4. Public Health Emergency with Tori and Tricia

**Pauline**

You're listening to public health emergency with Tori Hobbs and Tricia Maloney. I'm Pauline Vetuna. I'll just start by asking you to introduce yourself.

**Tori**

Yeah, sure. My name is Tori, I'm a disabled writer and disability justice advocate and COVID care nurse living on Ngunnawal, Ngunawal, Ngambri land. During the last few years I've been providing in-person and remote care to people in by the hospital and community setting as a nurse. I've been lucky enough to work in ICU, emergency department and community disability support work through the pandemic.

So I've been using my experience as a nurse and as a disabled person to provide information to the community about COVID built sort of on a framework of harm reduction, access and mutual aid. So in the first year of the pandemic, I volunteered my time to help translate resources about COVID in general, like COVID sort of myth busting things.

And more recently, through my work with the Disability Justice Network. Other than my paid work, I've been able to help distribute mutual aid, masks and rapid antigen tests. Now, I'm mostly doing remote work as a nurse providing care for people with COVID in the ACT. And in my free time, I like to research about COVID and annoy everyone on social media so that COVID remains at the front of everyone's minds (laughing).

**Pauline**

So the tremendous strain that the healthcare system has been under since the pandemic began, was a talking point for leftists and progressives for a period of time. But with the government's dropping of mandatory public health precautions, what I have observed is many, if not the majority of people abandoning any concern for frontline healthcare workers and the conditions for vulnerable patients in primary public health institutions. Can you talk a little bit about some of the critical health care worker led campaigns this year for better staff conditions and conditions for patients? And what the conditions currently are like for both workers and patients in the public health system?

**Tori**

Yeah, I mean… the pandemic has sort of had devastating effects on the healthcare system as a whole, like on every level. As someone who's both a care worker and a patient in the public system, I sort of understand it from both ends as well. So relaxing restrictions has generally- we've seen an increase in COVID infections and other communicable diseases like influenza, gastroenteritis, all those kinds of things.

You know, if you've visited an emergency ward recently, anywhere on this land, you've probably seen that kind of wait times people are facing. So people who may have presented to emergency in 2019 with something that would have been triaged within the hour are sometimes facing wait times up to six hours to have a face to face interaction with the doctor, which is pretty devastating, and can really delay people's care and make them quite unwell.

I know people who've come into emergency every day for like four days in a row because they haven't received care. And it's really distressing, not just for the patients, but for the nurses too, because we don't want to do that. That's kind of not how we operate. We want people to access timely and safe care and with the strains on the healthcare system at the moment, that's just kind of not doable. No matter how hard we try.

We’re nurses, especially in New South Wales at the moment repeatedly striking for an increased nurse to patient ratio so that nurses can actually provide proper care to their patients. When I worked in ICU and emergency during the first year and a half of the pandemic, I was just so stressed and I was coming home just because of the increased acuity of patients because not only were you just having regular things like people coming in for a heart attack or a stroke, but you will also getting people coming in now with COVID, and pneumonia with COVID.

And all of these different things that we just were not really equipped to deal with. And it's just accumulated as the years have gone on and the actual strains that were facing the system haven't really been addressed. It's really difficult to provide this care in a system that provides- well, isn’t really providing the resources and the staffing you need. It leads to major burnout.

I took a year and a half long break from hospital nursing after the first year and a bit of COVID because it was just too much for me and I know that I'm not the only nurse who's dealt with things like that, like in terms of not only just the hospital setting, but in community and outpatient care.

You’re lucky to see your specialists within three months of getting the referral which is annoying and devastating for everyone but especially so for people who are disabled, people who have chronic health conditions especially things with GP clinics doing away with bulk billing.

A lot of people are missing out on the care that they need. That sort of combined with relaxing of COVID restrictions means that people are just getting more unwell more frequently, because they're having more contact with people. Whether they're willing to or not. You can wear a mask in public, but it doesn't really ensure that the people around you are.

So it just creates a massive ripple effect on the healthcare system as a whole. Because, you know, if you put off a GP appointment, because you can't afford it, it often means that your symptoms are accumulating and your health is deteriorating, which means that you will present an emergency multiple times, your condition will worsen, your condition might become more complex.

And then people just fall through the cracks of the system and often end up really unwell or just end up with conditions that they can't manage on their own and need more intensive, everyday care. So the healthcare system has been under duress, it has been under duress for a long time. And I think that COVID has just highlighted that even further.

**Pauline**

You've been absolutely staunch in your willingness to call out the reckless disregard for those most at risk of critical complications or death from COVID. In your Instagram posts this year, you know, regardless of backlash, or tone policing, I'm thinking of a particular video you posted prior to the government dropping all requirements for people who have contracted COVID to isolate following being affected, in which you talk about the impact this would have on the patients you work with. Can you tell us about that impact and the ongoing ramifications of that?

**Tori**

I mean, the impact of people not isolating when they're sick is that they're just exposing themselves to vulnerable people. Unknowingly. People who might be older, people with chronic health conditions, people who are immune suppressed, pregnant, unable to get vaccinated. All those vulnerable communities are people that, you know, go out and about like any other person. They all go to supermarket, they'll go to the chemist, and they're not able to do those things safely. At all. I'm often the only person in the room wearing a mask, every day.

Other than at work. At work, we all love our masks, but in public, like I could be at the post office, and I could be one of 20 people wearing a mask. And the impact that we're seeing of, lack of mask wearing, lack of isolating, is that people who've avoided COVID for this long are now getting it. And vulnerable people are getting second infections. They’ve had COVID a year ago, and they're getting it again, it's just sort of disappointing. That common sense is kind of gone out the window a little bit.

I remember the first year or so of the pandemic people were talking about “Oh community care, we've got a center vulnerable people”. And it kind of now just feels like that was more of a buzzword rather than a true moment of solidarity and collective movement built on love and centering people who are most vulnerable.

At the moment, the reality is, once a majority of people - when I say people, I mean able bodied people - once a majority of people were vaccinated, they stopped seeing the need to mask because they thought, “hey, the government's eased restrictions, I've done my personal duty because I got the vaccine”. But vaccinations are more of an individual action that primarily protects you. It obviously does contribute to herd immunity and decreases risk of other people getting sick. But it's just one of the ways that we can help decrease the risk of other people contracting COVID.

Because there are thousands of people across this land who have been unable to get vaccinated due to immune suppression. If those people can't access the alternative - which is a medication called Evusheld, and which is a monoclonal antibody medication, which can be used for people who aren't able to get vaccinated - if they're not able to access that, what happens to those people? And what does that mean for their lives going forward?

You know, masking and social distancing have always been the most effective ways of protecting yourself and other people against COVID. The science has never really wavered on that. I talk to older people and disabled people every day at work, who are really distraught and so anxious and upset that they've caught COVID despite them wearing a mask, and they're often like “what did I do wrong? I wore a mask and dadada”. It’s heartbreaking and it's really sad.

I feel like people have forgotten that masking is a two way street. And there's been no changes to that like that has been the consistent messaging. The only thing that has changed is our attitudes towards whether that matters for a majority of us. That's the only thing that has really changed. Like through all of this what abled people tend to forget it.

Is that not only is COVID, like the acute COVID symptoms and issue for people were vulnerable, but long COVID is a common enough occurrence that it should be an issue for everyone. Everyone should be concerned of the risk of getting long COVID. I talked to a number of people a week who have relatively high functioning, able bodied people their whole lives, cycling every day going to work, all of that who are now unable to work, work, they're unable to mobilise, they can't play with their children, they can't go to McDonald's, like they just aren't able to contribute and participate in their life the way that they used to.

So COVID has always been a mass disabling event. And it's always been a mass death event for vulnerable people. If we continue to ignore the advice of immunologists and, you know, people who are much smarter than myself, we'll just continue to see a rise in COVID cases of long term effects, like could be felt for years to come for these people for their whole lifetimes.

**Pauline**

As a disabled nurse who didn't have the option of working from home, when you were a frontline primary health care worker, and who has immunocompromised loved ones, what do you want people who are working in this area to know and how they can show up in solidarity for disabled frontline primary health care workers.

**Tori**

I mean, in an ideal world, vulnerable people and health care workers and frontline workers shouldn't have to beg for this kind of compassion, and understanding. But it's really unfortunate that that's sort of what it's come to. What I'd like people to realise, from the perspective of a healthcare worker, is that many of us are disabled ourselves.

A majority of the nursing workforce on this land is migrant women. It is women of color, it is people of color. It is people who have migrated, people who have fled their countries, or they've been refugees, they've been asylum seekers. Often we are people who have experienced illness.

And we're people who have experienced physical and mental trauma, which is a massive contributing factors to the development of chronic illness and disability, so a lot of healthcare workers are disabled. And a lot of us are people who sacrifice a lot of time to look after other people. We miss out on time with our families and friends to work overtime, due to lack of staffing, we're working public holidays and night shifts, and we're the people who continue to be the people that COVID patients see in their last moments.

And people who are dying, we're the people who tend to look after them in their last moments. That can be really taxing on your mental health and your physical health and a lot of us are burnt out. And unfortunately, a lot of us are leaving the industry because of it.

When I worked in face to face nursing care. In terms of COVID, I went to work knowing that it took one interaction with a patient who had COVID and one time where my mask wasn't fitting properly, to possibly bring COVID home with me and change my life and my partner's life forever. And at the time, I worked these nearly 12 hour shifts overnight every week for a whole year and a bit on the backs of my community suffering from the bushfires in the ACT region and the New South Wales south coast.

So it's just been relentless, for a lot of nurses in my area. A lot of us in this area have just quit nursing completely or have just completely changed the type of nursing that we're doing because the anxiety and the trauma of the whole situation was just too much. There's been no respite for a lot of healthcare workers in general with COVID.

But a lot of people who have faced climate change as well - floods, the bushfires, everything - that all has a massive impact on our healthcare system and has a massive impact on healthcare workers. As long as we continue to prioritise individualism over collective community care, there will continue to be no respite for healthcare workers across this land.

**Pauline**

Finally, the theme for this year's broadcast is Rest is Survival. You've posted a lot of reflections this year, on the ways in which disabled and chronically ill people are robbed of the chance to rest through things like the administrative burden of having to fight for the health care we deserve. Being a healthcare worker, you understand the medical system a lot better than a lot of people outside probably do. But I'm sure the medical admin burden the time it takes as someone who has to work and doesn't have access to government support is still tremendous. So, given all of this, what is your relationship with rest at the moment? Where do you find it? Or do you find it?

**Tori**

My personal relationship with rest has always been difficult. I'm someone who finds it really easy to encourage other people to rest. And I find it really easy to help facilitate that for other people. But I have some kind of allergy to doing it for myself. So like many disabled people, I need the help of those around me to help facilitate rest.

I try personally to take time out, to check in with myself and make sure I'm not spreading myself too thin, which often happens in my line of work anyway. It’s difficult sometimes working in a caring profession where you are having to give a lot of that part of yourself to other people. Obviously, you do get paid for it. But it doesn't take away from the fact that it is sometimes very emotionally taxing, which means that at the end of the day, it can be really hard to provide that care for yourself.

You’ve kind of emptied that bucket. Like right now, I'm experiencing some uncertainties with my health, and it has been really rough. But it's times like now I do really need to prioritise risks, but it's hard to sometimes do that. When you're faced with all of these barriers. Like if you are facing a possible diagnosis of something that will alter the course of your life forever, what if you're one flat tire away from having no money and not being able to afford the care you need?

How are you meant to facilitate rests in a system, which is built off of ableism and inaccessible health care? To me, I feel like for me, rest is not attainable, under a racist and ableist system. And under capitalism as a whole. It’s really hard to facilitate that when you've got so many things working against you.

Rest is an act of self preservation and an act of self love. And it's also a destination for me, rather than something that I feel like I've attained at the moment. No matter how hard I try, and a lot of disabled people feel this way, it's one step forward, and two steps back kind of thing. You can do so much. And then you will always face barriers to attaining rest, because health and illness and stuff is relentless sometimes. But you can only really try your best, and take it a day at a time.

I think I'm personally very lucky that I know I can rely on my disabled kin to help me facilitate that for myself when it gets too tough. And I think that that is something that, despite all of the horrible things that I've personally experienced working during the pandemic, that's one of the things that I will value forever, is the relationships that I unfortunately was forced to make in the midst of the pandemic.

But they’re relationships which, disabled people are the only people I kind of relate to right now. So, it is really good to have built those communities during the pandemic and to be able to help each other do the things we need to do to survive.

**Pauline**

Tori Hobbs, thank you for your time.

**Tori**

Thank you.

**Voiceover**

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**Pauline**

Next up, I had the opportunity recently to catch up with Tricia Maloney.

**Tricia**

Sure. Sorry, I'm just recovering from COVID. So my name is Tricia Maloney, and I'm the chief accessibility advocate to the Department of Transport in Victoria. I do that three days a week, and in the rest of my time, I run my own business where I virtually annoy government and get them to make sure that they include people with disabilities in all settings.

My particular interest is around gender and disability. I'm also on the NDIS independent advisory council. And as part of that, I also bring gender to the agenda as well. In the past I've worked a lot around women's health, ensuring women with disabilities have good access to health services in the same way that other people do.

**Pauline**

The last time I spoke with you was in 2020, the first year of the pandemic. And we discussed policy at the time that was related to seniors and elders with disabilities. This year, the federal government has removed a lot of the mandatory public health measures.

Well, essentially all of them, to protect seniors and elders and other people at higher risk of serious adverse effects of COVID. I wanted to know, in your line of work, how you responded, both in terms of the work that you do, and also with regards to your own health, moving through the community and trying to negotiate this new landscape.

**Tricia**

Certainly, I got vaxxed. And I have been for quite some time, as the vaccinations have come out, because I have a disability, because I have chronic lung disease. I've been particularly aware of that. And also that I'm over the age of 65. So I have a few of those little obstacles in my way, that means I'm more likely to have an adverse outcome from COVID. And I've been masked up all the time. And my husband also is masked up whenever he leaves the house. So we're always quite amazed that other people aren't, you know, we'll look at each other and go “Good heavens, do they not realise this is still an issue for many people?”.

I've managed to avoid COVID until last Thursday, so a week ago. And I was quite surprised. It happened because I went out fully masked to a bank, and I saw somebody that I hadn't seen for quite some time. And she came up and threw her arms around me and gave me a kiss. And I sort of went, “Whoa, hang on. I don't do that anymore”.

But that small interaction, ended up with me getting COVID. Now, I was lucky that it hasn't been as severe as I thought it might be. I locked myself in my room for five days, until I felt a little bit better and tested negative. My husband fortunately didn't catch it. He’s 80. So I was quite concerned about him. So he masked up whenever he bought me food.

The only reason I left the room was to go to the bathroom. And that was fine for me. But I think we have a problem with people forgetting that, okay, they’ve had COVID, they managed to get over COVID, and will go out and we'll all have fun again.

But there are a lot of us who haven't had COVID. And we’re the ones that are more susceptible. So it's still dangerous. The people I work with in the Department of Transport are masked when they need to be so on public transport, they're still wearing masks, even though there's no mandate to do so.

So whenever I leave the house I mask, so that’s the simple answer for me. But I know many people who aren't and it worries me. The thing is to, like I'm starting to venture out again, because sometimes my work requires it. So I do a lot of public speaking. And I have definitely done that. So I'm going to an event tonight where I'm speaking. And I thought long and hard about whether I go but I know I'll be on the stage.

Other people won't be so be alone on the stage. And I'll just make sure nobody comes near me who isn’t masked, and the people who will be going that I know, who know me, will be masked up. I just won't go near anybody else. I'm also attending a gala ball tomorrow night because I’m one of the VIPs apparently, and then Noel and I are going to another gala ball on Friday night and you've sort of got to start reassessing your whole life. Do I go or do I not go? What do I do? If I can't go?

I mean, certainly if I had COVID still it’s not negotiable. But I'm missing out on things because other people aren't doing the right thing, that's what really annoys me. The other thing that’s annoyed me is that nobody from the Department of Health has contacted me. And I registered with them straight away. I registered with my GP straight away. The fella next door, he and his wife both got COVID.

Not from me. They went on a cruise. And she didn't get contacted even though she has chronic lung disease, but her partner did. And I'm wondering, why did he get contacted and I didn't? Is it because he's over 80? I think we need to reassess how the Department of Health is registering.

So there's nothing on the form for the Department of Health that says “do you have chronic lung disease, and register it”, but they do say if you have chronic lung disease, contact your doctor. Well I’d already done that. So, you know, so he got a daily call saying “are you okay?”, I got nothing.

**Pauline**

That's really strange.

**Tricia**

It certainly is. And then especially his wife didn't get any calls either. And she said the same thing as I did. “Hang on, I’m the one who's got the chronic lung disease”. And she's probably 74 or 75. So maybe that's, again, over 80 to get the call. People with disabilities don't.

**Pauline**

That’s quite ridiculous.

**Tricia**

It certainly is. And he's quite fit. He's out playing golf, he’s fine.

**Pauline**

So Trisha, when we spoke on the phone yesterday, you were talking about the fact that you are resting quite intensely at the moment, but that it's also probably the first time you've had rest in a long time. The theme of this year's broadcast is actually Rest is Survival.

**Tricia**

Absolutely. And it's not something I do well. And that comes I think, from having a lifelong disability, that we feel like we have to be better than everybody else, we have to show that we can do it, that we have to be on all the time, that you can't miss an opportunity. And being 68, my opportunities have come since I turned 60.

So I had plenty of time for rest before, when I didn't get the roles when I didn't get the work. So now that I've got the work, I really do have to be careful. So I've made the decision not to work on weekends. Now I've worked weekends all my life. And yet now, I'm actually stopping because I think I need to take that time to put my feet up and just say no, I'm just not doing it on weekends anymore.

But I really do think it is important. And I think it's important for people with disabilities to start going, I don't have to do everything, I can be like everybody else and not put in the extra hours that other people don't put in.

So it's a bit like, as far as I can compare it, to the women's movement. So if you look at going for a job, if a woman has 90% of the attributes of a position, she'll say “I better not go for that, I don't have everything”. Whereas a man will say “yeah, I could do that. No problems”. And for women with disabilities in particular, we actually go for jobs and find a way we get the qualifications that we probably don't need just to prove that we can do the jobs that other people can't. It's a funny sort of a, a perverse sort of reflection, I suppose.

**Pauline**

Completely. Tricia, was there anything else that you wanted to say?

**Tricia**

Good lord. There’s so many issues that are important. The issue of the sterilisation of girls, is absolutely appalling. The reasoning given by the previous government was that it’s therapeutic because they have problem periods. Well, if that was the basis for sterilisation, there'd be very few women in Australia who would be fertile. So we’ve still got that as a problem.

We've got the problem of violence against women with disabilities. It’s absolutely appalling. Rates of violence and different forms of violence, it's everywhere. The really big issue is that only 38% of participants in the NDIS are female. We make up more than half the population, and we're still not getting access to services. And it's all almost as though women don't really matter.

We know that people with disabilities don’t matter in society. And now we're getting to the stage where it's women with disabilities in particular, really are not seen as an important part. And so I spend a lot of my meeting time saying, “Well, what about gender? Where's gender in your thinking?”. Because until we're actually in there, we will never get a voice.

The other thing that I think we need to think about is we need to have women with disabilities running the show. So if you look at how many women are actually activists, we far outnumber the number of men, and yet we don't get the jobs. So listen to us for a while.

**Pauline**

That's wonderful. Tricia, thank you so much for your time. You've been listening to Public Health Emergency with Tori Hobbs and Tricia Maloney. I'm Pauline Vetuna. Stay tuned for more Disability Day programming.

**El**

Hi, I'm El Gibbs. You're listening to International Day of People with Disability on 3CR. Disabled people rock.