

My name is Christina Hoi Man Chan, my pronouns are she/her.

This has been an emotionally heavy process as I've never been asked to share my entire story about chronic illness and disability. I've done my best to keep my story to the essentials, but there is so much more than there is time to tell it. I am also not a fan of public speaking.

I am a first generation, Hong Konger, Chinese-Canadian, the daughter of over-protective and worried immigrant parents and originally from the GTA, the traditional territories of the Wendat, Anishnaabeg, Haudenosaunee, Métis and Mississaugas of the Credit. And since 2005, I have resided in Victoria, BC, on Vancouver Island, on unceded Lekwungen Territories.

I am a Community Acupuncturist, Owner/Operator of Heart & Hands Health Collective, community organizer, educator, rider of many things with 2 wheels, martial artist and immunocompromised, high functioning spoonie. As a woman of colour, the child of immigrants and survivor of chronic illness, I navigate a world that regularly reminds me that I do not quite belong anywhere. It has also been a full circle journey to reclaim my cultural traditions, as growing up, I was not always proud to be Chinese. I intimately understand what it means to feel broken, but also what it means to put yourself back together again.

I have lived with chronic illness since childhood. I was diagnosed with Lupus Nephritis in 1992 at the tender age of 12. I have lifelong experience navigating the medical system and have weathered the ups and downs of living with an autoimmune condition. During various periods in my life, I've cycled through immunosuppressant medications, weight fluctuations, life interruptions such as a stay at Toronto Sick Kids Hospital on Christmas Eve for a blood transfusion and struggling with the helplessness of not having control over my own body.

Despite all of this and fueled by the immigrant drive to succeed, I managed for better or worse to power through these adversities early in life. I've completed university degrees, played piano at the provincial level, worked as a lifeguard, first aid trainer and biology educator. I also had the formative experience of working at a bustling TCM clinic during my undergrad, which eventually set me on my current path. I've trained various martial arts, obtained my motorcycle license and most importantly, completed the rigorous training to become a Registered Acupuncturist and have built a thriving community-based practice. However, punctuated throughout my teens and 20s, the lupus would periodically make its presence known through complications such as shingles, an angry malar rash, suboptimal kidney function, enlarged organs and medication side effects.

A severe flare in my early 20s fully plunged me in my first experience of complete disability. In 2003, I was in the midst of finishing a grueling Master's degree. Two weeks following an appointment with my nephrologist, I started experiencing intense shortness of breath and fatigue, so I went to student health, received a chest x-ray and had my vitals reviewed. Later that evening, my specialist urgently called instructing me to head to the closest ER and he would meet me there. When all was said and done, I was in acute kidney failure and the months to follow involved monthly chemotherapy and the subsequent hair loss, intense physical fatigue, anemia, overstimulation from medications, more biopsies, chronic insomnia and panic attacks. It was during this period of my life that I created a strict separation between school and rest. I believe this was the only way I managed to simultaneously complete this bloody Master's degree and slowly patch my body back together. This was also a turning point when I decided to pivot, abandon med school applications and instead, apply to a non-profit TCM school in Victoria BC.

Fast forward to 2005, I move to the west coast, a little stronger and healthier. I am voraciously absorbing everything my TCM training offers, opening my eyes to a different medicine, a softer, holistic way of viewing the human body in relation to the climate, season and time. It also felt like my childhood memories of weird smells from the kitchen, being ridiculed for school lunches, being told to avoid fried foods because “yeet hay” and not going out with wet hair finally made sense. I was unknowingly embarking on a path in which the Chinese parts of myself were finally fitting in place. This was an exciting and very active period in my life, building community, getting back to physical activity, soaking up the Pacific Northwest beauty, training as an acupuncture detox practitioner and becoming captivated by the Community Acupuncture model. It was also during this period that had my final chemo infusion and I grew tired of and complacent about my lupus. I foolishly decided to take a good, long vacation from specialist appointments and medications.

In 2009, I became a Registered Acupuncturist and luckily, already had employment lined up at the first Community Acupuncture practice in Victoria. For those who have never heard of Community Acupuncture, it is both a practice and business model where treatments are provided in a peaceful group setting at sliding scale rates. It is in contrast to the more common, one-on-one, private practice setting with much higher fees. I have always seen this model as a tool for positive social change where individuals of all walks of life come together and receive affordable and accessible treatment, kind of like church...but with naps and needles. Community Acupuncture was a natural and logical progression from my experience working in addictions recovery.

By 2010, riding the high of my first Balance Method Acupuncture seminar, I opened my own Community Acupuncture practice, Heart & Hands Health Collective. I became part of a growing network of radical acupunks and was fully focused on becoming the leanest, meanest poking machine I could be. With enthusiasm and tenacity, I stepped into the role of owner/operator of my tiny social enterprise and 14 years later, Heart & Hands is still going strong. To this day, I still believe that Community Acupuncture can change the world. It is a means to transform the way we provide and interact with health care in our society. Life as acupuncturist was full, dynamic, stressful, but exciting.

Fast forward to November 2018, I step out of the shower and suddenly, the entire left side of my body feels weak, heavy and a diffuse tingling is felt through my arm and leg. I walk it off and decide to make an appointment with my GP. During my appointment, she runs through a typical neurological assessment and decides she'd like to refer me for further investigation. I shrug it off, assuming it will take months before I hear from the specialist. On Christmas Eve, I get a call from Victoria General...I have a referral to the stroke assessment unit and have been placed on the top of the list for a cranial MRI. Little did I know, what would follow was an year long fall down the rabbit hole of medical chaos and eventually, subsequent chronic disability.

It was a mild day in January, so I decided to ride my motorcycle to Victoria General. I'm sitting in the waiting area surrounded by other patients that were at minimum 30 years my senior. Thankfully, my neurologist is kind and patient and she runs through a more specialized neurological assessment and reviews my MRI. A major branch of my right cerebral artery has atrophied, but because I am young, my brain was able to regenerate smaller blood vessels to compensate, but the neurological episode I experienced in November was a mild stroke. Puzzled by why this happened and I have none of the usual risk factors, she ordered a ton of bloodwork and a fluorescent MRI. At our next follow-up, she speculated that during a 2nd shingles outbreak in 2012, the herpes zoster virus travelled into my brain and damaged the artery. She also strongly recommended I follow-up with my nephrologist, she was concerned my lupus was active again.

It's April 2019, I'm calling my coworker to cancel my clients for the day. A very rare occasion, I almost never miss work. I've been intensely nauseous and it's been coming out of both ends for half the night. After 48 hrs of unrelenting nausea and vomiting, my partner takes me to the ER...my favorite place. I've experienced this in the past and was always discharged without any answers. High on dilaudid, I manage to grab the clinician on shift and demand she order me an abdominal CT and good thing I did. The results were so startling, I was immediately assigned a gynecologist, urologist, gastroenterologist and my nephrologist was paged. The CT showed an unidentified mass in my right groin that was blocking the passage of urine from the right kidney. My poor right kidney was shrivelled like a prune and my left was 3 times the size to compensate. The following 10 days were a complete blur of multiple sedations and being shuttled around the hospital. I underwent a kidney biopsy, endoscopy, had a renal stent implanted to relieve the blockage as well as having them start the procedure for implanting a nephrostomy bag, only to have it called off, because my nephrologist misread the chart. I ended my delightful stay at the Royal Jubilee hospital by fainting in the bathroom because I was overprescribed antihypertensives and I self-discharged myself because I had lost 15 lbs from a jello-only diet.

The months that followed were an neverending treadmill of specialist appointments, diagnostics and procedures. I underwent an exploratory laparoscopy, pelvic biopsy and cystoscopy all to try to determine whether the mass was malignant. Despite all efforts, the origin and the composition of this mass is still unidentified, but being nameless, I decided to name the mass, "Gertrude" or "Gertie" for short. My urologist failed to inform me of the possible risk of pain, bladder spasms and bleeding that could result from the renal stent she implanted. I actually went back to the ER 24 hrs after being discharged because I thought I was suffering from a severe UTI, but that it was simply bleeding from the stent rubbing on the inner wall of my bladder. For months I lived with constant pelvic pain and bladder spasms. I eventually gave up cycling, motorcycling and Aikido because of pain and bleeding. For the first time, I needed to rely on a car so I could save my energy to be on my feet at work. My life was small, limited and exhausting. During those months, I rallied my friends' assistance for errands, home support as well as snail mail to keep my spirits up. I also developed a coping strategy of cooking large batches of soup for the freezer, which is something that I still practice today and it's come in handy whenever a friend is stuck at home isolating.

Finally, on Nov 1, 2019, I underwent an invasive, exploratory bladder reconstruction to relieve the obstructed right kidney. The pre-op experience was terrifying. The size of the surgical incision required was undetermined as well as whether I needed an epidural, but when all was said and done, the surgery was a success. I now live with a cone-shaped bladder sitting further to the right and a 7 inch battle scar on my lower abdomen. You would all be assuming that my medical ordeal ends here...no such luck. I took 8 weeks of medical leave, relaxing for the first 10 days and then the nausea came back, to stay. I spent the remainder of my medical leave scrambling to find relief and trying put meager nutrients into myself. Knowing what I know now, I believe this was a tipping point for my thrashed nervous system and it just could not withstand anymore. 2019 was nothing short of life altering and I am forever changed.

My existence from post-op to present day has been a liminal, uncertain period of my life. My body is a mercurial organism, interjected with brief periods calm seas. I regularly experience visceral and pelvic floor spasms, dysautonomic symptoms of brain fog, dizziness, muscle and joint pain and intense fatigue as well as varying levels of queasiness. My return to work in January 2020 was manageable, but nothing could prepare me for pandemic lockdown. It was a mixed bag of relief that I could just stay home, but also feeling completely purposeless and filled with dread. I contemplated changing careers and experienced intermittent suicidal ideation. I have consulted with each of my specialists about these ongoing symptoms, but because nothing appears medically abnormal, they are at a loss. And reflecting on my complex and lengthy medical history, it is without a doubt, I am suffering from PTSD, but have been unable to obtain a referral for assessment.

Luckily, I am resourceful, intuitive and unafraid of trying unorthodox approaches. Since, solutions from the medical system are limited, I have delved into alternative means. I have utilized cannabis, psychedelics, meditation, ancestral work, somatic experiencing, osteopathy, EMDR and an 8 extraordinary vessels approach to acupuncture. Each modality has provided insight, supported emotional processing and widened my window of tolerance. My recovery trajectory is overall upward, but day-to-day is unpredictable and I regularly experience deep grief and anxiety for the active life I used to have. And more recently, I had another setback and was hospitalized at the end of August, again with severe nausea, vomiting and weight loss. I try to keep things in perspective about how far I've come as well as my health crisis happening BEFORE the pandemic crushed our ailing medical system. But it is overwhelming and exhausting to live in such an unpredictable and traumatized body.

Currently, the most stressful thing about existing as a medically vulnerable person is the widespread lack of consideration for public health measures. I hesitate to enter public spaces and participate in community because of the poor of COVID safety. Many people no longer give a shit about simple measures like masking. Meanwhile, people are still dying of COVID and we're in the peak of cold and flu season. And as a business owner, I deal with disrespect and verbal abuse from clients when they find out our practice is still mask mandatory. It saddens me how certain clients do not value the safety of the practitioner providing their care. I feel the pandemic broke something in our society and the social divide is only getting deeper. On days when I'm at a loss, I remember at least I can keep myself and others safe at my practice and I will continue to do so for the foreseeable future.

I practice acupuncture and Traditional Chinese Medicine, modalities that are profoundly innovative, have stood the test of time, survived brutal racism and xenophobia and transcended cultural barriers. My practice is a bridge, like the hyphenation of my Chinese-Canadian identity and it is how I straddle two worlds, two cultures. With the best of intentions, the practice of acupuncture is my honest expression and offering to the world of what it means to be a person of the Asian diaspora. Heart & Hands Health Collective is my body of work. It is my politics in action, an expression of disability and economic justice. The same way TCM continues to persist, it is the lens of how I wish to see the world and an embodiment of my grit, determination and resilience.

Thank you for listening to my story.

Panelist questions

What are some accommodations you have in place for yourself as you work?

Since opening my practice in 2010, I have always kept 4-5 hr shifts and rarely work full days. It continues to be manageable with my current level of disability, so I can thank my future self for the foresight.

I've also maintained the same weekly hours since 2010 and I've always kept Sundays and Mondays off for appointments, errands and REST.

The pandemic forced us to decrease our hourly capacity from 6-10 clients to 4-5 clients hourly to maintain physical distancing, accommodate sanitizing between clients, but also this capacity is much more sustainable and manageable. And going forward, I plan to keep our hourly capacity the same.

I am lucky that my practice had reached a critical mass in 2018-2019, so in-person outreach and marketing weren't as necessary. I really shifted our community engagement to online strategies such as social media and I created a digital care package project during pandemic lockdown. This allowed me to create content and marketing remotely, so I could be at home in my pyjamas.

What is your favourite thing about being self-employed?

Calling all the shots, which is also my least favorite thing about being self-employed because when things go wrong, the buck stops at me.

Do you have one tip or recommendation to share with others who might be considering self-employment while living with an episodic disability?

Building community, you never know when you will need to lean on someone.

Having a contingency fund in the event you are unable to work – I was also very grateful I was to receive CERB because my disability occurred right before lockdown.

Having clear boundaries of when you “clock out” for the day, for individuals who work from home.

Maintaining regular self-care/healthcare to manage your symptoms and maintaining quality of life. Always an investment in your future self.