SICK, SOVEREIGN with Darcy and Em

Pauline: You're listening to Sick Sovereign, a special show for 3CR's 12 hour Disability Day broadcast. You're about to hear a written story by Darcy Hitt.

**Darcy:**

**Not a beginning.**

**II.**

Mobways, time spans everywhen. Time is not a straight line with a start and finish – an individual beginning on a journey from one end, facing the future, back to the past, their position along the line as they travel the present. Nah, not mobways.

Some mob describe our time as spirals, circling around and back over and over. Our time and all within it is as alive as we are. It is omnipresent, it breathes with us, breathes as us. It is all. Always all. No pastpresentfuture. Only all.

If we were to be placed in pastpresentfuture time, if we had to locate our being within it, we would not be the present. We would not be the border between the past, and a future that we definitively travel towards.

And if we were placed in pastpresentfuture time,

which is to say ifwe were to try to translate our ways of being into the language and epistemologies of the coloniser,

or rather,

to be subjected to the scalpel,

a colonial project,

a weapon

of epistemic violence,

that dissects and distinguishes and defines,

by choice or by force or by something in between,

we would be angled towards the ‘past’. Towards what is known so as to know to not know, to never assume to know. To face towards the future would be to assume to know. And to assume to know is violence.

And so, mobways, to oracle is to remember.

But cripways, I do not remember.

Cripways, I can’t tell if it’s my autonomic nervous system, or shifts in barometric pressure, or trauma, or the heat, or degranulated mediators, or the tomato I ate earlier, or the dead tissue in my high left frontal lobe, or my thalamus, or gravity, or any other number of things, that disrupts my remembering on any given day.

Often there’s no point trying to assign responsibility to a single perpetrator anyways. Always all? Only all?

The colony taught me to locate my problem, my pain, within myself. The colony taught me to wage a war on my body. To slice it up into distinct systems that I had to check reports and Google to confirm, to remember, to write into this piece. And in the spirit of this logic, a lone perpetrator must be identified, and found, hidden, lurking, as only the guilty do, and put on trial, reprimanded, punished. Naughty. Bad body. Your fault. *You* did this to *us.*

In doing so, the colony absolves responsibility for its violence, disappears into the soil (our soil, our Kin), only mist (manufactured – not our mist, not our Kin) remaining, hovering above the soil’s surface, until it too fades away. Such a gentle performance for such a violent Act.

A tale as old as time.

But not our time.

A time that pins us against walls, puts us in boxes, throws us in cells, hides us, chokes us, sends us home before we’re ready. The time that put me to sleep and then discharged me with injuries that weren’t there before I went under, but that it couldn’t have done. Which is the same time that took a child from his mother because he was acting up, put him in a boy’s home, horrors known later reduced to Royal Commission findings. The same time that pointed to the child’s bloodline to explain his shit parenting, called me disordered for being subjected to it. The time that wrote the book on the same disappearing act it claims typifies Black fatherhood when the child performs it. Where do you think he learned it from? How old is that time, really, anyways?

I try not to break apart my body into blame anymore.

But I do not always remember not to.

**V.**

Oracle, to remember, to oracle, as in a verb, as in a doing word, an action, a choice. Not merely a passive feeling or state of being.

Not remember, as in the absence of a choice, as in the removal of choice. A violation of autonomy. A violation of sovereignty.

Who is to blame for not remembering? Who violates such sovereignty? Who cracks and fractures and dissects and siloes and pulls apart and butchers and shatters and rips and takes and takes and takes and—

The mist evaporates.

I am the only one here.

As I write this, blood has started trickling down from my left nostril.

Is this the fault of my nose? My blood? My fingernail, the one that may have scratched the inside of my nostril? My body, sullied by clopidogrel and aspirin, weakened, useless, malfunctioning in the 34-degree heat?

This isn’t a metaphor.

I need to go clean this shit up.

**IV.**

What is mobways anyways, hey? Is it, too, a product of the scalpel? One sometimes named ‘pan-Aboriginality’? There is no one mobway. I bear the blood of a Country that this body has never known. Was born outways. Grew up on that one up there Country. But not there anymore. Living down here on this one Country. But also spent time out on that there Country, in between this one and up there. Taught mobways by Country and Kin from all over. All with their own relationships with the whens and wheres and whos of their trajectories. So my mobways is a bitza diaspora mobways. It is mine and mine only, in the same way that it is, in fact, not just mine at all. But all. Always all. Only all.

If it doesn’t make sense, I know I’m doing it justice.

If it’s frustrating for the white reader, good.

If it’s a bad explanation, shit writing, poor expression, contrived, lazy, then what the fuck is:

Small 4mm restricted diffusion in the high left frontal lobe white matter favours a small lacunar infarct. No significant mass effect. Basal cisterns are preserved and no shift in midline structures or hydrocephalus. Unremarkable MRA TOF.

Mobile interatrial septum and patent foramen ovale with significant right to left shunt. Strong positive bubble study, with right to left shunting detected at rest and post Valsalva.

Baseline tilting showed marked postural hypotension. Supine blood pressure was 130mmHg with a heart rate of 90 bpm in sinus rhythm. Vasodepresser hypotensive pre-syncope.

The PFO was closed under TOE and fluoroscopic guidance with a guide wire. A 25 mm PFO occluder was then delivered across the defect and deployed under TOE and fluoroscopic guidance. Atrial tissue was noted between both discs throughout deployment. Following deployment the device appeared stable and well seated without interference to the aortic root or mitral valve.

Oh, no, that’s just very specialised knowledge.

You just don’t understand.

Not all.

Never all.

Only some.

Only few.

**III.**

Alright.

So, mobways I oracle, but cripways I do not?

Well, no. To say so would be to succumb to the scalpel again. Same scalpel, though disguised. Always same. Always all. Only all.

There’s plenty I don’t remember mobways, too. And there’s plenty I do remember cripways. Because I have it written down.

Memory and trauma under anaesthetic - is it better to not remember even though the body does? Relationality/relativity of memory b/w traumatised patients and traumatising healthcare ‘professionals’.

Figure out who my LAC is & link in w them/their org re reviewing my stuff before it’s submitted & ongoing advocacy etc. I also need to look into specifics around cultural support & advocacy (like I want actual mob not just someone “trained” in “cultural safety” but idk how realistic that is) and support that is queer/trans confident/competent/safe.  
  
17/09 7:00AM arrival  
Building A level 2 green couch  
Fasting from midnight  
Nurse will call on Monday  
Discharged 6 hours post-procedure  
(procedure 8-10ish) – somewhere between 2-4  
Bring medication  
Will go on a second blood thinner post-surgery

If I die  
If i have another stroke in my sleep and die tell [redacted] it was worth it for the opportunity to know a love like theirs and that I’m so sorry they have to experience this pain again

Don’t smoke weed again. It’ll make u feel like shit.

I’m too scared to talk to people about my feelings because they won’t know how to reply so I’m writing them here instead  
Being forced to confront my own mortality is overwhelmingly terrifying and physically debilitating. It feels like a trauma response.   
I am scared because I don’t know how long I have left to love [redacted]. I only want for them to be happy. I want to be here to make them happy.   
What if I die before [redacted]? He won’t understand why I left and never came home.   
I am scared I will respond by either doing absolutely nothing, or trying to make changes so drastic that I end up doing more damage (terrified of my mental health either way).   
I’ve worked so so so hard to get to where I am but I still have so far to go. I want to live long enough to make a meaningful contribution to community.   
I’m always thinking about and planning for the future. Living in ideas about the future. I don’t want to die waiting for my life to happen.   
I could’ve died because of medical negligence. I may still.

I've never been so deeply genuinely sorry about something as I am for being mentally ill.  
I think about you constantly. In all states of rationality. Yet in each of these states, whether during a hellbrain meltdown, a hypomanic frenzy or a sensible calm, I come to the same conclusion, I make the same deductions.  
Maybe no matter what state I'm in, I'll never be able to consider the situation rationally. Maybe I'm completely wrong.  
All I'm certain about is that | yearn for the day that I can stop thinking about it.  
The day that the monster in my stomach can cease to consume me from the inside out when you enter my mind. The day that you don't appear vividly in my nightmares. The day that my view of you isn't skewed by the persistent inkling that you do not give a single fuck about me. Even if only for 24 hours.

Years of crip knowing, crip being – cripways. Fixed in place and time by a date written above, as if an overseer. As if an oracle. And if a date is an oracle, and to oracle is to remember, and the past is time, and time is all, always all, only all, and it breathes with me, it breathes as me, then I am time, then I am oracle, I do oracle, tracing cripways each time I mark paper with pen, each time I write thoughts in phone notes.

I do not pretend to like or agree with all of the remembering. I do not pretend that I don’t sometimes wince at it. But I do not blame the knowledge. I do not blame the author. I do not blame the oracle. To oracle is to know pain. I hold the pain with love, with care.

This is not just cripways.

Mobwaysiscripwaysismobways. Always one. Always all.

Reread those notes and tell me you don’t feel the colonial stench wafting from them, hard and thick, hitting with a sharp sting.

Reread those notes and tell me you can identify where mobways begin and where cripways end.

Tell me you see clear borders and boundaries between The Colonial Violence and The Ableist Violence.

Tell me it doesn’t make sense, it’s lazy writing, it’s pastpresentfuture, it’s some, only some, only few.

Gorn.

Wield the scalpel.

I dare you.

**VI.**

If a tree falls in a forest,  
And the tree was Throwing Leaves  
Before it fell, and while Throwing Leaves,  
The tree saw death in a Blackfulla brain,

But did not tell for longtime,  
Held in, sharp breath, for longtime,  
And if the tree, once fallen,  
Had Throwing Leaves stolen

By a thief so clever, so devious,  
She robbed the dead before joining them,  
Robbed the living once beyond them,  
Robbed the tree of its name,

Declared herself in its place,  
Who in the tree, peeled back a mask,  
Once obscured by Leaves, now bare,  
Revealing a mirror that owned the secret,

Does the tree fall mobways or cripways?

**I.**

Hi.

It’s me again.

I’m writing so that you can remember.

So that you can oracle.

Mobways.

Cripways.

Allways.

When I have a lapse in memory that feels scarier than usual, I often try to recall whether it’s of a severity that I experienced pre-stroke. But I did not know that I would have a stroke at 21.

Or was it 20?

20.

I did not know that I would have a stroke at 20 before I had one. So I did not write down anything about whether I attempted tasks multiple times within short periods only to realise I’d already done them, over and over. I didn’t record whether I’d ever been convinced that something I had just written was written by someone else, because I had no recollection of writing it, and it didn’t seem like something I’d write. I don’t know if I ever reread pages of a book to find I’d somehow misread most of it.

But I know now. And this knowledge terrifies me. Because I wonder about what else I should be writing down. I wonder what else I’m depriving you of because I don’t know, right now, at this moment, that it’s something I should record.

I’m sorry there’s so much of yourself that is unfamiliar and unknown and unexplained because I didn’t know to write it down.

I don’t know whether I should tell you that my eyesight has gotten noticeably worse in the past 6 months, and I always have to wear my glasses now. I don’t know whether I should tell you, because I’m sure it’s just because I started reading again, so my eyes are working a lot harder than they used to.

I don’t know whether I should tell you that I’m sitting at the kitchen table in my Always Was shorts and recently-cropped Mitski shirt, and that the back of the chair is scratching up against the gap between them.

That I’m listening to the carbonated bubbles of my Vanilla Coke burst inside the can less than a metre away. Counting the seconds between pops like lightning to measure how flat it is.

That I’m eating a gross, grey TV dinner–a vegan shepherd’s pie that’s been sitting in the freezer since I bought it when I was terrified that I was going to get COVID. Almost exactly a year ago now. I lathered it in shredded cheese to try disguise the look and textures I know I’ll hate.

I feel like I should tell you that I know my heart has felt funny in ways that it didn’t before surgery.

I get the sense that this is something you should remember, because it is so vivid to me now, but I don’t want to assume. I also don’t want to underestimate the power those doctors hold over you, and your memory and sense of self.

The medic alert bracelet on my wrist still reads [redacted].

Please don’t forget that that’s not your name anymore.

**Not an end.**

**Darcy:** Hey mob my name's Darcy Hitt. I'm a Palawa person, born on Kaurna country, raised on Yorta Yorta country, and joining you from Wurundjeri Woiwurrung country, where I've lived for the past six years. We've just listened to a recording of a piece that I wrote called Not a Beginning. I wrote that piece in December of 2022.

And I kind of wrote it in this heat of the moment. It honestly felt like a fever dream a little bit. I remember it was stinking hot.

**Darcy:** And I wrote it in a couple of days. And It just kind of happened, and then I after writing it realised that I really needed that outlet.I had all of this built up stuff happening inside that I didn't realise that I hadn't really dealt with. So, a lot of the piece talks about medical negligence.

It's centred around a stroke that I had when I was 21. I had that stroke in, I think it was October of 2020 and it happened in my sleep, and so I didn't know that I had had a stroke.

I woke up and I had decreased feeling and mobility on one side of my body. And I thought that it was a progression of my small fibre neuropathy. And I managed to get in to see my GP that day, and he said, "look, I don't think that there's anything urgent that you need to worry about. I don't want you to be too concerned, but I do think that you should go to the ED just to make sure that everything is okay.".

So I went to the ED of Box Hill Hospital and that was the beginning of a very long and awful and arduous journey of medical negligence at the hands of mostly Box Hill Hospital, but Eastern Health more broadly. I was going to be sent home. I was in the ED for I think about six hours or so. And was seen by multiple doctors who concluded that I was just fatigued.

**Darcy:** I'd never heard of fatigue causing lack of mobility and feeling in one side of your body before. But that is just what I'd been told. But they decided to keep me overnight.

Neurology wanted to keep me overnight to monitor me. And so they kept me overnight and ended up discharging me and didn't think that there was anything happening, but they ordered an outpatient MRI just to be sure.

And so I had that MRI a couple of days later. And I was told that if I didn't hear anything, that no news was good news. I didn't hear anything for three months. And three months later, I got a call from the neurologist at Box Hill who told me that I had had a stroke. They'd never sent the results through to my GP, so my GP wasn't aware of it.

**Darcy:** That was how I was meant to find out about the results. And they didn't follow up with me in the meantime for another three months. So there was a three month period after I had just had a stroke where I wasn't on any stroke prophylaxis medication. I wasn't aware that I had had a stroke.

**Darcy:** I wasn't doing anything to mitigate the risk of a stroke reoccurring and yeah. That was kind of just the start of things. But that kind of enters Into our yarn about health sovereignty today, and I'm joined by my sis and very good friend Em Randall who I will now hand over to introduce herself and tell youse a bit about who she is, and what she's doing here.

**Em:** Hi, Giinagay, [speaking in language]. Adyi ngaya Yaygirr. Adyi Kabi Kabi wadyarr. Adyi ngaya arraygi Yayarr yangidawu. Adyi ngadya arraygi ngulungginy, ngamiiga. Wadyiiway.

**Em:** My name's Em. I'm a Yaegl [unknown], who lives on Kabi Kabi Country, and I'm so excited to be part of this Deadly Broadcast. I was offered to do it last year, but I was a bit busted up with psychosis, so I'm really excited to have the opportunity to do it this year.

And real Blakfella style I'm doing it outside, so if you hear some birds, that's why. A bit about me I'm a peer worker. I am a writer and an artist, and a pretty staunch abolitionist. I live with schizoaffective and so I've spent a lot of time on involuntary hospitalisation.

I've been on case management for 10 years. Been on, still on pretty hectic meds and I live currently in supportive accommodation. So that psychiatric system really plays a massive part in my life. And I also am physically disabled. So yeah, I'm not sure if I've forgotten anything about myself, but I'm sure I'll touch on it throughout the yarn.

**Darcy:** Yeah I'm sure you will. I love that you mentioned last year, cause yeah, last year Pauline invited the contributors to Sick/Sovereign to come have a yarn as part of last year's Disability Day broadcast, and that was real deadly, and yeah, it was pretty sad that you weren't able to make it Em, but I feel like we've kind of come full circle now.

We're doing a new Sick/Sovereign broadcast, 'cos obviously Sick/Sovereign was the name of the zine, but it's more than just the name of the zine. It's a way of living. It's like a disabled Blak mantra, I guess. Or just... way of existing or navigating the world as sick and sovereign Blakfellas.

And, yeah. I hold the contribution that you made to Sick/Sov so close to my heart. I think about it regularly. I love your work so much. I love your visual artwork and your poetry. I think that everything that you do is real deadly. I feel like I'm probably one of your biggest fans.

**Em:** Stop, knock it off.

**Darcy:** I don't know. I'm ready to start some things with anyone else who's contending for first place.

*[Both laughing]*

**Em:** You and Afrida, I reckon. You and Afrida.

**Darcy:** Ah, look, I feel like Afrida and I could reach an agreement. I don't think we need to.

*[Both laughing more]*

**Darcy:** I think that we could maybe share the spot, actually, if it's Afrida that I'm up against. But I did-

**Em:** It was so special to be a part of that zine. I actually did that zine while I was in the psych ward. I was just, real bored and Darcy reached out to me and said that there was this project and I was like, well, got nothing else to do. And so then I started to get into drawing a bit.

A lot of that writing was actually about my physical disability because I've been physically disabled since I was 15, but when I got COVID, ‘cause I was a frontline worker, there was not much protection. I was an early childhood educator and when babies are like coughin' and everything on you, you can't really put them in the corner and say, "go away now", so.

So yeah, I developed COVID while working as an early childhood educator. And from that, I developed POTS and my fatigue and my physical disability basically just compounded. I was still really coming to terms with the worsening of my physical disability.

And basically it felt like.. I feel like reborn is not the right word, but I feel like, after my disability worsened I felt like a new person. I felt like I had a new life.I was, I still am walker bound. Yeah, it was like everything I'd known and all the skills and the way I'd been living my life had suddenly completely changed.

And there was definitely some disabled people that I was friends with, including Darcy, that supported me to find that new way of living. But it made me like.. it was just different. And I hear in some books that they talk about disability doulas. And I really think that that is an amazing community position.

**Em:** I'd love to see more of that because I don't think people talk much about when you gain a new disability or when you become disabled for the first time. It changes your life. And especially with COVID being a mass disabling event, the genocides going on all around the world, mass disabling events.

So I think conversations about disability by people who are victims of colonisation are really important because I think mass disabling events aren't really talked about much. But basically what I'm trying to say is I wrote a lot about physical disability.

And that project was really important for me to find pride in my disability and find acceptance because when I first got sick I could not understand disabled pride at all.

I was so angry at the world. Because I'd lost my job, I couldn't fucking walk. And I was reading disability pride and care books, and they definitely connected to me, but it took me a really long time to become someone who was proud of their disability. Because I was just so wild at the world.

**Em:** I was like, "all you dogs...". My life's changed now. Everyone just gets to walk around and continue. I felt like my life was over. And now obviously coming to nearly a year and a half, two years I'm definitely finding my place in the world. And it was such a challenging time, but now I know that I wouldn't be who I am without that disability.

And those experiences that it's gave me. Even things like when you just start walking with a walker or a wheelchair and you realise how busted up the concrete is and you're like, "oh my god, how does anyone get around?".

It's so eye opening because I was using a cane before so I mostly just thought about stairs and stuff like that. But this whole new world opened up to me and I was like, "oh my gosh, how do people get to the shops?

How do people get around when the roads and the concrete is all so busted up?" And even my experience in a wheelchair with ramps. They're so steep! And you're like, "oh my god, no one with a disability designed this", because anyone in a wheelchair would know that you just go flyin' into the wall. Yeah.

**Darcy:** Yeah, I think that another thing that immediately comes to mind about that is like, elevators. And how elevators are considered the alternative for a lot of people who can't use stairs - where there are elevators - which often there aren't.

**Darcy:** But for a lot of people, the buttons in an elevator are out of reach because they go up real tall and there are no horizontal buttons or accessible buttons.So it's like, what's the point in having this accessible alternative when people can't use it still? And that's such a thing with these ramps and stuff like box ticking exercises.

That's so clearly haven't actually had disabled people involved. But yeah, I wanted to come back to a couple of things that you were saying earlier about how when your disabilities were worsened by COVID, you felt like you were experiencing a rebirth. And I feel like that's such an accurate and powerful way of describing coming into your disabledness.

For me, I had a similar experience where I've been disabled my whole life. I have been neurodivergent my whole life. I have had psychosocial disabilities for most of my life. I don't know how long I've actually been physically disabled for, but since I was at least 14, that's the earliest I can remember experiencing those symptoms, but I didn't realise that I was disabled until I was about 20.

**Darcy:** And coming into that realisation, I think that it can be a similar experience whether you're coming to realise that you've been disabled your whole life or for a really long time, or you've recently become disabled, whatever that experience is, coming into your disabledness really is an experience of rebirth.

You're coming to relearn how to exist in a world. And I think that that is a really frustrating experience and the anger is so real. And I think that it's important not to minimise those experiences, not to water everything down to disability pride. Disability pride is a really important part of our experience, but it doesn't come without tension and without difficulty.

And without a lot of really intense and painful emotions. I think that sometimes, it's hard to always have that disability pride. Even if we've reached a point where it makes sense to us now to be proud of ourselves as disabled people and to have disabled pride.

It's still something that you're navigating on an ongoing basis. It's still something that you're in relationship with. And it is tense. And it is full on. And it comes and goes. It's not static and it's not fixed. It's not just, I reached the pinnacle of disability pride and now everything is fixed.

*[Em laughing]*

**Em:** I won!

**Darcy:** Yeah, exactly. Yeah.

*[Both laughing]*

**Em:** But disabled rage, we need to be making space for that too, because that's just as important.

**Darcy:** 100%. 100%. And rage is a powerful, impactful emotion that pushes us into action. We use our rage for wonderful things. But yeah, with that rebirth and with disabled doulaing, which is also such a brilliant experience and such a brilliant I guess, community innovation that I really love.

I think that those experiences can be linked back to mob systems of knowledge and ways of being, really well. Because in our dreaming stories and in the ways that we're brought up these things are really normal.

We have ancestral beings who are reborn as completely different entities or experience things in completely different bodies and have these really expansive...I really don't want to say expansive experiences.

But [they] go through these experiences of death and rebirth, and existing in a completely new way, time and time again, and that's just a part of existing, and a part of being.

And it's never something that's considered the end of the world. It's never something that's something to be upset about, or think that your life is over, or anything like that.

**Darcy:** It's just a part of the experience. And so I think that because of those ways, like those stories that we're raised with, and the ways of existing that we're raised within, really enable us to be able to come into our disabledness in a way that is much smoother and much more comfortable.

Because we know that there's so many ways, so many different ways of existing within the world. And that there being a fundamental shift or change or broadening of how we exist in the world doesn't mean that it's the end of anything or that it's a bad thing.

**Darcy:** A lot of the time it is expansive. It opens us up to so many new experiences and ways of being in community and ways of learning and growing and it also builds compassion and acceptance.

All of those sorts of things. I just feel like it's so natural. Like mob ways of being and ways of knowing make so much sense within disabled ways of being and knowing.

**Em:** True god. Yeah. For me, the biggest thing - yes, it was the actual physical, the pain and fatigue was hard to overcome. But really, as I reflect, the hardest part of my disability changing and becoming - I don't like the word worse - but just becoming more intense I suppose, was more the societal factors, like I'd lost my job.

I was very isolated from everyone because I couldn't get out of bed. Accessing the world was so difficult because the world is not accessible at all. It really wasn't. It was mostly those societal factors. The hardest part wasn't actually the disability itself.

**Darcy:** Yeah. And that's so real. It's so hard sometimes to separate our actual experiences of disability to how they impact our everyday experiences of the world and people and, buildings, structures, infrastructure. Footpaths, grass. Everything that we come into contact with.

I have Mast Cell Activation Syndrome, and often joke that I'm pretty much allergic to everything, and so leaving my house on a day to day basis, there are so many things that I can interact with that have such a significant impact on my experience within my body. And some of those things, a lot of those things, in fact, are environmental, but a lot of them are also social.

Things like perfumes that people are wearing. Air purification, stairs, all of those sorts of things are to do with social and infrastructure issues. And I think the infrastructure very much is heavily linked to our social priorities and expectations.

I think that it is a really big process to separate our disabledness from how our disabledness is received and treated and respected or not. Or valued or not. Within broader society, in the broader world, and the world that has been built by those societies, physically built, from yeah, our experiences within ourselves. And I'll admit it can be really frustrating experiencing disabledness within ourselves as well. It's painful a lot of the time.

**Darcy:** There's so many things going on and having dynamic disabilities as we do means that, our capacity and Our level of disabledness, varies on a day to day basis, which can make it really difficult to plan in advance or do things or just have any sense of consistency.

But when those things are understood and respected more broadly and accommodated more broadly, that can make that experience of our disabledness within our own bodies so much less difficult, intense, so much less frustrating. Because it's so heavily linked to what is expected of us in our day to day lives.

And if we were just given the time to sit back and have a flair, and be super disabled and bed bound for a couple of days without that impacting our ability to pay rent, or impacting our ability to contribute to teams or communities or our families or anything like that, then our experiences within ourselves wouldn't be so tense and fraught.

**Em:** And I will admit that I'm in a very privileged position because I was one of the very lucky few that has been given the disability pension. I'm very grateful. I honestly feel like I won the lotto.

Because going in, I was like, there's no way I'm gonna get the pension, there's no way. But I got it. And yeah. It's wrecked that as a cripple and as someone with intense psychosocial disability, that you feel lucky for getting to support from the government.

**Darcy:** Right?

**Em:** Every morning I wake up and I'm like, oh my god, I can't believe I've got the DSP.

**Darcy:** Yes!

**Em:** I feel like I won the lotto, and it should not feel like that at all. You shouldn't... I acknowledge the privilege of having DSP, but it shouldn't be a privilege, it should be a right. If you are too sick to work. You know what I mean? It's so gammin.

**Darcy:** And it shouldn't come at the expense of other aspects of your life. Being able to afford to live shouldn't come at the expense of being able to save for things that you need without having your pension suspended or working a number of hours that's comfortable for you.

**Darcy:** Those sorts of things. I feel very similar about being on NDIS. I don't have the DSP. I've never been on DSP. I tried to when I was 18 and I was rejected. And they were like, "you need more diagnoses that are applicable". So eventually I worked more and saved enough money to be able to get these really expensive diagnoses and get the supporting documentation I needed for DSP. And then they were like, "no, you're working too much". So double si-

**Em:** Oh, see we have opposite ways.

**Darcy:** Yeah.

**Em:** You've got NDIS and not DSP and I've got DSP, but I can't get NDIS because-

**Darcy:** Yeah.

**Em:** They don't care about my physical disability. They're not interested. Yeah. Weird. Because all my treatment team were like, "oh my god, if you got DSP you'll get NDIS it'll be so easy and so quick”. I've been turned back so many times, because I don't know, apparently I haven't been on schizoaffective treatment for long enough.

**Darcy:** Yeah, that's the excuse this time.

**Em:** I don't understand how it's gonna change in two years. But anyway, yeah. They really don't want to give me NDIS and now with the funding cuts for NDIS it's looking pretty unlikely if I'm going to be honest here.

**Darcy:** I spent five solid years building up a repository of diagnoses and supporting documentation for the explicit purpose of getting NDIS. So that I could afford to live and in the end, the only diagnosis that they accepted was autism.

And if I want to have any of my physical disabilities added, which, we have a lot of overlap in our physical disabilities, I have to go get that supporting documentation all over again.

I have to start from square one. And most of the things that I am diagnosed with, most of the physical disabilities that I'm diagnosed with, they likely still just won't accept because they don't like the ways that they're diagnosed. They're not diagnosed within really strict parameters compared to, say, autism, where it's level one, two, or three.

**Darcy:** Things like MCAS and POTS and those sorts of things don't have those same really strict criteria. MCAS, for example, is ' airy fairy'. It's like, if you have any of these things that show up on a blood test or a multitude of other tests that you can do that are within this range, then you might have MCAS.

But also all of those levels can change at a moment's notice. They can be different, or one minute of the day to what they are literally two minutes later and you just have to try catch them at the right time.

And my immunologist says that like the strongest indication that you actually have MCAS is that you respond well to the medication. But that's just because he's a good immunologist and has a decent understanding of MCAS.

A lot of other immunologists wouldn't accept that. And so we're still trying to catch those levels at the right time to tick those boxes. But still then, it's not a clear enough and defined enough box for NDIS to be satisfied with.

And yet that's probably the disability that impacts my day to day life the most, and that I need the most support with. I really like yarning to you about psychosocial disability, neurodivergence and physical disability. Because they are things that we both experience.

**Darcy:** We have that whole range of experiences. And a lot of the time in activist spaces or advocacy spaces or just community spaces, those experiences are very siloed.

And unfortunately, it can be really difficult to find people who are active in physical disability community spaces who care about psychosocial disability and neurodivergence and vice versa for those other things.

For example, you'll find a lot of neurodivergent and psychosocially disabled people who do not care at all about COVID and COVID safety and precautions and the accessibility of venues and all. And it can be really, really frustrating. So I find a lot of like value and care and love in yarning to you about those intersectional experiences.

And even though I tend to focus a bit more at this stage on physical stuff in the things that I talk about and write about in the yarns that I have, and you are focusing more at the moment on psychosocial stuff, we have those experiences and those connections with each other.

**Darcy:** And I did want to ask you about your experience within psychiatric care. You talked about at the start of this yarn, how you've been in and out of psychiatric care for the past 10 years, was it? Yeah I wanted to ask about your experience as a young one and having grown up in that system and how that's changed.

I remember us having yarns over the years about how you were just spat out of these systems once you aged out of them and left with nowhere to go. Not referred to anything that was for adults.

I just wanted to ask you about the sorts of similarities and differences that you've identified growing up through that system, and how that has informed your psychiatric abolition work.

**Em:** Yeah I guess one of the biggest things is that public psychiatric treatment and especially involuntary treatment is designed to take away your sovereignty and I feel like that hits especially hard when you're a Blakfella. These systems are very paternalistic.

They're designed on the fact that you cannot make decisions about your own life. I was just talking to one of my case managers about it this morning, that these systems are designed to take away your choice and control.

And that can be especially traumatic as a First Nations person because you already have that trauma and intergenerational trauma of that stuff happening and I just feel like psychiatric systems are just another arm of the colony.

**Em:** It's very intergenerational for me because my dad has schizoaffective as well, except he was never, he has been very criminalised and in the jail system and such. And then he was never given any treatment. I don't think he will ever get treatment.

And then there's me on the other side that has been forced into treatment, and forced into hospitalisation, and forced into case management. And in both sides, we've lost our autonomy, and we've lost our, not independence, but we've just lost the right to our lives, almost.

Like, in peer work we talk about a really big thing called dignity of risk. So a lot of clinical workers, they'll be like, "duty of care, duty of care, duty of care". But we as peer workers look at things as dignity of risk. Because for some reason in this world, once you are diagnosed with a serious mental illness, you lose the right to make choices about your life.

**Em:** So as peer workers, we believe in dignity of risk. We believe that you deserve the right to be able to make choices about your life. They may be not great choices. They might be even potentially dangerous, but you deserve to make choices about your life.

Just because you've got a magical diagnosis, why does that suddenly get your rights taken away? My biggest thing is, I think a lot of people understand abolition in terms of police and prisons, but they seem to think that psychiatric abolition is just that step too far.

I think people still have a wider idea that psych wards are places of care and places of safety when they are not. They are places of containment. A jail is a jail. If I get arrested by police and taken to a hospital and I can't leave, that sounds like incarceration to me. I

f I'm forced to take medication under the threat of re-incarceration, that seems a bit similar to an ankle bracelet to me. I think people I think people with severe mental illness are just put in the lower rungs of society, especially if you are BIPOC.

And they're just not really interested in what happens in psych wards, and I think that those conversations need to be had. You should be able to choose if you want treatment or not.

**Em:** I just don't believe that the world has the right to force treatment onto people, based on what your ideals are of sanity and what your ideas are of what the world is. You cannot force treatment on someone based on your version of reality. That is not fair. And that's what I love about that intersection of being a Blakfella.

Is that there's not these rigid lines about reality. I think that First Nations reality is a lot more expansive, and a lot more, I don't know what the word is, but I just think that if I had experienced psychosis without colonisation on this continent, I don't think I would have been treated the same way that I was treated by these colonial health systems.

And that's like reimagining my idea of psychosis. I used to see it as a burden, and now I see it as a gift. Because for abolition, we need to imagine a new world and way of living. And I think people with psychosis have a very important stake in that because we can imagine things that maybe people who don't experience psychosis can't imagine.

**Darcy:** Yep.

**Em:** I think that people with psychosis and our position as storytellers and especially First Nations people with psychosis, and especially First Nations people with schizophrenia. I think we have such an important role to play in this world and the reimagining of this world. And that's what's really important to me, is that we are seen as people who have very important gifts to share with this world.

I don't care if people aren't ready to hear it. I'm gonna fucking share it anyway. So we're wrapping up and I can't believe I was like, I have no idea what I was going to talk about. We could literally talk forever.

**Darcy:** Yeah, that's true.

**Em:** But I'm going to finish off with a poem. about being hospitalised and talking a bit about how my spirituality and sovereignty as a First Nations person has actually been mistaken for psychosis by some doctors.

And it's just basically a poem about being involuntarily hospitalised. It's called, Do You Feel Safe? Because when you're in hospital, that is the one question that they will ask you two billion times. They'll ask you every five minutes, do you feel safe? Do you feel safe? Do you feel safe? So here's that poem.

**Em:**

Have you been taking your medication?

She thinks she's talking to her ancestors again

Do you think you might hurt yourself or others?

She's not making much sense

Does it get worse with age?

Does it get better with age?

Warped in a plastic mirror to be an eagle flying over the agar

Security guards hold my limbs like cat claw around a native tree

Injection into the muscle, I feel like honey and I will sleep for a day

And arise tomorrow and I won't remember

And it'll happen again tomorrow like my time machine got stuck

Like the uncles used to time travel

Revolving door patient like the seasons roll around

But I didn't choose to be here

Involuntary.

Locked up into every hospital in Southeast Queensland

I think I need to get my passport stamped

Hard to feel country when you're on the top floor

And the outdoor area is a concrete balcony covered with thick mesh and bars

Just to remind you that you aren't free

Just to remind you that you've done something wrong.

Can I charge my phone? Can I go to the toilet?

Can I go grab something out of my room?

Can I have a vaporiser?

Can I have something to help me sleep?

Can I wear normal clothes again? Can I have another blanket?

Can I have my shoelaces back? Can I have my phone? Can I have a nicotine patch? Can I go to the toilet?

Can I talk to someone? Discharged. See you again in six months.

**Em:** And yeah, that's me. That's my poem. Hehehe. *[laughing]*

**Darcy:** Damn. Oh god. Yeah.

**Em:** Can you tell I don't like psych wards?

**Darcy:** Yeah. *[laughing]*

**Em:** Yeah. How do we finish this up? I don't know, because I just feel like talking forever, to be honest. Maybe we need to start a podcast.

**Darcy:** I reckon we do hey.

**Em:** Love it.