. More mundane, sometimes stupid, wonderful love. More resistance. More care. So much care, we can survive in it together.

JOELLE BARRON

PHONE APPOINTMENT

He won’t hear
of my bleeding; it’s what

I’m bred for. To collapse
in the grocery store

is to be alive in this body,
trail of blood

and milk. Miscarried
five years ago, now

I hemorrhage every
month, new curse. He

suggests Naproxen
again, as a clot the size

of my fist slips
from me. Won’t waste

taxpayer money on
another test, won’t accept

more of my blood,
through vagina or

vial. My hands are full
of viscera so I put him

on speaker with the tip
of my nose. Any pain?

he asks, but what’s
the point in saying yes.

[Jane to Helen]

At a certain point in childhood, both of us,
with our strange haircuts, realised that to earn

love we must learn to be Real Girls. So we studied
Cosmo and *Teen Vogue,* wiggled mascara wands

to prevent clumping and traded colourful
Northern Getaway sweatpants for low-rise

jeans and overpriced American Eagle. Still,
we couldn't stuff down our screaming

strangeness. The changeling myth is thought,
by some, to have been inspired by autistic

children. Such happy babies we were,
said our mothers, until one day a faraway look

invaded our eyes, and we were no longer easy.
Our struggle contained, little worms eating away

at our bright filaments. We didn't know
that the fairies had brought us to our real selves,

and that "girl" was a mask,
though we wore it well, and still do.

Joelle Barron's first poetry collection, Ritual Lights (icehouse press, 2018), was nominated for the Gerald Lampert Memorial Award. In 2019, Barron was a finalist for the Dayne Ogilvie Prize for Emerging LGBTQ Writers. They live on the Traditional Territory of the Anishinaabeg of Treaty 3 (Fort Frances, Ontario, Canada).

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RECOMMENDS

My life,
though
different than
I may have
imagined it,

is still mine.

— Grace Vedock

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