HEALTH & CARE IN THE TIME OF COVID HEGEMONY

Them Fatale: During this time when we are all becoming increasingly aware of just how much propaganda we're being fed on a daily basis, can you please, (please, please, please), try to also internalise the idea that maybe, just maybe, your understanding of COVID has been similarly influenced.

Maybe there is a reason why we have a disease that is currently the third leading cause of death that has been shown to damage every single organ system in the body, that's been shown to have long term effects in 1 in 10 infections.

That's not 1 in 10 people, that's 1 in 10 infections, so if you're on your third, the math is mathing. Maybe there is a reason why we can have all of that going on at once. Meanwhile, word on the street, and word according to a lot of common media, is that it's either over or it's mild.

It's ripping through communities enough to still be the third leading cause of death and people are surprised to get it.Level of misinformation out there is immense and none of us are immune to it.

**Them Fatale:** It's really tempting to believe this stuff because it's fucking everywhere and it's nicer to believe. None of us want to still be in this mess. That's the thing about propaganda. Often all it has to do is cast doubt.

Our governments were incredibly clear about the fact that they opened up for the health of the economy, not for the health of the people. If we all had access to the data that demonstrated the long term impacts of this virus, that should have caused fucking riots.

But everyone was exhausted and traumatised and lonely and the idea that we could all go back to our normal lives was a really nice one. So being told that it was mild despite the mountains of evidence to the contrary was enough.

It's enough to just doubt whether it really is that bad and that's extremely easy to do because for a lot of people it does feel mild, but this is the thing. You can't feel organ damage. You can't feel vascular damage. You can't feel immune system damage. So if you can't feel them, what would we see if they were happening?

**Them Fatale:** What would see is more people getting more sick, more frequently and staying sick longer would see more heart events, more strokes would see more diabetes, more cancers, and if you look at the data on a health scale, that is exactly what we are now seeing.

The level of misinformation is so fucking wild. I distinctly remember them saying that this disease couldn't hurt kids. And now children are one of the fastest growing groups experiencing post COVID damage.

And here's the kicker, right? None of what I'm saying, according to the actual empirically reviewed data, is in any way controversial, but this feels terrifying to say, because I know that none of you want to hear this.

And so if I have a request for you today, just take a little bit of time to sit with the fact that the data that we have is so different from the lives that we are being encouraged to lead. Sit with your gut and look around you. It is not normal for this many people to be coughing in fucking late November.

**Them Fatale:** Everyone is sick. Can you remember a time pre-pandemic when it was like this? Is it possible that maybe the people who are ignoring climate collapse and who are telling you that genocide that you can witness with your own eyes isn't happening - maybe they wouldn't be super honest with you about a disease that would stop the economy if they actually paid attention to it?

And I know the buck stops with this being a public health failure. I know this is ultimately not your fault. But we have been made into the vessels via which we enact harm upon one another and I'm sick of watching it.

It feels genuinely sanity destroying to have had my shit rocked so severely and to have had my life be made so small by this disease and to have people who care about me not do anything to stop it from happening to them, to stop them from doing this to other people.

So I guess if I'm asking you one thing today, it is just to take a moment to sit in the discomfort of the fact that we have all internalised propaganda.

We have been asked to take on appealing, but ultimately untrue ideas about the biggest fucking global ongoing event of our lifetimes in order to make us prioritise keeping the economy alive instead of each other.

**Pauline:** Hi there, it's Pauline Vetuna, the Disability Day Worker for 3CR. What you just heard was a video by performance artist Them Fatale, discussing what a lot of people who are keeping up with the science on COVID and long COVID have been bullied into not talking about.

I was actually going to write a whole page describing the seriousness of COVID and long COVID, and capitalist overlord propaganda. But then I saw that video and they really said everything that needed to be said.

So I just asked them if I could play it for you today. You're listening to Health and Care in the Time of COVID Hegemony. Resisting the state's abandonment of immunocompromised families.

*(Music plays)*

**Pauline:** That was a song by singer songwriter Martha Marlowe, a track called All of My Days off of her debut album Medicine Man. Martha's work has been shaped by her experience of living with a disability, which includes a rare autoimmune condition, limited mobility and chronic pain.

She was one of 10 artists to receive a COVID Restart Sound On grant from Accessible Arts to help them to continue to make music after the initial devastation to the music industry of the pandemic.

So at the top of this program you heard a video by Them Fatale on instagram who articulated so brilliantly the dissonance between the enormous amount of data and evidence that now exists regarding the danger that being repeatedly infected with COVID puts a person in.

And we have a growing body of evidence about the varied manifestations of long COVID as well. It's worth remembering that the World Health Organisation never said that the pandemic was over. They never said that. They actually said that it would no longer be classified as an international public emergency, but urged the world's governments to stay vigilant.

In May, three years after the World Health Organisation declared a public health emergency of international concern over the global outbreak of COVID 19, and after almost 20 million deaths, the Director General of the World Health Organisation said "this virus is here to stay. It is still killing, and still changing. The risk remains of new variants emerging that cause new surges in cases and deaths".

**Pauline:** He also said, "The worst thing that any country could do now is to use this news as a reason to let down its guard, to dismantle the systems that it has built. Or to send a message to its people that COVID 19 is nothing to worry about".

COVID hegemony was a term coined by Dr. Blair Williams of Monash University this year to explain the transformation of our pandemic outlook. "COVID hegemony", she wrote, "can be understood as the normalisation of widespread infection achieved by those with power. Through coercive persuasion to gain our consent and even approval.

Divorced from realities of widespread transmission, the media, politicians, and certain experts have been pushing for a return to normal, to quote, live with COVID, and to move away from quote, COVID exceptionalism. So with the minimisation of this disease and denial of the data, conditions for people most at risk of serious complication or death".

It's been really upsetting just to watch policy wonks argue about public health policy in a way that is completely disconnected to the actual human beings and whole families who have been condemned to the margins because of ableist public health policy. I recently caught up with a friend for whom this is the reality.

**Pauline:** As Melbourne goes through its eighth wave of COVID, I spoke to my friend Cubbie, a disabled parent of two children. One of whom is disabled and immunocompromised, to ask about how this whole experience of COVID hegemony has been.

Cubbie is a Naarm based writer who has contributed to Resilience, Growing Up Disabled in Australia, Collisions: Fictions of the Future, and is the winner of the Writers Victoria's Grace Marianne Wilson Emerging Writers Competition.

**Cubbie:** Here in the western side unfortunately, there is that, call it the eighth wave, but it never really stopped throughout the entire year of 2023. There are many school children who have been catching COVID more than once. So we look at what is the effect of your future workforce with those with long COVID.

Both my kids now have long COVID apart from myself, which means they wear face masks, even though it's not a mandate to wear a face mask to school. The other one is remote learning because despite it being a specialist school, there are no mitigations.

**Cubbie:** The teachers, the staff, no one is wearing a face mask. I recently discovered That duty of care is different from one carer to another. I found one parent bringing their child to school while coughing, like, what? No way. You're spreading germs to my kids.

So I've got my kid now at home and just doing their NDIS plan and other things in school via remote learning. But I am shocked by the very low standard of care among disabled students.

So that's a very big concern coming from the west side of Naarm. Because during the pandemic, we had one of the highest rates of COVID in the west side. So what is the level of care? It's still the same since my kid had cancer.

It's a very meticulous kind of care, which is we enter from the back house or where we have this holding bay. If someone is listening and had cancer, you know there's this holding bay inside the cancer ward and we strip all the clothes, outdoor clothes, put it in the washing machine straight away, straight to the shower.

And then once we're all clean, that's the time we meet the immunocompromised child. We don't touch her until we're all clean from outdoor bugs, germs, whatever, because no one is masking.

**Cubbie:** But we still mask, and I don't care if they're glaring at me. It's rare to see the mainstream, non-disabled wear masks. That's the bare minimum. That's all we ask. Wear a mask when you're coughing. Just wear a mask. But no, no one. So it's just shocking.

We still have our food delivered all these time. Going out is very minimal only when we need to top up medication. Because of our long COVID, our movements have been greatly reduced.

And so is our capacity. It's just shocking how catching covid from my child's disability school exactly a year ago when the government removed all the mandates, because there was a state election. They took out the mandates. Everyone took out their masks and there you go. We caught it straight away.

We still have the whole set of PPEs, hand sanitisers. We take RATs, the rapid antigen tests. When we see the NDIS therapists, that has to be a basic requirement.

**Pauline:** So just to clarify, you have two children yes? They're both teenagers, and when you mentioned cancer and the NDIS, that pertains to one of the children?

**Cubbie:** Yeah, one of the children. The other one, they're neurodiverse and have long COVID as well. You'd be surprised. We caught it from the same child, but the manifestation of long COVID was different from each child. Myself, I was hit in the heart and lungs. So I used to cycle all the way to the city. Now my maximum is two kilometres. That's all I can do.

Despite all the tests we had, they can't explain it at all, what long COVID is in the medical settings. We've either been gaslighted or minimised, or "no, you don't have long COVID". Then explain this. They can't. I don't know what's happening.

There should be more research. We are looking at research from other countries. There is a community as well for long COVID called with a hashtag #longcovid, and we share resources and where to go for allies of doctors who do believe there is long COVID. Because there is no help. Once you catch COVID now, there are no PCR clinics.

As of 31 October, the government removed all the respiratory clinics. They don't exist anymore. So where are you gonna go when you catch COVID at this late stage of life, of so called "COVID normal", whatever they use to normalise getting sick.

They say "oh it's just a flu", but it's not. No. No matter what you tell me, it's not the flu. We are being silenced and erased from the everyday narrative.

**Pauline:** I wanted to know how the decision of the government to pursue this let it rip policy and so called living with the virus affected you emotionally and mentally as a parent and as someone who also is immunocompromised.

**Cubbie:** It was very scary. Many of us considered it... It's eugenics. It's plain, simple eugenics. You are erasing us from the world. What do you plan to do with us? Why is this narrative of COVID normal that it's just a flu, but it's not? I'm very negative about it, but I have to be optimistic towards the children.

Say, my year 11 has to go through VCE, but is so stressed. With their long COVID, they decided to take a different course that would not affect them too much, because it's so much on their plates.

**Cubbie:** This is the generation that came out of lockdowns two years after. In terms of social development, personal development, they're two years behind. So we've got a generation that not only experiencing long COVID, they're also behind their development.

So we're taking things slow and the teachers are very "chop, chop, chop", you know, "let's do this within schedule “. Oh, come on. There's still long COVID, so you have to acknowledge that and substantiate that with letters from doctors that are out there.

"My child has this, this, and this. Take it easy, please". The absence of mandates, not giving the schools the power to say "okay, please just wear masks". No, they can't do that. I did ask.

All they can do is provide a HEPA filter. Clean better, but they still were not wearing masks, despite someone's coughing. The teacher, the staff are coughing because it's not mandated.

**Pauline:** So were you happy with the state and federal government's responses to the pandemic prior to the let it rip policy?

**Cubbie:** There were no COVID payments when we got sick, but there was help coming from the local LGAs. They provided meals for us when I could not cook. And hashtag mutual aid, we called out for help because we were at the tail end of the 'let it rip' already.

We were at the let it rip stage when we caught COVID. It was the community who helped and not the government. Because there was nothing from the government except they would check on us on the phone.

How are we doing? That's all. Medication wise, it would be the GP. But nothing. So it was the community, hashtag mutual aid, who helped us. Fellow disabled, fellow immunocompromised, other artists, because I'm also a writer and an artist.

They were the ones who signal boosted our request for help. Nothing from the government except In Kind, which is the local one, which is food. Fellow westies and fellow people who've gone through COVID were the ones who were more empathic of the situation we were in.

**Pauline:** I want to talk to you a bit about the forced isolation that some disabled people experience. Something we had conversations about prior to 2020 was the marginalisation of disabled people from community spaces. Including and perhaps especially spaces for communities of colour.

But I would like to know what impact the added danger of a disabling airborne virus has had on your social life and your ability to access community spaces of healing and support.

**Cubbie:** I'll give two concrete examples. The moment that the government removed the mandates, that means all our organisations that are out there in the arts decided to stop doing hybrid.

Hybrid is a combination of online and also in person. Once the mandates were gone, so did the online basis. Each time I get an invite, I ask for a hybrid setup. Or I advocate when I see an event. The first thing I ask, is this accessible? Are you able to broadcast via the internet? Is there a live stream?

So there are other options, but you have to ask them nowadays. There is an event coming up. I'm in the middle of negotiations. Unfortunately, they say because there are no mandates, they cannot tell the people who will attend face to face to wear a face mask. So we decided, "okay, let's just do this 100% online".

**Cubbie:** Make sure there are captions, make sure there's Auslan interpreters, sign language, and make it accessible in that way. We can still have a workshop online. I have to pitch it in a way, I tell them "when you're online, you get a bigger audience, a wider audience. Even the interstate participants can join in to your workshop".

Some say, "Oh, I already have this zoom fatigue", or online fatigue. Like, nope. That's our main access for the disabled community. So when you say you're having zoom fatigue, are you being ableist? You have to really see that our main communication has always been online since the pandemic.

We still advocate to tell them please do not take them out. Technology is still improving, which is good. We can see that in instagram, you can go on instagram live, and watch say for example, the protests online.

They can do that. They can add captions as well, which is fantastic. And one of the instagram accounts I know, they even include Auslan.

**Cubbie:** So there are ways to sustain that community online for those of us who cannot be there face to face, but it is a battle you have to negotiate. They did say having this online is very expensive, it's not sustainable. But it is sustainable. It is the way of the future. The future is accessibility. Got t-shirts for that!

*[Cubbie laughing]*

**Cubbie:** Another example is it's the Lord Mayor's creative writing prize. I was shortlisted for that, but I said, I have long COVID. I can't go. What they did is they made it accessible and streamed it.

So it's a matter of just asking and they will make accommodations again, depending on the organisation, but there are changes coming in.

Carolyn Bodich of Arts Access Victoria is now on the board of, they call it now Creative Australia. So hopefully in 2024 we'd be seeing more accessibility. More funding for disabled artists. That we are still here and they will include us in the mainstream narrative.

*[music plays]*

**Pauline:** You're listening to Health and Care in the Time of COVID Hegemony on International Day of People with Disability. You just heard the track Cinema Engines by Reality Instructors. Their lead singer, Daniel Pash, was a recipient of a Sound On grant that supported 10 artists to create new music after the impact of the pandemic.

The band's new five track EP explores the final stages of Daniel's hearing loss and what is possible in the areas of songwriting and recording when faced with the limitations imposed by profound deafness.

Today we've heard from my friend Cubbie, writer, long COVID patient, and disabled parent living in Melbourne's West, but Cubbie's experiences aren't uncommon across English speaking Western countries.

As difficult as it is for disabled friends here who are immunocompromised and still trying to avoid getting this virus, I know from disabled friends in the UK and in the US and even in Canada, that it's even more difficult overseas.

**Pauline:** So to find out more about what is happening in the UK, I spoke to my friend Amer. The UK is currently holding an independent public inquiry set up to examine the UK's response to and impact of the COVID 19 pandemic. And quite frankly, some of the revelations so far have been appalling.

One example, a note apparently from a meeting between Boris Johnson and Rishi Sunak in March 2020, "Why are we destroying the economy for people who are going to die anyway?".

As one UK disability campaigner said in response to this revelation. 60% of people who died during the pandemic were disabled. Here is Amer.

**Amer:** My name is Amer Kangizer and I am currently a Marie Curie research scholar at the University of London. I am immunocompromised and I'm on immunosuppressive medication.

I have multiple autoimmune diseases that put me at extremely high risk of severe illness and/or death when I contract COVID, which I have done now twice. I am in the UK at the moment, not really by choice.

 I moved here for work after a protracted negotiation with my funding bodies around disability, reasonable adjustments and disability allowances.

The result of which ended up in my fellowship being cut until I relocated to the UK, which was not a decision that was made lightly. It was made entirely on the basis of needing to work over here. So it's been a very difficult and complex situation as an immunocompromised person coming from Australia into the UK.

There have been a lot of parallels with the Australian discourses and actions around COVID and also a far more extreme and catastrophic state in the UK around COVID denialism, COVID action. And just generally, I think the social response to COVID in the UK is, was eye opening.

**Pauline:** You have a child in primary school, yes?

**Amer:** Yes, I do.

**Pauline:** How have you tried to minimise the risk of your child catching COVID at school, and what have been some of the obstacles to doing so?

**Amer:** I think the thing that I find really interesting across a lot of different contexts is the way that people who, in the UK, we have a very conservative government at the moment.

We have the Tory government in power that is led by Rishi Sunak, and I'm sure a lot of people are familiar with the ultra conservative, ultra racist, transphobic, anti migration policies just really anti poverty. The Tory party is a very conservative, economically conservative, politically conservative party.

And I'm sure that people are familiar with their policies. The thing that has really surprised me with the COVID response is how so many people that I know - who would unequivocally say that they are in no way aligned with the Tory party - that they find the Tory party's policies draconian and horrific - are aligned in the way that the conservative government and similarly with the Labour Party, like their approaches to COVID, which has been a very reckless.

I think everybody knows the statement now, "let it rip" approach that the UK government and therefore the UK society have had with this so far. When we got over here, one thing that I was immediately surprised by was how vehemently anti-mask. A lot of people are to the point where people will say things to you on the street if you're wearing a mask.

**Amer:** Nobody wears a mask here. There are no masks worn in hospitals, despite the fact that COVID cases here really have been... I don't know that they ever really fell. I think that kind of narrative around rising and falling is a false narrative. I'm not sure how much they've ever fallen.

Because in the UK, there's very little mechanism for tracking or tracing what is going on with COVID. You don't really know where things are at. So when I got here and enrolled my child in a school, we asked immediately.

We introduced ourselves and said we're an immunocompromised family. High risk of severe COVID and we asked the school what they were doing to minimise transmission.

And interestingly enough, I think this is something that ties into this as well. Where we are in South London and across London actually, there has been a lot of campaigning done around clean air, also being a disability justice issue and affecting a lot of people that live in the South, particularly.

**Amer:** So I feel like the COVID response could have really nicely tied into the clean air campaigns as well, but you know, a missed opportunity, perhaps it'll still come around. But anyway, when we approached the school, which is in South London about COVID mitigations, they were quite obstructionist, I suppose would be a way to put it.

So they have no COVID mitigations whatsoever. And obviously, this is despite the fact that a lot of the teaching staff are off sick, which is also coinciding with a huge wave of strikes that have been going on across the country of teachers. So there's a lot of teaching staff that are out, a lot of pressure put on teachers in terms of health.

So they don't really open the windows very much. There is no air filtration or anything like that. And when we did approach the school and we ended up going all the way to the governance board, we offered to fundraise to get HEPA air filters into the classrooms across the school.

What was really surprising, and this was based on various levels of bureaucracy that I will not go into, but what was really surprising was that the school basically said that they would absolutely not take HEPA air filters. So it wasn't even a matter of, "we can't afford, or we are not enabled by the government to provide ventilated classrooms".

**Amer:** It was that they point blank refused. Even if there was no work done on the school's part, even if it was collectively fundraised. We found companies that would quite cheaply rent HEPA air filters out for the periods of time where it was less possible to get ventilation through windows and things like that.

The school completely refused us. And on top of that, we also encountered pushback from the parents parroting the line around children getting sick due to the immune system deficit or the idea that children have to get sick in order to build up their immune system resistance to COVID, which there is a lot of debate around.

So it functions here on multiple levels. There's the bureaucratic obstructionism that goes up to the government through the department of education into the individual school. And then of course, there's also the social obstructionism that is very much the very typical colonial mindset of it's about individualism.

People were saying my child's immune system is fine, so why should we care? We don't need to care about what's happening to other people.

**Amer:** As well as the intense misinformation that's being peddled across the UK around this idea of immunity debt and that children are not affected by COVID, that children are fine, despite all of the scientific evidence that's coming out against that.

And I think what we see here, and I'm curious to know what it's like in Australia, is that there's a social consensus here that's not based on science whatsoever. There's a governmental consensus that's not really based on science either. And there are these scientific arguments and evidences that are coming out that just seem to not factor in at all.

And I could talk about this for a very long time because I've really developed a much clearer understanding of the mechanisms around colonialism and the absolute disregard - not only of disabled life, because I think that's very clear already - but also the way that these kinds of deeply colonially founded countries also have a very deep disregard for the life of children and the lack of autonomy or consent that is given to children around this.

**Amer:** It's these decisions that are getting made on behalf of children that are decisions that can hugely affect their health into the future, where children have no capacity to decide what kinds of situations that they put their bodies into.

And it's something where we have gotten to the point where we've considered taking our child out of school, finding other alternatives, but to be honest, even trying to get a child of her age to wear a mask in a school where nobody masks and she would receive bullying for masking.

It's a very difficult position to put parents into, or families into where there are immunocompromised people within that family or that are concerned about their child's health in the first place.

**Pauline:** You said up top that you actually have had COVID twice. Could you tell us about those cases and what your experience was?

**Amer:** I first got COVID in Australia. Again, I've been out of Australia for a little while now, so I don't know where things are in terms of access to antivirals and things like that.

My first experience in Australia in mid-2022 was that it was very easy for me to access antiviral medication. I think I got it within a few hours. So my experience in the UK was, it was very bad.

**Amer:** But I did find out from other people that have similarly tried to access antiviral medication, Paxlovid, that I had a far better experience than what they did. So when I got COVID in June this year and this is despite having vaccines and everything, when I got COVID in June this year, it took about two to three days for me to be able to access the medication because of the intense complexity of even getting to the Paxlovid in the first place.

In the UK they established COVID medical delivery units in particular hospitals, which is the only place where you can get Paxlovid. So you can't just pick up Paxlovid with a prescription in a general pharmacy. There's a certain set amount.

I don't know how much, but a set amount of Paxlovid that is available and it's held by the COVID medical delivery units. The pharmacists around don't even know about Paxlovid. What we were really surprised about was that they'd never heard of Paxlovid, which speaks to maybe the small amount of circulation of Paxlovid here.

**Amer:** I'm not quite sure, but it took many, many doctors, letters calling emergency departments, calling the COVID medical delivery unit to be able to access the Paxlovid. In the end, what I was told by one of the pharmacists at the COVID medical delivery unit, was that he said" you are quite lucky to be able to access this because 1 in 10 people who are on the high risk list who are in urgent need of Paxlovid don't get it".

So we're talking here about people that are immune suppressed, people that are chronically ill, that are really needing this medication and only 1 in 10 of us are able to actually access that medication.

I'm guessing that's because there's limited numbers of the medication. It's kept under lock and key so much that they courier the box to your house. I was lucky in that I had someone that was able to go there and pick it up for me. But even in that situation, there was so much complexity with the outpatient pharmacist who had never heard of Paxlovid himself.

He'd never heard of the COVID medical delivery unit. It was just on every level, so much confusion. And it felt like there was just no coherent system to be able to get people the medication. On top of that, other reports that I've read and people that I've spoken to, they started the same process as what I started.

**Amer:** I was very lucky and privileged, I would say. In that I am able to advocate for myself quite hard because I'm quite used to it. But other people who just gave up and then just never got the (Paxlovid).

And I'm talking about people who are in remission from cancer, who also have immunosuppressive conditions. I just also read the other day that the delivery system has now changed.

That's the other thing. There are changes that happen here around how high risk people can actually access medication, which is never communicated to us. And so as a high risk person, you have to be doing your own research all the time, because often GPs don't know, and you don't really know who to talk to.

There's no one that you can really talk to about it. So you have to find out how am I able to access this medication if I need it? It's a very opaque process, and it definitely feels like you are actively discouraged from being able to access that medication.

Even going into the situation with the vaccines that we have now is a whole other arena, which is equally changing. So I'm eligible for vaccines whenever they come up, which is. It's every three months, but I've been getting them every six months.

**Amer:** And the variant that's quite predominant in the UK now is the Pirola variant. And because of the rise of the Pirola variant as the variant of interest, they brought forward the autumn booster. So, your spring is our autumn. The autumn booster.

And what happened was, because of cost cutting measures, the pharmacists actually gave people, or the people who are giving the vaccines, actually gave people outdated vaccines.

So because the new vaccine that is now in circulation, which is the Omicron vaccine, the new Omicron vaccine, the vaccine that was given was the vaccine from last autumn, which was the bivalent vaccine.

And so a whole bunch of the most high risk people in nursing homes, people in hospitals, people that were contacted by the GPs, were given an outdated vaccine for the Omicron variant from last year. Nobody told us this. So this was not we thought we were getting an updated vaccine. We were thought that we were getting the vaccine for this year.

**Amer:** Nobody told us that we were getting outdated vaccines. So you can imagine, people at the most high risk are going in to get the vaccines. I was really lucky because I'd had COVID.

And so I waited a month later and unbeknownst to me, I was very lucky that I was able to actually get the new updated vaccine for this autumn 2023 season. But the people who got the outdated vaccine, who had gone in as soon as the doors open for people to receive vaccines, were not able to get the updated vaccine.

So effectively they got a redundant vaccine. The argument that the Joint Committee on Vaccination and Immunisation has been using is that some vaccine is better than none.

But we don't really know that's true. And all we do know is that the outdated vaccine is definitely less effective for this new strain of COVID and circulating variants.

And I think these kinds of things where people are not told the stakes of what's going on, there is really no public health communication around COVID whatsoever.

**Amer:** There's no public health communication around the COVID vaccines. For instance, I only found out when I tried to get my child vaccinated that she was no longer eligible. They weren't vaccinating children in immunocompromised families.

All of this information is hidden away to the point where a lot of the time pharmacists don't even know. I spoke to my pharmacist and to my GP about the outdated vaccines and they had no idea. There's just on every level, this kind of erasure, misinformation, obfuscation about what is actually going on with COVID.

Which reflects a broader social sense around COVID being gone, COVID no longer being an issue. And particularly as well from a governmental level. It's as though COVID does not exist here anymore. COVID was something that happened in the past. It's no longer an issue. It is done. Nothing.

**Pauline:** Final question. What are the mitigations that could be adopted to make whole communities safer and keep immunocompromised people in communities, the communities that they are currently being shut out of?

**Amer:** I really feel like everything that is possible has been already said. I don't think we're working here with unknowns. I don't think that there's this sense of, " Oh, we have to do so much".

It feels that what we have taken as the bare minimum, even things like hand washing, and I know hand washing is not how COVID is spread, but even things like hand washing has completely dropped out of any kind of conversation. I noticed this in schools and stuff.

And I think the bare things that we already know, adequate ventilation, HEPA air filters, wearing masks in crowded spaces, if you are able to wear a mask, staying home or trying to stay away from people when you're sick, or again, wearing a mask, the bare things that we already know work, or at least help to mitigate COVID.

That's just the bare individual things. Not obviously the support, the social and economic support required to enable people to be able to take off work when they're sick and the supports for people with long COVID.

Again, they've just brought in a thing here in the UK now that disability benefits will be curtailed unless people also work from home. Which is clearly a response to the amount of people that have got long COVID.

**Amer:** Forcing people to work from home now is a whole new level of response of trying to take people off disability supports. So I think the things we already know that work, it's just a matter of implementing those things and to bring it back into a social discourse again, where it's about think of people who aren't here.

Think of who is not in this space. It feels so basic to say, and yet so hard to implement. And again, I think it requires a complete reconfiguration of how we think about ourselves and each other within community.

Within a collective understanding of how we care for each other in terms of interdependence, there's all of those things missing about how we just consider other people outside of ourselves.

I think we'll just have to keep coming back to that over and over again. Because it doesn't seem to me like there is any future that doesn't require that kind of consideration of others. That doesn't require us, this hyper individualisation, hyper capitalist, very driven mindset that we are just here for ourselves, is so destructive.

**Amer:** And so I think just coming back to that idea of caring for one another and using the mitigation strategies that we already have, that we already know about is really something.

**Pauline:** That was my friend Amer Kangiza, sharing their knowledge accrued through several years of surviving the COVID 19 pandemic and the UK health system, in the heart of the empire that spawned this colony.

As I was listening to Amer talk about the need for relationships of care, I started to think about the emphasis many Indigenous peoples around the globe place on relations of care, first and foremost, and as part of that, accountability. But not in a bureaucratic sense, and definitely not in a carceral sense, but rather as responsibility to care for the needs of people you are in relation to.

There was this article that I read in June by a woman called Sandra Yellowhorse, who is a Diné person, Indigenous to Turtle Island and who writes about, quote, being in relation to disability for as long as she can remember. The article title is Indigeneity and Disability: The Teachings of Our Ancestors, and Being in Relation Towards Harmonious Outcomes.

It is a beautiful essay and insight into her culture, so definitely check that one out. It's on the Disability Visibility blog. In the article, she describes a lifestyle of caretaking and an ethical framework amongst the Diné people named k’é. Now, I'm not doing justice to the pronunciation, so forgive me for that.

**Pauline:** Sandra writes, "*K’é* is committed to the principle that to be in relationship with someone is to be accountable to that person. Again, accountability is not a eurocentric or American understanding of accountability, as a slew of checkmarks and regulation one follows. Accountability in a Diné context could be seen as a kind of service.

A critical understanding of how our relationships are prioritised through our understandings of interdependence. We think, act, respond, and live to care for the relationships we all have and honour this inherent interdependence we all share as human and non human beings in this world. Tewa educator Gregory Cajete reminds us that nothing exists in isolation.

We all impact one another. Our actions or inactions shape the world in some profound way, whether we acknowledge it or not. K’é is a tool that teaches people this realisation. And it also becomes the ethical framework to live an accountable existence in relation to all life and land". End quote.

**Pauline:** As a disabled person of an Indigenous lineage myself, something that I have thought often about in this time of COVID-19, were the ancestors who, in times of incurable viral disease outbreaks and before effective vaccination programs, were separated from their families and lived in exile.

That's a trauma that exists in my own family. My paternal great grandfather was suddenly and permanently exiled to a leprosy colony by colonial administrators in what is now known as Papua New Guinea. When his daughter, my paternal grandmother, was a really young child. And he was never heard from again.

We don't know what happened to him, or how he felt, or what his life was like after that. We don't know how long he lived, or how he died, or if he was alone when he died. Being exiled because of a disease is deeply traumatic. It has generational consequences upon the descendants of those who are forced to live without pain.

**Pauline:** So when I look at discourses around solidarity and relationality that don't reckon with the ways almost everyone has become an agent of the state with regards to COVID transmission, and ableist public health policy, I can't reconcile that. What is relationality without an ethic of care for all people?

Not just the strong ones. Not just the normal ones. Not just those whose immune systems are better able to fend off disease. And I'm really saying this out loud to myself. Because I cannot with my whole heart embrace a relationality that unintentionally mimics and extends the violence of colonialism through neglect.

I want to explore Indigenous approaches to disability justice as much as I want to explore what material solidarity in anti capitalist, anti imperial struggles, a solidarity that doesn't abandon disabled people looks like . That's an ongoing and unfinished thought. So I'm going to leave you with that.

Thank you for listening to Health and Care in the Time of COVID Hegemony. Stay tuned for more Disability Day Health Sovereignty Programming.​