

# SICK

ISSUE 01





# SICK

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Olivia Spring

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*£5 RRP*

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# Editor's Letter

I was 11 years old when I got sick. I went to bed one night as a healthy kid and woke up with a pain in my body that I would still feel eleven and a half years later, as I write this letter. This pain has been with me for so long, I can't remember what it feels like to not be sick. I can't remember what it's like to wake up without at least one symptom to remind me that this is who I am now - a woman with chronic Lyme disease.

I am lucky in so many ways - to be alive, to have a diagnosis, to have received an education, a degree. As I got older, however, I realised how difficult it would be to find a space for myself in a society that places so much value on being reliable, consistent, hardworking, and able-bodied.

When I was fired from my waitressing job for being 'unreliable', I was scared that I would never work again. It didn't matter if I wanted to be a part-time bartender or a full-time journalist, the word 'reliable' was always in the job ad. Was there no middle ground, no flexibility or empathy offered in the working world?

My body is not reliable, and probably never will be. It doesn't give me a heads up when I'm going to be up all night with joint pain or suddenly unable to stand for more than a few minutes. But as a person, you can still rely on me to be honest, kind, and to do the best I can if I'm given the accommodations I need. I found myself in a space I call the 'in-between': I was able to do work, but on my own terms. And most jobs won't consider someone who can't do anything before noon and has no control over her symptoms.

With 13.9 million disabled people in the UK and 15 million living with chronic illness, I knew my experience wasn't unique. According to Scope, disabled people are

more than twice as likely to be unemployed compared to non-disabled people, and on average spend £570 more a month on living costs. And while disability and illness affect everyone differently, I knew there were other people in the 'in-between', too.

Instead of trying to navigate around it, I wanted to occupy this space and make our existence heard. I wanted to work, but in an environment where I didn't feel guilty or get yelled at for needing a day off. I dreamt of others who felt the same joining me, all of us being unreliable and sick and supportive together. I wanted, so badly, to be the employer that offered all the things I desperately needed. This is why I decided to start SICK.

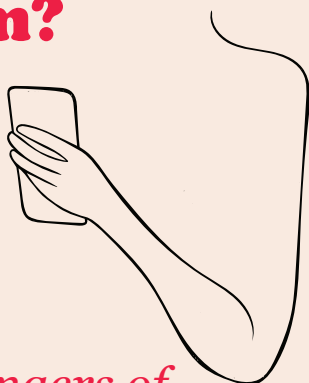
SICK is a space for those who need one. We are completely written and created by chronically ill + disabled people, exploring topics beyond just illness and disability. Issue 01 is just a small preview of SICK, with a much larger issue 2 on its way. I want to thank everyone who submitted to this zine, and the wonderful contributors who shared their ideas and work with me. SICK wouldn't be possible without you.

While putting together this zine, I had major imposter syndrome. I wanted more time to gain experience working in publishing, writing, and editing - but the reality is that I am physically not able, so I am trying to embrace the idea of learning as I go. I realised that is what SICK is all about - pursuing something that you otherwise wouldn't have access to because of illness or disability.

I hope you enjoy the essays, features, stories, and art that are in these 34 pages.

With love,  
Olivia Spring

# What's The Harm?



## *The Dangers of Social Media While Managing Chronic Illness*

*by Natasha Lipman*

*Natasha Lipman is a journalist, chronic illness blogger, and collector of vaguely obnoxious do-gooder titles from London. You can find her on Instagram @natashalipman, where she writes about everything from her wheelchair to wellness and flare ups to fashion.*

If you scroll through any of the major chronic-illness-type hashtags on Instagram, it's pretty hard to avoid pictures of food, juices, 'natural supplements', and people beaming as they proudly declare that they're 'healing' their illnesses through diet. I should know, I used to be one of them. Well, I never did the beaming thing. But I did post pictures of food that the internet had convinced would make me better. And whilst it may seem as though these images are harmless - people just sharing how they're trying to manage their conditions, after all - things can be far more problematic and dangerous than they may appear at first scroll.

I've lived with Ehlers-Danlos Syndrome for as long as I can remember, and in my mid-twenties, shit hit the fan when I developed PoTS and Histamine intolerance. Confined to my bed, barely able to stand, and unable to eat, I thought my life was over. When I'd exhausted all the options that the doctors had to offer, with many of them making me even more unwell, I felt abandoned. So I turned to the only doctor I could think of: Doctor Google. Within an hour, I'd found people my age, with the same conditions, who claimed they had 'healed' their illnesses by changing their diet, and overnight I went (get ready): gluten-free, vegan, 'sugar'-free, low histamine, high nutrient, anti-inflammatory, and rotation.

What was the harm, right? I could hardly function anyway, and it was just food. It seemed so simple, so easy. I was angry that none of my doctors had ever talked about diet and nutrition to me before. I didn't think

that people would be sharing this information, that there would be books and documentaries by people with legitimate-sounding qualifications, if it wasn't genuine. So why did I, someone who otherwise prides themselves on their critical thinking skills, get sucked into something that ultimately had no scientific evidence?

"I think when people are diagnosed with a long-term chronic illness or health condition, they want to exhaust all options that they've heard may have the potential for a cure," says Harriet Smith of Surrey Dietitian, who also lives with chronic illness. "Unfortunately, this often doesn't happen. I think it's probably quite a natural way of coping with a long-term diagnosis. People are often at a vulnerable time in their life, and when people are vulnerable, it's when they're probably more susceptible to pseudoscience and misinformation. It's very easy to be swayed into the world of faddy wellness cures, like celery juice."

The testimonial can be a powerful draw, and when you see people claiming that an intervention as seemingly innocuous as changing your diet, it feels like an effective yet simple way of helping yourself. But what many people may not know is that there is no scientific value to many of these testimonials. Experts have spent years trying to debunk certain trends, such as the Medical Medium's claims that a spirit gives him diet advice that will help cure people of everything from eczema to thyroid issues. Other trends such as the Keto diet (which is prescribed to help some people control seizures) and restrictive vegan diets

spread like wildfire on Instagram and Facebook, and are touted as miracle cures for all, often leaving patients feeling like failures when they don't get the results they're promised online.

A few years after its heyday, we're starting to see more of a backlash against wellness and clean eating in the mainstream media, but it's something I still often see in chronic illness spaces. On top of this, we also see people being shamed for taking medication or eating an 'unhealthy' diet, which can also be just as damaging - there have been well-publicised cases of people dying of treatable cancer because they turned to the false promises of the diet cure.

Whilst these are obviously extreme cases, it should give us pause for thought. Smith explains the dangers we should look out for, saying "just because something involving diet has been shown in clinical trials to work well in healthy people, for example probiotics, there's not a lot of data for people with specific health conditions. Just because it's good for someone who's healthy, it doesn't always mean it's suitable for someone with chronic illness, so you always have to ask for evidence."

It's difficult when you feel abandoned by doctors with little support available to help you figure out how to actually live with a long-term condition, so is it any wonder people are seduced by these false promises? Alongside the potential medical dangers, the sense of guilt that someone can feel when they aren't able to cure their (incurable) illness can be overwhelming, especially

because social media can reinforce these beliefs to an almost religious fervor. Constantly ‘fighting’ my body stopped me from getting to a place of acceptance where I could learn to live with my illnesses, and that has been the most transformative experience for me.

That’s not to say that lifestyle doesn’t play a huge role in managing chronic illness. We are all so different, and how we manage our conditions varies dramatically. There’s also a huge amount of privilege that comes along with being able to get the support to safely manage or treat chronic illness. But we all have a responsibility to be aware of how our actions impact other people online. There are so many reasons why people may believe a particular intervention worked for them, when in reality it may have been something completely different. There’s so much misinformation floating around online, and we all need to be aware of this, especially when we’re in a vulnerable place with our health. The best place to start? Ask for evidence from qualified professionals, Google the claims made with the word ‘pseudoscience’ and see what comes up (there’s often tons of people debunking this stuff!), and don’t take medical advice from someone you follow on Instagram. ●



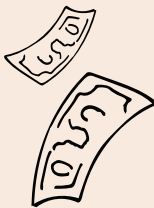
***Things I've Seen, Not Seen***

*by Marie-Louise Eyres*

a mystical fox sneaking up to my leg in the night while I make tea  
a small dragon hiding in the shrubs waiting to pounce -  
then slinking away into shadow  
so the dog doesn't bark or pull on the leash  
my grey cat coiled and asleep on the spare bed  
with a blue and white tamarind cover  
but it's not the cat -  
it's my dark tartan nightshirt  
discarded in a heap  
I see things that aren't there  
and I see things that are wrong  
I see my strong legs that take me walking  
and walking for miles on end  
and I honestly don't see  
how I can be all clapped out  
just yet.

*Marie-Louise Eyres is joining the  
Manchester Writing School in  
September 2019 to upgrade her MA  
in Poetry to an MFA. She is currently  
working on a sequence of poems called  
"Imagined Afflecks".*

# When it Comes to Dating the Ultra Wealthy, Let the Buyer Beware



by Rachael Brennan

*Rachael Brennan is a freelance writer from Connecticut. Her work has been published by Glamour, Cracked, and Rebelmarket. You can follow her on Twitter @rachaelbwriter where she shares funny thoughts and pictures of puppies.*



Matchmaking is a profession as old as humanity itself, with examples found as far back as the book of Genesis and the works of Aristophanes. There are still professional matchmakers working today, but in 2019 it is far more common to find a match online than it is to hire someone to help you find your true love. Almost anyone who has ever used an online dating site can tell you stories that are both hilarious and adorable, from first dates gone awry to meeting the love of their life, but there are some stories from the world of online dating that would shock and appall even the most jaded Match member. In the wake of the college admissions scandal in the U.S., where celebrities, CEOs, and other wealthy elites were found guilty of bribing college admissions boards so their children would be guaranteed entrance to the university, stories are coming out about the seedy underbelly of limitless capitalism and the world of online dating is no exception.

Several months ago, I applied for a freelance writing job that had been advertised online. The ad mentioned helping shy, wealthy men with their online dating accounts. Thinking that sounded cute, I applied for the position. Upon filling out the application, however, I realised there was more to the job than just helping rich guys fill out their profiles for eHarmony. It turns out they were hiring writers to actually pretend to be the men in question, texting and messaging back and forth with unsuspecting women while the men did other things – I’m assuming work, given the cost of the service, but I wouldn’t know for sure. Neither would the women “he” met online, for that

matter. It became clear that the very first time these two people would actually interact with one another would be on their first date, but only one of them would actually be aware of that.

When it comes to dating, almost everyone gets a little help. Professional stylists and photographers help people look their best, while 91 million people worldwide take advantage of more than 5,000 active dating sites and apps. It is also fairly common to reach out for help setting up your profile, with 22 percent of people receiving guidance from friends and family when setting up their dating accounts, according to Pew Research Center. Getting some assistance with the dating scene is perfectly normal.

This modern day, horror story version of *Cyrano De Bergerac* is a completely different thing. Wealthy people have always had access to different goods and services than your average person, from their own version of eBay where you can buy multimillion-dollar private jets and private islands to pills that make you poo gold. While the average billionaire isn't likely to casually throw up a profile on Plenty of Fish, I'm sure whoever they connect with on Millionaire Match would expect to actually be messaging the man featured in the profile.

Hiring writers to pretend to be someone they're not also seems potentially dangerous for all parties involved. Both the U.S. and the U.K. have laws against fraud and deception, especially in cases where bodily harm is involved. This means the person

impersonating the man in question, as well as the man himself, could both potentially be taken to court if the date goes the wrong way. All legalities aside, the person who was hired to do their best impersonation of a loveable millionaire could have many sleepless nights ahead of them if they helped bring together a couple and one of them hurt or killed the other.

Unfortunately, one of the things that money can't buy is a moral compass. Hiring someone to impersonate you on a dating site is just the tip of the iceberg. Beyond the aforementioned college admission scandal, wealthy people have been known to pay disabled people to accompany them to Disney World so they can jump the line, hire emergency rescue services while leaving non-wealthy people without help, and even pay up to £7000 to have young blood transfusions, where they have the blood and plasma of teenagers and young adults pumped into their bodies in hopes it will have a rejuvenating effect. That exorbitant sum doesn't go to the donors themselves, of course, but to the questionable entrepreneurs who decided they could convince people to pay for this service.

As one of the 5 percent of Americans who married someone they met online, I'm inclined to see the industry through rose colored glasses. That being said, if I found myself in a position to use the services again, I might insist on having a video chat with anyone I was considering going on a date with in the future, just to make sure I wasn't talking to a university student or stay-at-home-mom earning £15 an hour to woo me. ●

**#Why  
Disabled  
People  
Drop  
Out**

*by Ruby Jones*

*Ruby Jones runs Chronically Cute Cards, where she sends out free, handmade cards to chronically ill people. She loves reading, writing and fighting stereotypes that surround what it means to be disabled. Follow her on Twitter and Instagram at @Chronicallycute.*

I was only a few weeks into my first year of university when I realised how difficult being a disabled student could be. At times, it felt like a near-impossible task. I was once denied necessary transportation assistance because my illness was deemed 'not serious enough', and I have been placed in inaccessible seminar rooms located on the top floor, meaning I either had to miss classes or traipse up a flight of stairs and be in too much pain to participate effectively. I luckily had supportive tutors to help right these wrongs for me, but unfortunately, this kind of support is not as common as it should be.

The education system is inherently ableist – whether it be being graded on attendance or required to participate in sports day - and many students are simply forced to leave. Deaf activist Christine Marshall recently created a hashtag on Twitter that highlights these experiences, called #WhyDisabledPeopleDropOut. Although I have been lucky to stay in school, my experiences have shown that discrimination against disabled people within the world of education is a widespread issue.

Chrissy, @life\_laughter\_ '#WhyDisabledPeopleDropout was created to expose the frustration and challenges disabled students face daily in public institutions. Becoming exhausted from advocating for yourself is valid af and the educational system wasn't developed for disabled people to succeed.'

When I first showed signs of Ehlers-Danlos syndrome during secondary school, my teachers were incredibly supportive and allowed me to work from home a lot of the time. A few years later, I was allowed the same flexibility when I developed severe anorexia during my A-levels. I was very lucky to be supported through this by my teachers, my doctors, and my family, without which I would most likely not be where I am today: about to enter my final year of university. My family and I spoke directly to the school about making changes for future disabled students as well as myself, including disabled parking spaces, automatic doors, and regular meetings with teachers and tutors. While these may seem like simple things, they are not always provided, and I would have seriously struggled without these accommodations.

Erin Novakowski, 17, recently tweeted a photo of herself at graduation, explaining that the stage was not accessible and therefore as a wheelchair user she was unable to cross it – a pivotal moment for most graduates. Erin explained that she faced many oversights when it came to her school and their access. “This included everything from teachers speaking to my education assistants instead of me directly, to having to sit at the very front of certain classrooms, separate from my classmates, because of stairs.” Erin says that the school was apologetic and changed their attitudes – yet the physical layout of the building is still inaccessible.

When it comes to access at university level, things began to get a little more difficult for me. I was given an accessible bedroom and bathroom in my first-year halls of residence, but that is pretty much where the support stopped. If it wasn't for the incredible staff and teachers in my department, I definitely would have dropped out. Despite it being clearly stated on my timetable that I required an accessible classroom, my seminars were always in rooms on the top floor, which was a nightmare. I was once given an incredibly low mark for my seminar participation grade due to my lack of attendance, despite meeting with my tutor out of hours multiple times to catch up on all the work I missed. Being penalised for my lack of attendance, which is not something I can control, was incredibly frustrating and unfair. I was dismissed immediately when I suggested they take another look at the grade.

Mia @AwkwardAutist

'Showed up to class hooked up to an IV and fluids. My program coordinator called an ambulance and told me I wasn't allowed back on campus until I was healthy.  
#WhyDisabledPeopleDropOut'

Amber Wolfe, who has autism, depression, and anxiety, told me that she had to drop out due to a lack of understanding and inaccessibility. Amber took part in the hashtag by explaining that her professor refused to grant her a one-day extension after she spent the entire weekend in the emergency room due to a medication complication. “Every day in her class was anxiety-inducing,” says Amber. “I felt I was constantly being shown how I didn't measure up to the other students, with no way to come out on top.” This professor, who consistently made Amber feel like she was competing with the other students on an uneven

playing field and wasn't welcome in the class, has now gone on to receive awards for her 'brilliant' work within the autism community – a terrifying thought that Amber says “had a severe impact on my mental health and grades.”

While disabled students do their best to succeed within a structure designed for able-bodied people, it's not uncommon for teachers to actively encourage their students to drop out. Charlie, 21, dropped out of both secondary school and college due to access requirements not being met. Charlie missed classes due to therapy appointments and fatigue, which led to them falling behind on work. They were even told they couldn't attend their prom because they were not up to date on assignments. “I was made to feel as though I didn't belong, and my disabilities and access requirements were a burden,” says Charlie. Teachers and other staff members pressured Charlie into dropping out, saying they ‘were not cut out for education’, leaving them feeling even more isolated and unwelcome. However, Charlie says that the hashtag “made me feel less alone, as I've been able to find other people who have dropped out - which used to be a source of shame and embarrassment for me.”

Jenna @thisisjennaf

#WhyDisabledPeopleDropout During transfer orientation we had to go see a motivational speaker/comedian who made fun of/mockd my interpreters in front of the thousand person crowd. I wanted to drop out and school hadn't even started yet.'

This hashtag has brought attention to the wide range of injustices disabled students face, from people with undiagnosed conditions being refused services to being shamed and disbelieved by faculty and other students. It is clear from these stories of experience that the current system of education is set up in a way that forces disabled people to fail. It also goes to show that those who do graduate have done so by having to navigate ableist policies and attitudes. I hope that hashtags like #WhyDisabledPeopleDropOut begin to highlight the current ableist environment in which disabled people are learning and growing up in and that it will eventually spark a chain of change that will make disabled kids able to go to school without having to fight for it. ●

# Mimi Butlin







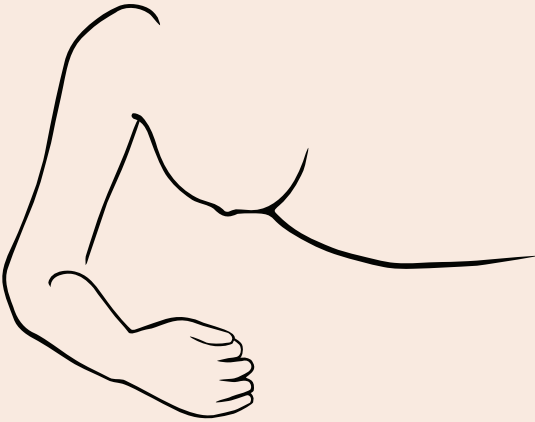
*Mimi Butlin is the artist behind @cantgoout\_imsick. She makes illustrations that focus on chronic illness and disability. She is particularly interested in the 'gender-pain-gap' and how women and other marginalised groups are less likely to be believed in their pain and not taken seriously by the medical community.*



WHAT DO YOU  
DO FOR A LIVING?

SLEEP, CRY.  
WATCH DAYTIMET.V  
YOU?

**“You Can’t Blame A Man For Trying.”**



***A Conversation on Youth, Girlhood,  
and Insidious Sexual Pressures  
by Eleanor Persić***

*Eleanor Persić is a pro-labour, feminist, and otherwise leftist Canadian writer who focuses on gender, labour, and social movements. She is also still grappling with her recent epilepsy diagnosis.*

“Wasn’t that the dude who called you dykey?” Clémentine’s eyes widened and then narrowed again as she tried to remember the details of my old story. “Wait, tell me that story again. I love how you tell it.” She was talking about the first night I spent with a man we nicknamed Shitty Max, a twenty-six-year-old I had briefly dated in my late teens. “I was lying on his air mattress in the middle of his empty bedroom just staring into the abyss,” I said. “I couldn’t stop thinking of armadillos. I kept trying to remember what they look like.” I hadn’t thought about that night in a long time; as I spoke, I felt the feeling again. I envied armadilloes for their built-in armour, for being able to curl into a shield. But I wasn’t an armadillo, so I laid there, my soft belly bare, waiting, until he asked me to touch his penis and the idleness of it all suddenly became too unbearable and pathetic to stand. As I walked home, I thought about how they say dogs can smell fear, and I wondered if that was true for men and shame as well.

It was a beautiful day. Clémentine melted into the chair, one leg up on the armrest, her arm flopping towards the ground. She had turned twenty-three just a few days ago; we were now all in our mid-twenties and had survived together the tumultuous years that mark the end of girlhood. “Stories like that were the foundation of our friendship, if you think about it,” said Rosa. She was an old friend: she had gifted me the first bottle of liquor I ever owned. She had hit a rough patch with Dimitri at the time, a caring but dysfunctional man thirteen years her senior. They started seeing each other after having sex in a walk-in fridge at work; she’d later describe it to me as ‘the physical act of porking’. In one of our first conversations, Rosa told me about waking up on Dimitri’s parents’ living room carpet with his fingers pawing at her waistband.

“I’d flirt with someone and end up in bed with them. I wondered how I was supposed to know if I was into it,” she said. “During sex, I’d be staring at the ceiling thinking ‘Damn, I’d love a taco right now.’ But I’d keep seeing the guy. I’d not enjoy a single minute with him and keep seeing him for months. That kind of

seemed like the thing to do, you know? Like pursuing sex was inherently revolutionary.”

I thought of my grandmother, who could barely afford groceries as a teenager. The birth control pill, which had recently become available, was a distant dream. But pill or no pill, it was the swinging sixties: women were liberated, apparently, and men didn't feel they had to fear pregnancy when having casual sex anymore. What could they have expected but to fuck plentifully now that gender equality had been achieved?

I met Shitty Max not long after I turned eighteen. He was handsome enough and finishing a prestigious masters degree, but most importantly, he was of that prized age that seemed safe, but also made me feel mature, and therefore sophisticated. He was a 2010s-era eligible bachelor – nevermind that I had never felt any attraction towards him. With him, my friends' stories sometimes felt like a cheat sheet. The first time I had sex with Shitty Max, I remembered the story Rosa had told me about Dimitri and his parents' itchy carpet. I thought about this as Shitty Max slobbered all over my legs. As I waited to feel something, I remembered the indifference Rosa had described and thought, *Huh, I get it now.*

“I think we sensationalised this stuff for each other. I started collecting these random hookups and during sex I'd think, 'Wow, I can't believe I'm doing doggy in a grown-ass man's Scooby-Doo bed sheets,' and it'd be another card in this absurd stack of horrible sex stories we pulled out at parties,” Clémentine continued. “So many times I wanted to leave. But I never did, because I couldn't convince myself I was miserable enough to justify making an awkward exit. So I'd just grit my teeth the whole way through.”

“Me too,” said Rosa. “And I'd find an excuse to make it feel like a powerful choice. It was that 'weaponised femininity' thing, remember that? There was that gif that went around on Tumblr - a woman in a slinky evening dress sitting on a guy's chest, limply holding a gun, looking vacant while smoking a cigarette. And the comment said 'eyeliner sharp enough to kill a man.’”

“You’re right,” I said. For a moment after Rosa spoke, I couldn’t quite remember why we had idolised that image so much. “For some reason, there was that idea that if only we catered to men enough, if only we could be cavalier enough about sex, then we’d be subversive. Like if we were good enough at manipulating men, then we’d control how they sexualise us. I don’t know about you guys, but for me, sex usually felt... fine at best. The reason I had it most of the time was because I used it to pretend I was taking power from it.”

My relationship with Shitty Max had never been formal, but it spanned over a handful of years in sporadic, weeks-long bursts. In retrospect, my time with Shitty Max was not dissimilar to my cappuccino habit. I always ordered one, assuming I wanted it by default, and would only realise how nauseous I felt once I had it in my hands. But I’d drink it, not enjoying a drop, making myself sick, resenting myself the whole way through.

“The history is weird,” said Clémentine. “You look at the history of the free love movement, all the activism that happened around the birth control pill - a lot of the history of sex-positivity was radical. The idea was that institutions should not control sex; people should. Women should. And a part of that idea was women seeing their bodies as a place of pleasure, a thing to enjoy and not fear. I guess that message kinda missed me when I was young. People said ‘no is no,’ or they’d push for enthusiastic consent - but I only really understood those things conceptually. Even knowing about the history, I never really internalised that I don’t have to have sex that feels mediocre.”

I once asked Shitty Max why he didn’t cease the physical act of porking when I started physically recoiling to his touch. I knew I had consented, even when he had checked in with me during sex, but I didn’t understand why he didn’t take that as a sign to stop. “You cannot blame a man for trying,” he said. He said it with a hard emphasis on ‘cannot’. I couldn’t help but read some admiration into it, like it was a man’s god-given right to try to fuck, and Shitty Max wished only that he’d try more.

“I always had that moment when I knew I was going to sleep with someone new. That trepidation and excitement and anticipation.” As Clémentine described this, she sped up, mimicking the trepidation. “But I was also wildly nervous because I knew it could go great, or it could go horribly. And I always just accepted it, because either way, it would be something, and when I was eighteen that felt like the most I could ask for.”

I thought of one night when I went out with Shitty Max. I was dancing, he left for drinks, and suddenly I was trapped by three men who’d been circling me like hawks all night. “Did I want a shot? Come on, have some fun. Just a shot,” they said. One of them pulled my hands onto his waist, awkwardly moving my hips at the beat of the music. “Come, dance with me. Why don’t you give me a kiss? Just a kiss.” I was backed up against a wall, and his lips kept finding mine no matter how much I tried to move away. Finally, Shitty Max came for me, and I flung myself into his arms, clasping onto his hand. I thanked him the whole ride home. Later, as I froze up in bed, he said: “Hey, I’m sorry that happened to you. But you can’t blame a man for trying.”

Still, my grandmother was in the back of my mind – both of my grandmothers, in fact, all of my friends’ grandmothers, too. I was thinking of every woman who went through puberty at a time when men made it sound like copious sex, regardless of quality, was freedom. That it was empowering for women to have sex, and that as long as there was verbal consent, men could wash their hands of any responsibility.

“I know what you mean,” said Rosa. “It was like, if I don’t go through these things, then I’m not a real adult. I haven’t suffered as much as other women, and I’ve cowered out of femininity.”

“Do you still feel like that? I do, sometimes. But only sometimes. It’s better than it used to be.” And at twenty-three, that felt like all I could ask for. ●

*Names have been changed.*



## **Pain**

*by Neff Maxwell-Kavanagh*

Nerve pain feels like static, I don't tell them -  
Feels like hot car doors on summer days, lightning fast  
and so sudden that you flinch  
But from within your skin, as if you, too, could be driven away,  
radio up, windows down  
And escape

When there's deeper pain, I don't say -  
I am a mine, emptied of all worth and slowly flooding  
with cold, dead water  
No fish to swim, no birds to gather on my shores,  
And still

Brain fog is like being lost, I never mention -  
Adrift in my own head, the geography confusing  
and twisted out of shape  
Until my mother's name is as alien to me as if I had arrived  
on a distant planet for the first time  
And stepped out

*Neff Maxwell-Kavanagh is a short, excitable writer of both poetry and prose. Their favourite things are watching wrestling and spending time with their wife and cats. They write about disability access and wrestling at [www.rasslinrehash.com](http://www.rasslinrehash.com). Their Twitter is @neffactualism.*

# Pam Jones





*Pam Jones (1934 - 2018) was born in Niagara Falls, New York. She earned a masters degree in fine art from Rosary Hill College and worked as an artist in Buffalo before moving to Maine in 1970. As a single mother of six, she continued to make art throughout difficult periods of depression.*





Barbara Jones August 1980





**The Sound of  
ecnelis**

*by Mairi Macpherson*

*Mairi MacPherson lives in the Scottish Highlands, where she grows vegetables with her husband Seamus and their many pets. A former academic, Mairi became ill with ME and PoTS a few years ago and now gets frazzled by noise.*

Not all silences are equal. Some are more silent than others, and some are noisier. Our house for example: it creaks and shifts and sometimes birds walk across the roof and sometimes mice scurry through the walls. Sometimes I can hear bits of rubble fall down in the wall behind my head, and I can distinguish between different kinds of rain from the sound each makes on the skylight. I always know which cat is padding up the stairs – Nigel thuds with each step while Penny walks silently with only a hint of the jingle from the little bell on her collar. I've learnt the sound of each neighbour's car as they come home from work, and the pattern of their footsteps as they walk their dogs. I know when the geese are back and when the sheep are particularly angry and when the chickens are hungry. I can tell all of this from the darkness of my bedroom, with the curtains closed and the windows shut. Double glazing only filters out so much. And so do earplugs: the silence they create is like a soft cloudy pillow that cradles your head gently and makes you feel like you've just woken up from a long, involved dream.

I have become well acquainted with the sound of silence over the past three years. I spend at least 20 hours a day in bed, with no music or audiobooks or radio chatter to break the silence. I can only tolerate sound in lower doses, and I save my entertainment for the evening, when Seamus is home and we watch an episode of a TV show or listen to one side of a record. Quiet shows are a must – most modern films and TV shows have too much background noise and music and explosions and shouting for me to be able to take, but the comforting repetitive noises of the bridge on TNG and Voyager are just about doable.

There are always noises. Right now, I can hear: a plane overhead in the distance; Penny scratching her ears, her bell jingling; Seamus measuring out pasta for this evening's dinner while listening to a documentary; our dalmatian breathing softly next to me on the bed; a lone sheep in the field at the bottom of the garden

calling for its mates. You might not even notice these sounds, but for me they are always there. They are all constantly competing for my attention, fizzing around my brain like the bubbles in a champagne glass. I don't often leave the house, but when I do I wear little foam earplugs to be able to cope with the music in shops, or the chatter in cafes.

I haven't always lived in a silent world. I used to be an academic, rushing about from class to meetings, and surrounded by people all day long. Before I became ill, I worked in an open plan office that contained 52 people, phones, computers, photocopiers, coffee makers, and a drippy tap. For awhile I kept a record on the noise levels in there: it averaged 60 decibels. That environment, with the noise and the bright lights and the reflective surfaces and the lack of privacy, had a huge effect on my health. That world was so different from the silent one I inhabit now. A world that was fast paced and exciting, with more tasks than time to do them in, and the daily frustration of never quite being on top of things. There was a particular kind of noisy busyness in that open plan environment and it did not take long before it started to wreak havoc on my brain.

Soon, increasingly bad migraines with excruciating head pain, dizziness, nausea, and visual disturbances began to creep into my working week and my time at home, until one day I lost my ability to read or write. All I could do was lie in bed and hope it would go away. It never did, really; reading and writing returned slowly over a few days, but any kind of exertion can trigger it now, alongside slurred speech, overwhelming exhaustion, widespread joint and muscle pain, and a whole host of other symptoms that make you feel like you're hungover, haven't slept, and have just finished running a marathon. This is brought on by tasks that healthy folks wouldn't even register as tasks: showering, going to the loo, eating, going up and down the stairs, talking to friends and family, or going to a café.



I take refuge in my garden whenever I can. Our garden is across a little lane, in a quiet village in the Scottish Highlands, on the east coast not far from the sea. To me, the garden is a noisy place: birds, sheep, cows, chickens, dogs and cats, neighbours, cars, lorries and tractors; the primary school at break time and the old ladies that walk past on their way to the shop, folks working on their cars or mowing their grass or cutting their hedges. The wind, always there, rustling in the trees above me. The rain, falling softly onto the roof of the polytunnel. But most of the time this is welcomed noise: it reminds me that I am part of the world even when I spend so much time hiding from it, and on the days when my brain can tolerate the tweeting, buzzing and baa-ing, I love nothing more than taking time to listen to the world around me.

Do you want to know what my favourite noise is these days? The small quiet crackle from inside my worm farm. You have to listen very carefully, but it's there, and it makes me smile every time. ●

***BAD SLUTS GO TO HEAVEN, TOO***  
*by Cade Leebron*

There was that one dream of a bar, on Rambla de Catalunya,  
where you pour your own liquor. We couldn't find it again, too  
bad for our wallets. In A—'s heart is a tally of my worst teenage sins.  
In her hand, my phone list of boys I've gone home with. Our lists  
have overlap. Our hearts have overlap, too. Her body taught mine  
how to grow up. Or wait, the other way around. Other women tell  
me I don't know what sisterhood is, but I found it. Mickey Mouse  
pancakes after she lost her virginity, I made them both breakfast,  
then ran off with her man. My heart is a bar, she can pour her own  
whatever. We did boy scout shots, lit marshmallows into drinks,  
then downed our hatches. I passed out on the sidewalk. She can take  
me home. No parting ways, because our ways have overlap, too.  
Other women have been wrong about us since the first unluckiest  
Friday, the train running late, the two of us right on time.

*Cade Leebron is a disabled writer living in Columbus, Ohio. Her work has appeared in The New York Times, American Literary Review, Electric Literature, and elsewhere. She exists online at [www.msifeisbestlife.com](http://www.msifeisbestlife.com), and on Twitter @CadeyLadey.*

*Special thanks to Courtney Ferrell, Dana Laffey, Matt Rey, and Bob and Betty Spring for making this zine possible. To learn more about how you can help support a paying platform for chronically ill + disabled writers and artists, visit [www.sickmagazine.co.uk/support](http://www.sickmagazine.co.uk/support).*



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